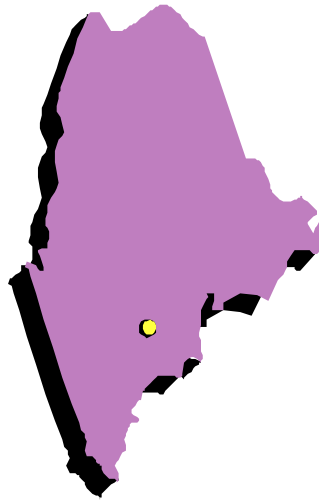


HIV Risk Among Transgender People in Maine



A Statewide Needs Assessment of
Behavioral Risk

2003

Maine HIV Prevention Community Planning Group

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Appendix A – Survey Tool

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HIV Risk Among Transgender People In Maine

INTRODUCTION

This evaluation report presents the results of a needs assessment conducted by a sub-committee of the Maine HIV Prevention Community Planning Group (CPG) and is an addition to the CPG 2002-2003 Statewide Needs Assessment. The focus of the committee's work was to gain knowledge of the HIV prevention needs of people in Maine who identify as transgendered. "Transgender" is an umbrella term used to describe all persons who do not conform to the societal gender norms usually associated with male and female. Such individuals have gender identities, expression or behaviors not traditionally associated with their physical sex at birth. Transgender persons may or may not choose to undergo hormone therapy or sex reassignment surgery.

Nationally, people who are transgendered, particularly male to female trans* persons, have been shown to be at higher risk for HIV infection and have correspondingly higher HIV infection rates (Nemoto et al., 1999; UCSF Fact Sheet, 2001). This is due to a number of factors including pervasive stigmatization and marginalization which often results in barriers to healthcare, employment and housing opportunities; lower self-esteem; and increased likelihood of drug use, survival sex work and engaging in high-risk sexual behaviors (Nemoto et al., 1999; Bockting et al., 1998; Clements et al., 1999).

A literature review of HIV-related risk among transgender people could find no studies related to transgender people living in rural areas. The CPG wished to gain more insight into the HIV-related risks of transgender people living in a rural state.

The committee investigated the association of recent HIV risk behaviors among male to female (MTF) and female to male (FTM) transgender persons. The assessment used a two-part approach that included individual surveys and focus groups. The survey questionnaire investigated the association of recent HIV risk behaviors among MTF and FTM transgender persons related to sexual behaviors (with primary sex partners, casual sex partners and paying sex partners), use of drugs, HIV/sexually transmitted disease (STD) status, and various demographic characteristics. Focus groups were used for further exploration of the perception of risk within the community, and barriers to service.

The questionnaire focused on behavioral risk assessment and was designed to answer the following research questions:

- What are the HIV-related sexual and drug-using risk behaviors of transgender people living in Maine?

* NOTE: In this report the terms transgender, transgendered and trans are used interchangeably and have the same meaning.

- Do transgender people in Maine have access to health and hormonal-related care?
- Are there other risk factors that transgender people in Maine face, including homelessness, lack of educational or employment opportunities, etc.?
- Are transgender people being tested for HIV antibodies? Why do they choose to test or not to test?
- Where do transgender people go to socialize and meet potential partners?

The goal of the focus groups was to obtain a better understanding of the knowledge of, and attitudes about, HIV among transgender people in Maine, and their risk for infection. The groups were designed to gather more in-depth information in the following areas:

- Perceptions of HIV related risk in Maine's transgender community;
- Access to, and barriers to, obtaining transgender-specific HIV prevention information and competent and trans-friendly healthcare and HIV prevention services; and
- Availability of social support in the community.

The following report describes the questionnaire survey methodology, its distribution and the demographics of survey participants. The survey results are combined with the focus group outcomes and include selected comments from focus group participants.

METHODS

In December of 2002 contacts were made to JRI and to JSI Research and Training Institute in Boston for background information on their research of transgender people in Massachusetts. Survey questions were developed by the CPG sub-committee which included transgender advisors. Risk assessment questions that were used in the 2002 – 2003 Statewide CPG Needs Assessment were specifically adapted to the transgender population. The survey was pre-tested with transgender individuals and, based on their feedback, further modifications were made.

Due to the barriers inherent in trying to identify and survey a substantial sample of people who are transgendered, particularly in a rural state, convenience sampling was used as the method to distribute surveys. The CPG signed contracts with two organizations that provide education regarding, and/or support to transgendered people in Maine, to conduct the focus groups and distribute the surveys. Maine Gender Resource and Support Service (MeGReSS) was engaged to conduct focus groups with adult transgender individuals and Outright in Portland which serves gay, lesbian, bisexual, transgender and questioning (GLBTQ) youth, would conduct groups with younger (24 and under) transgender individuals.

To be eligible for inclusion in this needs assessment, participants had to identify with a gender identification different from that assigned to them at birth. An effort was made to include people from different regions of the State.

Initially the CPG was going to focus on male to female (MTF) transgender persons, as previous research in urban areas (Nemoto et al., 1999; UCSF Fact Sheet, 2001) showed that MTF individuals are at much higher risk for HIV. After lengthy discussion and on the advice of the transgender committee members, a decision was made to try to incorporate both MTF and FTM individuals in each focus group as none of the earlier national studies had looked at differences between MTF and FTM in rural areas. The sub-committee felt that including both would be an asset and would not interfere with people's willingness to speak up during focus group discussions.

Between March and April of 2003 MeGReSS sent out invitations to approximately 60 MTF and FTM transgender individuals to recruit people for participation in the focus groups and inclusion in the survey mailing. Two (2) focus groups were conducted in April with people who were 24 or older. Each focus group included six (6) people. One group was largely MTF (5 people) with one person identifying at FTM. The second was a split between 3 MTF's and 3 FTM's. Outright in Portland conducted one (1) focus group in June of 2003. Participants were recruited from Outright organizations throughout the State. Six (6) people who were under 24 participated in this focus group which included 2 people who identified as MTF, 1 who identified as FTM, 2 people identifying as "GenderQueer" and one person who said they were "pre-hormones." A second focus group with youth had to be cancelled due to transportation issues and difficulty coordinating times with this younger population. As a result a broad regional representation was lacking.

Focus group facilitators obtained informed consent from participants. Participants filled out the survey questionnaire prior to the start of the focus group. Great care was taken to assure the anonymity of people filling out the surveys and of focus group participants. Surveys were distributed in plain envelopes that included the survey and a postage paid envelope for its return. Focus group participants were encouraged to use a pseudonym or initials if they so chose. Participants received financial reimbursement.

Focus groups were tape recorded, and another person took ongoing notes of responses from the participants. The facilitator and recorder wrote a summary of their impressions of the focus group and the concerns and trends that emerged during the discussion. These materials were returned to the CPG Coordinator for analysis. The facilitator and recorder were from each of the organizations contracted to conduct the focus groups and were known to the participants. The facilitators were part of the initial CPG sub-committee that organized and designed this needs assessment and followed the protocol that was developed for conducting the groups.

Additional surveys were distributed by the two contract organizations through their mailing lists or hand delivered to transgender members of their organization at various times during the spring and summer. They were also distributed at a workshop on

transgender issues that took place in September of 2003. People were asked not to fill out a survey if they had already done so. Completed surveys were returned to the CPG Coordinator in their postage paid envelopes. Final reports from the facilitators of the focus groups were completed and turned in to the CPG by December of 2003. A total of 29 surveys were returned. The Coordinator reviewed returned surveys to help guard against respondents submitting more than one survey. There did not appear to be any duplication.

Results were entered into an Epi Info database and frequency of response was used as the measure. Additional statistical analysis was impractical due to the small sample size. A second CPG sub-committee that also included some members from the original planning sub-committee reviewed the questionnaire response frequencies, the focus group recorder notes, the facilitator summary and a draft report. Sub-committee feedback was incorporated into the final report.

LIMITATIONS

The convenience sampling method used for the survey questionnaire provides helpful information about a segment of the transgender population; however, the results cannot be generalized and may not represent all transgender persons in rural areas or in Maine. The sample size was not large and did not lend itself to some types of statistical analysis. Additionally, although surveys were anonymous, respondents may have minimized their risk behaviors.

The focus groups for people 24 and older were conducted by a facilitator and recorder different from the facilitator and recorder who conducted the focus group for people under 24, and although the same protocol was followed, there may have been some differences in the way that the groups were held. Also, the mix of MTF and FTM in each of the groups was not the same and having a mix may in and of itself have made a difference in the outcome of the discussion, although the facilitators did not see this as a problem.

RESULTS

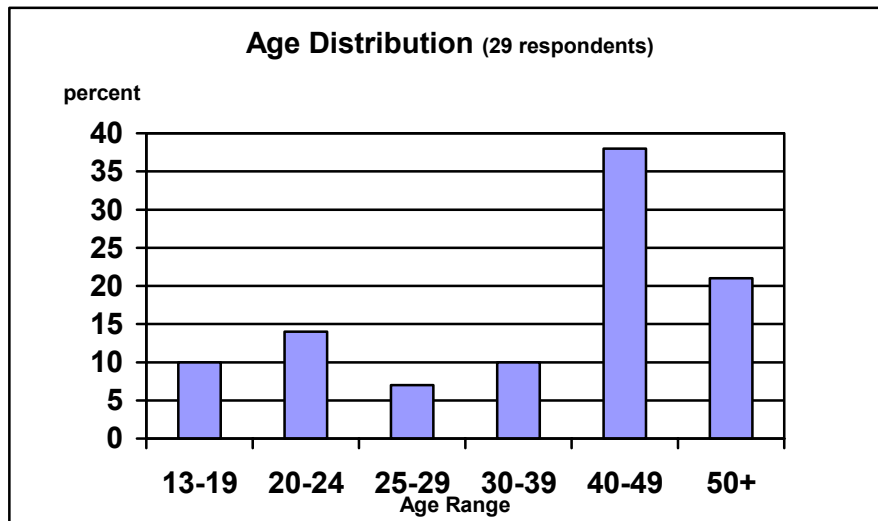
Results are split between demographic information (Part I) and health factors and risk assessment information (Part II). Sections discussing results also include insights from focus group participants. When reviewing the results it is important to note that for some questions totals add up to more than 100% because respondents were able to choose more than one answer to certain questions. Also, when a range was given for the number of times a behavior occurred, the average was used when compiling the answers.

**PART I
SURVEY RESULTS:
DEMOGRAPHIC INFORMATION**

1. Age

Age ranges were broadly distributed (from 16 – 60 years) among the 29 survey respondents. Thirty-eight percent (38%) were between forty and forty-nine years-old. Twenty-four percent (24%) were under 24 years. Age range distributions are shown below:

Figure 1

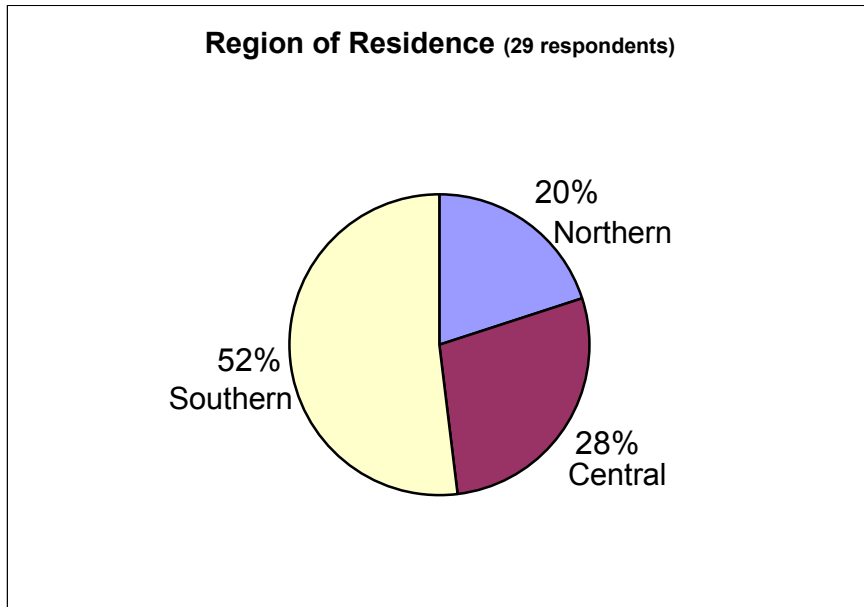


2. Region of Residence

Respondents were asked to indicate the county in which they live. For the purposes of this document, and in HIV prevention planning in Maine, counties of residence are grouped into Northern, Central and Southern Regions. The Northern Region represents Aroostook, Hancock, Penobscot, Piscataquis, and Washington counties; the Central Region includes Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset and Waldo counties; and the Southern Region includes Cumberland and York counties.

Six (6) respondents (20%) live in the Northern Region, 8 (28%) live in the Central Region, and 15 (52%) live in the Southern Region of the State. It is important to note that although in terms of overall population the Central Region encompasses the largest population base (followed by Southern and then Northern Regions), the Southern Region includes the Portland Metropolitan Statistical Area (MSA) which is by far the largest MSA in the State. An MSA is defined as a core city or urbanized area of at least 50,000 people and its surrounding area. Figure 2 (next page) shows the region of residence of survey participants.

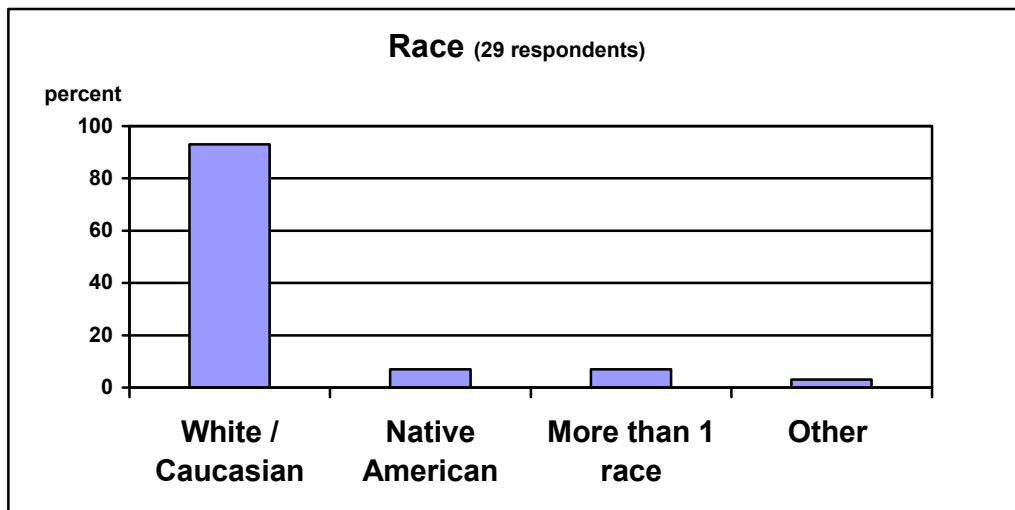
Figure 2



3. Race

Maine is a racially homogeneous state with racial and ethnic minorities comprising only 3% of the population. Similarly, the majority of respondents in this assessment (93% or 27 people) identified as Caucasian/White. Two people (7%) identified as Native American and multi-racial; one person identified as "Other." Figure 3 shows the racial breakdown of survey respondents.

Figure 3

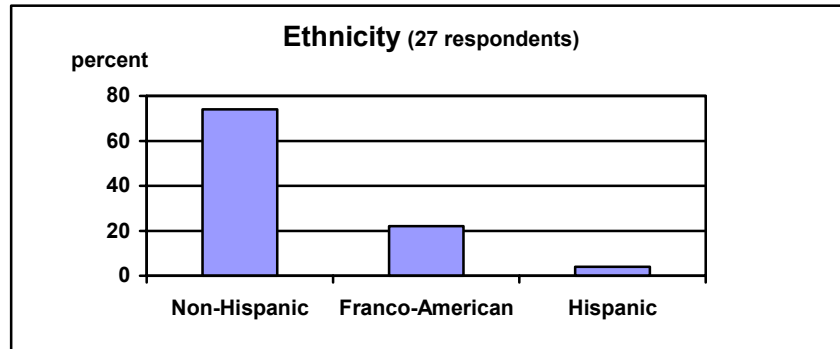


Note: respondents were able to choose more than 1 category.

4. Ethnicity

Twenty-seven (27) out of 29 respondents answered the question on ethnicity, two left it blank. Of those who responded, 20 (74%) chose non-Hispanic, 6 (22%) chose Franco-American, and 1 respondent (4%) indicated that they were of Hispanic ethnicity. Figure 4 shows the ethnic breakdown of respondents.

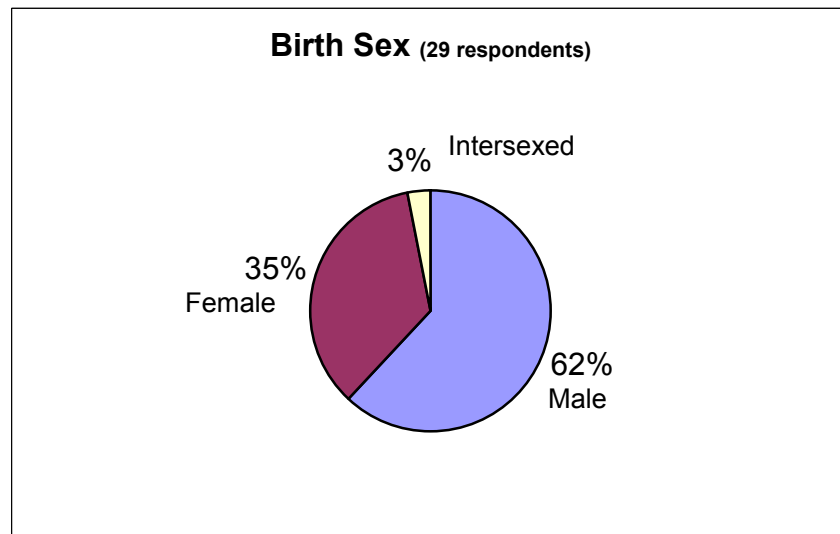
Figure 4



5. Sex at Birth

In response to the question regarding which sex they were assigned at birth, 62% (18 people) responded that they were assigned male, 35% (10 people) were assigned female, and 3% (1 person) was intersexed (someone born with both or ambiguous external genitalia, or internal reproductive system and/or sex chromosomes not considered "typical" for either male or female). Figure 5 (below) shows birth sex.

Figure 5

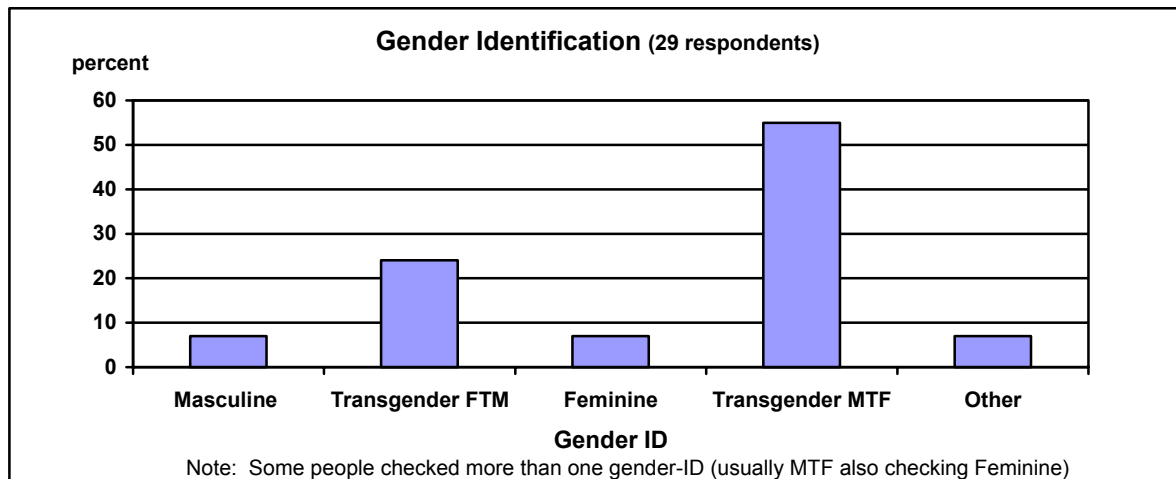


6. Gender Identification

Current gender identification covered a broad range of responses with a majority of 55% (16 people) identifying as "Transgender Male to Female (MTF)," and 24% (7 people) identifying as "Transgender Female to Male (FTM)." "Masculine", "Feminine" and

“Other” each had 7% of the responses (2 people each). The respondents that choose "Other" wrote in “GenderQueer” as their gender identification. Masculine and feminine were included as options along with MTF and FTM on the advice of transgender committee members in order to be more inclusive of the different ways in which people choose to identify themselves. Some people who have had surgery (post op) do not identify as MTF or FTM and may prefer the masculine or feminine options. Gender identification distributions are shown in Figure 6.

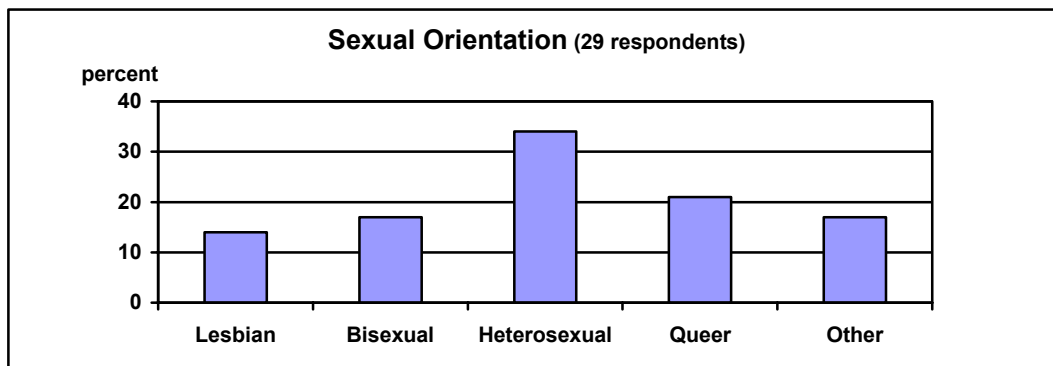
Figure 6



7. Current Sexual Orientation

Ten of the respondents (34%) identified their current sexual orientation as “Heterosexual.” There were a range of additional responses which included 6 responses (21%) identifying as “Queer;” “Bisexual” and “Other” had 5 responses (17%) each; and 4 (14%) chose “Lesbian.” Of those who checked "Other," responses were written-in as follows: 2 people self-identified as “Pansexual;” and “Pomosexual,” “Transsexual MTF,” and “Undecided” were each written-in once. One respondent chose more that one response identifying as both “Queer” and “Pomosexual” (both of these responses are reflected in the above totals). It is interesting to note that no one identified their sexual orientation as “Gay Male.” Figure 7 shows respondent’s sexual orientation.

Figure 7



8. Income

Respondents were asked to indicate their sources of income over the past year. They could check off as many responses as applied so totals add up to more than 100%. The majority (62%, 18 responses) indicated full time employment and 14% (4 responses) indicated part time employment often combined with other income sources. However, 20% (6 responses) indicate some type of state or federal assistance such as General Assistance, Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI) or Temporary Assistance for Needs Families/Aid to Families with Dependent Children (TANF/AFDC). Two (2) responses mentioned selling drugs and one (1) mentioned sex work. Three (3) of the responses were written-in as “Other” and included one response of “family, foster care & student financial aid;” one response of “unemployment;” and one response of “union.” Table 1 shows sources of income.

Table 1

Type of Income	Percentage of Responses	Number of Responses (29 respondents)
Full Time Employment	62%	18
Part Time Employment	14%	4
General Assistance	7%	2
Other	10%	3
Selling Drugs	7%	2
SSDI	7%	2
Sex Work	3%	1
SSI	3%	1
TANF/AFDC	3%	1

➤ FOCUS GROUP INSIGHTS

The focus group discussions brought out the problems that transgender people have with employment and the financing of hormones and/or surgery. Loss of employment when transitioning was mentioned in several groups as well as the difficulty of finding employment that is safe while transitioning. Some felt that, “loss of employment while transitioning can lead to sex work,” and another commented, “It’s hard to find jobs where transition is safe, it’s easier to do sex work two nights a week and make money there instead of a job that won’t be safe to transition at.”

This seemed to be a particular issue for youth who did not have other resources. One person commented that they felt sex work was, “more prevalent among young people because older people have more...they can draw on. The safety net for a young person is non-existent.”

9. Type of Residence

The vast majority of respondents have a stable living situation. When asked where they currently live:

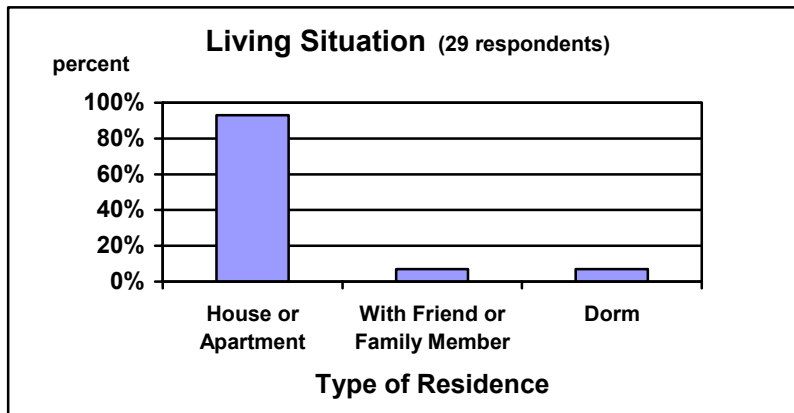
93% (27 responses) were “in a house or apartment”

7% (2 responses) were “in a friend or family member’s home or apartment”

7% (2 responses) were “in a dorm room”

Figure 8 illustrates these responses.

Figure 8

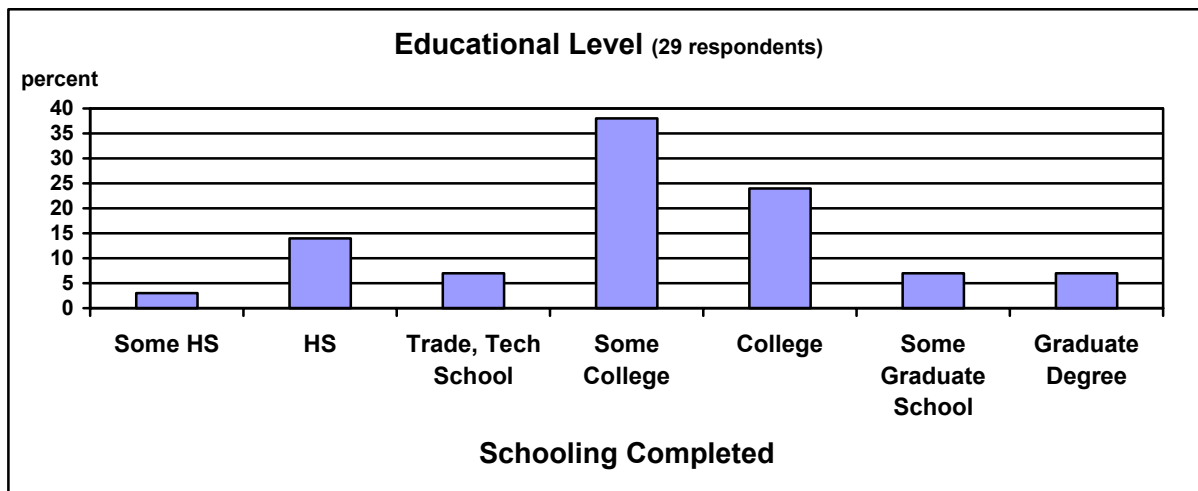


Note: respondents were able to choose all that applied.

10. Education

The respondents were well educated. In answer to a question on the highest level of schooling achieved, 83% have more than a high school education. There was one response of “some high school,” however the person who checked this is under 18 years of age. Figure 9 shows respondent’s level of education.

Figure 9



PART II
SURVEY AND FOCUS GROUP RESULTS:
HEALTH FACTORS AND RISK ASSESSMENT

1. General Healthcare

Respondents were asked where they obtained their general healthcare (not including hormone therapy) in the past year. Most respondents have had some type of health care in the past year with the majority (24 responses or 83%) having a private doctor, another 5 (17%) going to a public clinic, 2 (7%) using healthcare services outside of the United States (“Other” responses) and 1 using the Veterans Administration (VA). The hospital emergency room (ER) and alternative/complementary care had two responses each (7%). Two people (7%) had not had healthcare in the past year. Table 2 shows the type of healthcare survey participants used in the past year.

Table 2

Type of Healthcare (Utilized in past year by 29 respondents)	Percentage	Number of responses
Private Doctor	83%	24
Public Clinic	17%	5
Alternative/Complementary Care	7%	2
Emergency Room	7%	2
Other (healthcare outside the US)	7%	2
Veterans Administration	3%	1
No Healthcare	7%	2

Note that totals add up to more than 100% because respondents were able to choose all that applied.

➤ **FOCUS GROUP INSIGHTS**

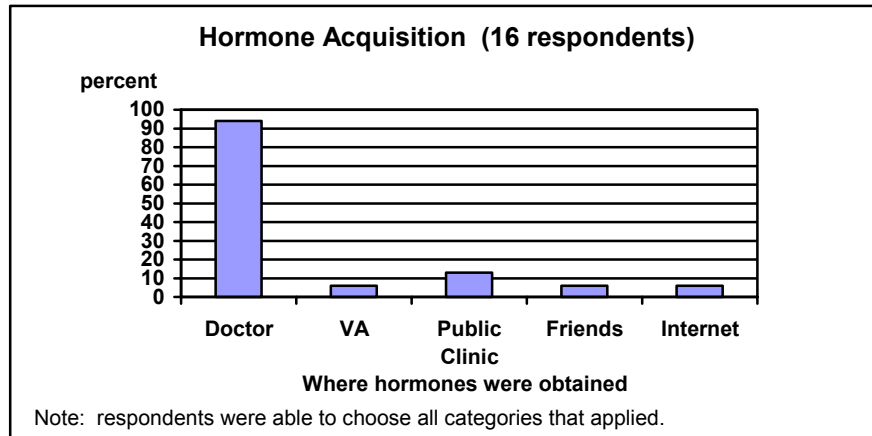
All focus group participants agreed that there were problems with healthcare services and that there was a need for training of healthcare workers. Issues included the lack of any trans-specific information or healthcare, confidentiality, discrimination by insurance companies and lack of mental health services. Specifically, people agreed that, “...most hospitals/clinics are non-accepting of trans issues,” and that, “Health care professionals should be better trained.” Another person added, “There is a tremendous need for reliable people who know about the subject.”

One focus group participant stated, “My issue was always confidentiality. I never trusted the medical community with my information. Never used my health insurance. Would get healthcare away from my local community and under other names etc. so that my confidentiality would be OK. There is general agreement that insurance companies discriminate against trans people and that affects our ability to access health care.”

2. Hormone Use, Acquisition and Hormonal Healthcare

All 29 survey participants were asked if they had taken any cross-gender hormones in the past year. 55% of the respondents (16 people) had used cross gender hormones. When asked to indicate where they got their *hormonal* health care in the past year, all of these 16 respondents received hormonal health care from either: a doctor (94%), the Veterans Administration (6%), or a public clinic (13%). In addition to these sources, one (1) respondent also obtained hormones from friends and another also obtained hormones from the Internet. Figure 10 shows the breakdown for hormone acquisition.

Figure 10



Respondents were also asked if they had injected any hormones in the past 6 months. 31% (9 people) responded that they had injected hormones in the past 6 months, and 69% (20 people) had not. None of the participants had received silicone injections. Of the nine (9) who responded that they injected hormones no one shared needles to inject.

When the nine (9) people who injected hormones were asked where they obtained syringes for hormonal injections: 89% reported from a pharmacy (8 people); 22% from a clinic or doctor (2 people); 11% (1 person) got needles from the Portland Needle Exchange and 11% (1 person) got needles from a partner or friend in addition to other sources. One person noted that it was difficult obtaining the needles from pharmacies. Respondents were able to select all answers that applied when answering this question.

➤ FOCUS GROUP INSIGHTS

Focus group participants did mention black market hormone purchases by some transgender individuals. One participant stated that, “a lot of MTF’s get injectable hormones on the black market,” and another stated, “people [are] getting black market hormones from the Internet.”

In general they did not see a huge problem with obtaining needles (“Needles are not hard to get”) although sometimes pharmacies are not cooperative with needle sales and needle exchanges do not always have the right gauge needles. One person stated that, “local pharmacists will not fill needle prescriptions ... I’m glad I have resources such as a car and money.”

3. HIV/STD Status and Testing

Respondents were asked a series of questions regarding their HIV status and any sexually transmitted disease (STD) diagnoses within the past 12 months. None of the survey respondents had been diagnosed with an STD during this time period.

When asked whether they knew their HIV status, 86% (25 people) said that they were negative, 10% (13 people) said they didn't know, and 3% (1 person) had tested HIV+. The person who tested positive did not identify any risk behaviors in response to risk assessment questions on the survey.

Survey participants who were negative or did not know their status were asked how long it had been since their most recent HIV test. Twenty six (26) of the 28 respondents who were negative or didn't know their status answered this question. Of the 26 who answered, 7 (27%) said that they had not been tested, 10 (38%) said that it had been longer than 12 months since they tested, 4 people (15%) said they tested within the last 4-6 months, and 4 others said they tested within the last 3 months. One person tested within the last 7-12 months. Further analysis of the 7 respondents who had not been tested revealed 4 who cited that they have not been sexually active, 2 who were in monogamous relationships, and one whose only reported risk was oral sex (their mouth on someone's vagina).

Although there were 7 respondents who said that they had not been tested for HIV, 14 respondents answered the question "If you have not tested for HIV which of the following relate to your decision not to be tested?" It is unclear why respondents who previously said that they had been tested answered this question. Of the 7 who had never been tested, 6 were MTF and all were at low risk. The reasons given by respondents for not testing (both those who never tested and those who had tested previously) are shown in Table 3. Respondents were able to choose more than one reason for their decision not to test. The majority of responses had to do with low/no risk.

Table 3

Decision not to Test	Never Tested (7 respondents) Number of Responses	Tested Previously (7 respondents) Number of Responses
• I am at low risk for HIV	3	6
• I have not been sexually active	4	2
• Other (been married to same woman, monogamous, never crossed my mind, plan to)	3	2
• I don't worry about HIV	-	2
• I don't know where to go for testing	2	-
• Privacy/confidentiality	-	1
• I don't think I can get HIV	1	-

Survey participants were also asked what reasons they had for not returning for HIV test results. Two people responded to this question. Both had been tested in the past 4-6 months. One responded that the testing site/hours were not convenient, and one responded that privacy/confidentiality were a factor.

➤ FOCUS GROUP INSIGHTS

Most people agreed that the testing clinics were, “warm and friendly,” and testing for most was a positive experience. However focus group participants mentioned several important barriers to testing for HIV. All groups agreed that the lack of trans-specific information, forms that only include male and female gender identities, and the lack of training of some staff regarding trans issues were problems. Some comments included:

- “Part of the process of changing behavior and realizing that you’re at risk is for the info to reflect how you see yourself.”
- “No images representative of our sexual experiences...want to see brochures that speak to my experiences...don’t see info for hormone use/injection.”
- “... an assumption was made about my gender but I wasn’t asked to clarify it. It was not a very positive experience. I haven’t been tested again since.”
- “...things like forms do not include different gender identities. Gets grouped into MSM, demeaning to me as a person, no other option for them as staff because there is no category for trans.”
- “Don’t want to have to do trans education with the staff.”

4. Sexual Risk Assessment

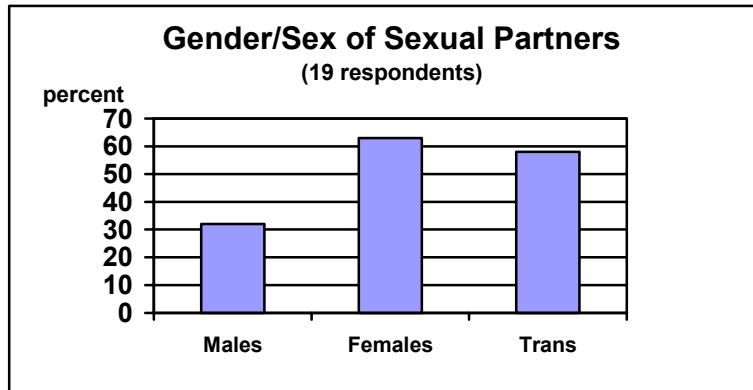
Survey respondents were asked a series of questions about their sexual behaviors during the past six months. Questions were related to specific sexual activity as well as to the gender of their partner(s) and the type of partner (main, casual or paying partner). Unless otherwise noted in the sub-sections below, the sample size was too small to draw meaningful conclusions regarding any differences between respondents who identified as Male to Female (MTF), or Female to Male (FTM).

Of the 29 survey respondents 10 (35%) had not had any type of sex during the past 6 months. Eight (8) of the 10 who had not had sex identified as MTF or feminine, and 2 identified as FTM or masculine.

Of the 19 who were sexually active, 10 identified as MTF or feminine, 7 identified as FTM or masculine, and two identified as “GenderQueer.” The sample size was too small to distinguish many differences between respondents’ gender identification and the gender/sex of their partners, however, no one who identified as FTM or masculine had a sex partner who was male. Of all those who were sexually active, 63% (12

people) had sex with females, 58% (11 people) had sex with transgender partners and 32% (6 people) had sex with males. Figure 11 shows the gender/sex of sexual partners.

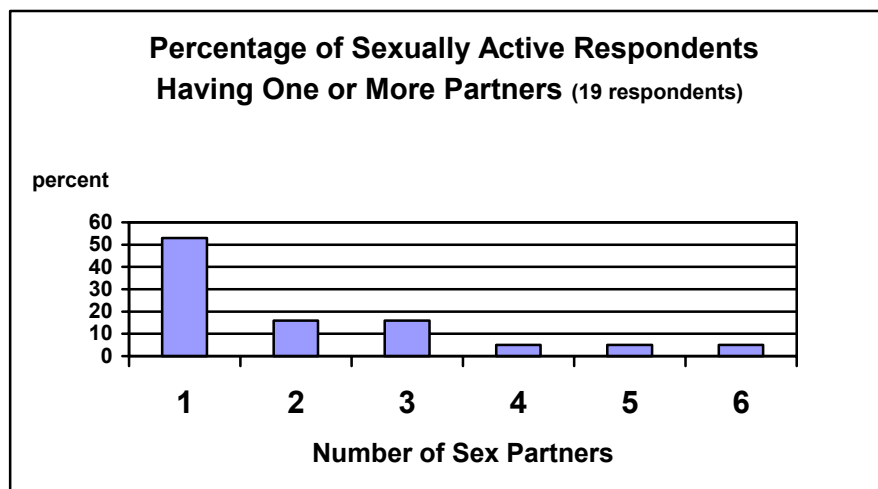
Figure 11



Note: some respondents had multiple partners of different sexes and/or genders.

Survey respondents were also asked to indicate the number of partners they had sex with over the past 6 months. A little over half of survey participants (53% or 10 people) had sex with only one (1) partner, 16% or 3 people had sex with two partners, and another 16% had sex with three partners. One person had sex with 4 partners, one person had sex with 5 partners and one person had sex with 6 partners. Of the respondents who indicated sex with more than two partners, all were younger (under 24 years of age). Figure 12 shows the percentage people who had sex with one or more partners.

Figure 12



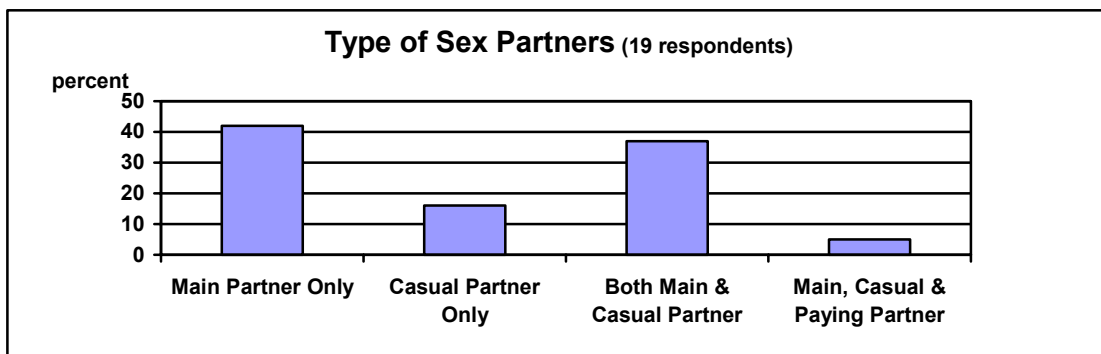
➤ **FOCUS GROUP INSIGHTS**

Focus group participants discussed what was going on in the community related to sex. Some felt that people often had more than one partner, one person commented, “Multiple partners are common...i.e. partners in succession (and as threesomes).” Experimentation, sometimes fueled by transitioning and using hormones, was discussed in several groups. Another person commented, “Generally speaking, folks in our community ARE sexual and there are not a lot of traditional ways to express that sexuality, therefore you’re going to do a lot of experimenting to learn how to express that.”

Survey respondents were asked a series of questions related to the kind of sex that they had with three different types of sex partners. The first type was a *main partner*, which was described as someone with whom they have a close, intimate relationship ~ more than anyone else. The second type was a *casual partner* which was described as someone they have sex with, but do not consider their main partner. The third type was a *paying partner*, which was described as someone with whom they would exchange sex for money, drugs, shelter or food.

During the past 6 months 8 (42%) of the 19 people who had been sexually active responded that they had sex with a main partner only, 3 (16%) responded that they had sex with casual partners only, 7 (37%) had sex with main and casual partners, and 1 (5%) responded that they had sex with a main partner, a casual partner and a paying partner. Figure 13 shows the percentage of people who had main partners only; casual partners only; both main and casual partners; or main, casual and paying partners.

Figure 13



The survey also compared the actual number of sexual encounters with each type of sexual partner (main, casual or paying). The number of times respondents had sex with casual partners was much lower than the number of times reported for sex with main partners. Respondents who only had sex with a main partner reported sexual encounters ranging from 4-26 times. For respondents who only had sex with casual partners, the number of sexual encounters ranged from 1-6 times. For those who had both main and casual partners, the number of times they had sex with their main partners ranged from 2-50 times, and the number of times they had sex with their casual partners ranged from 1-6 times. The number of sexual encounters was not reported for one respondent who had both main and casual partners and for a respondent who had main, casual and paying partners.

➤ **FOCUS GROUP INSIGHTS**

There was a lot of discussion about sex work in the focus groups with participants generally agreeing that sex work was happening in Maine. When asked if sex work was prevalent, one of the comments was, “Yes, everyone knows someone.”

One participant commented, “Sex work is a big market – not something you look for, just something that finds you.” Another commented that, “Sex work is alluring to trans people because transpeople have huge money issues, they have to pay for normal stuff - an apartment, food, transportation, but then you add to that hormones and surgeries.”

Additionally, survey respondents were asked if within the last six months they had had sex where they used dildos, sex toys, penile prosthesis, butt plugs, etc. Overall, out of the 19 sexually active respondents, 10 (53%) had this type of sex. Specifically, 7 (37%) had this type of sex with a main partner, and 5 (26%) had this type of sex with a casual partner. Note that some respondents had both main and casual partners. No one had this type of sex with a paying partner. With main partners the number of times they had this type of sex ranged between 1-26 times and with casual partners it ranged between 1-6 times.

Sexual risk assessment questions relating to specific sexual activities with main, casual and paying partners and the use of condoms, dental dams or other barriers were studied for the six month period prior to the completion of the survey. Note that an attempt was made to determine differences in risk behavior between people who identified as FTM or masculine, and those who identified as MTF or feminine. This analysis was not possible due to:

- the overall low risk of the entire sample;
- difficulty in distinguishing how to classify people who identified themselves as “GenderQueer,” and

- when the responses to the risk behavior questions were separated into FTM and MTF categories, the numbers were too small to draw conclusions.

Table 4 summarizes the survey responses of the 19 survey participants who had been sexually active during this six month period.

Table 4

BEHAVIOR	TYPE OF SEX PARTNER (19 respondents)		
	Main % (Number)	Casual % (Number)	Paying % (Number)
Receptive anal sex in previous 6 months (someone's penis in their anus)	16% (3)	21% (4)	5% (1)
• Anal sex w/condom	11% (2)	21% (4)	5% (1)
• Anal sex w/o condom	-	-	-
• Anal sex w/ and w/o condom	5% (1)	-	-
Receptive vaginal sex in previous 6 months (someone's penis in their vagina)	11% (2)	5% (1)	-
• Vaginal sex w/condom	5% (1)	5% (1)	-
• Vaginal sex w/o condom	5% (1)	-	-
• Vaginal sex w/ and w/o condom	-	-	-
Penetrative anal sex in previous 6 months (their penis in someone's anus)	-	5% (1)	5% (1)
• Anal sex w/condom	-	5% (1)	5% (1)
• Anal sex w/o condom	-	-	-
• Anal sex w/ and w/o condom	-	-	-
Penetrative vaginal sex in previous 6 months (their penis in someone's vagina)	11% (2)	5% (1)	-
• Vaginal sex w/condom	5% (1)	5% (1)	-
• Vaginal sex w/o condom	5% (1)	-	-
• Vaginal sex w/ and w/o condom	-	-	-
Oral sex in previous 6 months (their mouth on someone's penis)	26% (5)	21% (4)	5% (1)
• Oral sex w/condom	5% (1)	5% (1)	5% (1)
• Oral sex w/o condom	11% (2)	5% (1)	-
• Oral sex w/ and w/o condom	11% (2)	11% (2)	-
Oral sex in previous 6 months (their mouth on someone's vagina)	32% (6)	32% (6)	-
• Oral sex w/barrier	-	11% (2)	-
• Oral sex w/o barrier	21% (4)	21% (4)	-
• Oral sex w/ and w/o barrier	5% (1)	-	-
	5% (1 person did not specify)	-	-

Note: In Table 4 the groups of people who used condoms and those who did not are not mutually exclusive; also some respondents had more than one type of partner in each behavioral category. In addition, three (3) people who had reported having some type of sex in the previous 6 months did not respond to any of these questions. While the reason for non-response is not clear, it may indicate sexual behavior not included on the survey such as receptive oral sex, or perhaps discomfort in answering specific questions.

The following summary observations can be made from the preceding table:

- Overall this survey population had little or no sexual risk for HIV during the past 6 months.
- For the riskiest sexual activity, receptive anal intercourse, one (1) person said that they only used a condom “sometimes.” This was with a main partner; their other risk was oral sex (fellatio) with “casual” partners.
- For receptive and insertive (penetrative) vaginal sex only one (1) person never used a condom and they were in a relationship with only one (1) main partner.
- Condoms were always used with casual and paying partners for insertive and receptive anal sex.
- Survey respondents were most likely to “sometimes” or “never” use condoms for oral sex than with any of the other sexual activities on the survey. According to various sources (CDC, 2003) and (UCSF, 2003), unprotected oral sex carries much less risk than unprotected anal or vaginal sex. Survey respondents may be using unprotected oral sex as a type of risk reduction strategy although there is no way to ascertain this from the survey questions themselves. Even in this area however, the reported risk behavior is relatively low.

➤ **FOCUS GROUP INSIGHTS**

Focus group participants discussed how much of a problem HIV/AIDS is in their community. Most felt that it was a big problem and that transgender people were engaging in a lot of risk behavior. There were a variety of reasons for this that were mentioned including:

- “...many trans don’t like using protection because they felt it defines their gender, it reminds them that they have body parts that they don’t like/want.”
- “Before transition, I was not really identifying with my body. The idea that I could get pregnant was something I never even thought about. I had a lot of sexual experiences physically, but I wasn’t really there psychologically.”

➤ FOCUS GROUP INSIGHTS CONTINUED

- “Talking about body parts is uncomfortable for transpeople. People are willing to engage in risky sex because they or their partners don’t acknowledge transpeople’s physical body parts and so won’t take measures to have safer sex as a biological male or female.”
- Feelings of marginalization which could result in choosing partners from higher risk populations (bisexual, drug using, etc.). One participant mentioned that people who are transgendered, “Need to seek out acceptance and validation among high risk populations because that’s where the potential partners seemed to be.”
- “There’s such an overwhelming need to be accepted as you perceive yourself that you could be willing to go with anyone to get that validation.”
- “The transgendered community in general, the post-operative community specifically, tends to have other things on their mind other than safety.” They are less worried about safe sex because they have ‘wild oats’ to sow and are not focusing on safe sex.”
- “A lot of people don’t feel like they’re going to live beyond 40 anyway.”

These issues are often not discussed. As one person commented, “It’s not talked about within the FTM community,” and another felt that there was confusion with sexual orientation and assumptions that MTF transgender persons would be interested only in men and FTM transgender persons would only be involved with women.

Additionally, a comment was made that, “There is a lack of knowledge (a misperception) that they are physiologically incapable of getting AIDS. The people aren’t even aware that it’s [HIV] a problem, and that’s scary. They have a lot of other things on their mind so that gaining knowledge about their susceptibilities is low on their list of priorities.”

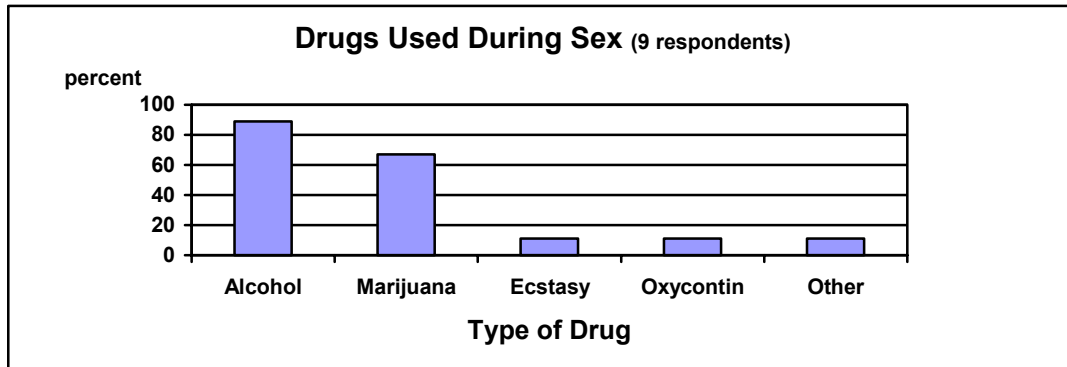
5. Alcohol and Drug Use

A series of questions related to drug and alcohol use during the past 6 months were included on the survey questionnaire. Needle sharing, whether for drugs, hormone injections, etc. is of major concern for HIV transmission. Hormonal needle sharing was discussed previously (see Section 2 above). When queried about injecting street drugs within the past 6 months, one (1) respondent reported that they had done this one (1) time and that the needle that they used was obtained from a clinic and had not been shared.

Survey participants were also asked if within the past 6 months they had sex while high on any type of drugs or alcohol. Out of the 29 respondents, 31% (nine people) had sex

while high on drugs or alcohol. Of these, eight (8) indicated alcohol use, 6 indicated marijuana use, and Oxycontin, Ecstasy, Klonopin, and Ambien had all been used once. Figure 14 illustrates responses to use of drugs during sex.

Figure 14



Note that some respondents chose more than one type of drug.

➤ FOCUS GROUP INSIGHTS

Focus group participants mentioned crystal methamphetamine and cocaine use in addition to the alcohol, marijuana and ecstasy use mentioned in the survey results. There were a range of different feelings about alcohol and drug use among focus group participants including:

- “Starting transition, I’ve been seeing it as an opportunity to be clean, treat my body well; I don’t want to screw up transition and want to live in my body now for a long time.”
- “It’s hard for me to see myself as I am, and deal with stress, [I] control my feelings with drugs and alcohol...a coping mechanism.”

6. PERCEPTION OF RISK

Perception of risk was measured by a survey question that asked respondents if they had put themselves or their partner at risk for HIV infection or re-infection during the previous 12 month period. While overall risk among respondents was very low (see Sections 4 and 5 above), respondent’s perception of their risk was higher. Four (4) people (14%) felt they had put themselves or their partner at risk and 2 people (7%) didn’t know if they had. In addition, focus group participants perceived very high HIV-related risk behaviors within the transgender community (see next page). This was in contrast to the survey questionnaire results which included focus group member answers.

➤ FOCUS GROUP INSIGHTS

Focus group members discussed their perceptions of HIV-related sexual risk in the transgender community and these perceptions were different from the results reported in the survey questionnaire. In comparing the two results, it appears from the focus group discussions that risk-behavior is higher under certain circumstances. These circumstances appear to be related to self-esteem, need for validation of identity, and changes brought about by transition and hormones in addition to those having to do with financial need, drug use, and not identifying with one's body parts. The need for validation appears to be a significant factor that drives risk behavior. Specific comments included:

- “The trans community is more susceptible to low self-esteem because we’re marginalized, discriminated against, and have more trouble finding work.”
- “It’s easier to exploit the trans population. It has low self-esteem...it has a smaller population of potential partners to pull from.”
- “The basic nature of trans-ness is an identity crisis. We’ll do almost anything for acceptance and validation of who we are and how we feel about ourselves. And that ID crisis coexists with all the other “usual” crises that everyone has in life.”
- “There’s such an overwhelming need to be accepted as you perceive yourself that you could be willing to go with anyone to get that validation. I was so eager to be female, to be taken as female, to function as female, that in spite of knowing about AIDS and STDs I was just off. The sense of final validation was so powerful, that it led me against all knowledge of safety.”
- “Pre-op hormones definitely affected sexuality.”
- “Transitioning (and going on hormones) was like going through a second adolescence with all of its physical and mental angst and insecurities and experimentation.”

There was a sense that came out in some of the focus groups that while people might be willing to engage in behaviors that put them at risk in order to get a sexual relationship, they are likely to use safer behaviors if they have supportive and validating relationships with others. As a participant in one of the focus groups stated, “The more validity I could get from the regular world, the less I would need it from more risky behaviors.”

7. Venues for Meeting Partners

The survey tool used in this needs assessment included a question regarding where people went to meet potential partners. Twenty three (23) people responded to this question. This information was sought because it might be helpful when designing intervention strategies. The majority (12, or 52%) of respondents met partners at affinity groups such as Gay, Lesbian, Bisexual, Transgender (GLBT) organizations. This was followed by parties and social gatherings (9 or 39%), and community events (8 or 35%). Table 5 lists the top venues for socializing as noted by respondents.

Table 5

VENUES FOR MEETING PARTNERS/SOCIALIZING (23 respondents)	
• GLBT Organizations	52% (12)
• Parties and social gatherings	39% (9)
• Community events	35% (8)
• Bars	26% (6)
• School	26% (6)
• Internet	22% (5)
• Nightclubs, discos, raves	22% (5)
• Workplace	13% (3)
• Club meetings	13% (3)
• Beach or pool	13% (3)
• Movie theaters	13% (3)
• Camping, hunting trips	13% (3)
• Museum or gallery	13% (3)

Note that respondents were able to choose more than one answer to this question.

Other venues that were picked by one or two people included sporting events, public parks, hiking trails, personal ads, the gym, dating/escort services and friends.

It is interesting to note that no one chose either of the two venues typically used for outreach interventions for males who have sex males (adult book stores/theaters and rest areas).

Note: The survey was designed so that respondents who had not had any type of sex in the past six months were instructed to skip over the series of sexual risk questions. Six (6) of the respondents who had not had sex missed answering the above question related to venues due to a flaw in the survey directions. In addition three (3) of the

respondents who did answer this question said that it was not applicable to them as they were not looking for a partner.

The survey tool also included additional questions related to venues used to meet casual sex partners and paying sex partners. Most people met casual sex partners through social networks. Four (4) respondents mentioned that they had casual sex with friends or met partners through friends. Three (3) respondents met sex partners through the Internet or online. Other single responses included meeting partners at parties, the local pub, the workplace, coffee shop and at conferences. One person who met a casual sex partner on the Internet subsequently met them at their home. The respondent that had a paying partner met them on the Internet and the street. Table 6 illustrates these responses.

Table 6

VENUES FOR MEETING CASUAL AND PAYING PARTNERS	
(10 respondents)	
• Friends	40% (4)
• Internet/online	30% (3)
• Parties	10% (1)
• Bar	10% (1)
• Workplace	10% (1)
• Coffee Shop	10% (1)
• Conferences	10% (1)
• Street	10% (1)

Note that respondents were able to choose more than one answer to this question.

9. Support

Focus group participants were asked where they found support. Almost all mentioned some type of positive support. Friends, significant others, families and therapists were mentioned along with peer groups, others in the trans community, a doctor, the theater community at USM, church and the Portland trans community in particular. One person commented that, “People of color have been very supportive of my identity; they understand the power and privilege dynamic.” Members of the youth focus group discussed the strong trans community in southern Maine. Comments included: “I feel very fortunate to have this community here, there are transpeople in Maine in more rural communities that don’t have support of other transpeople.” and, “The Internet has been a huge resource, other people contact me because they know me from the Internet. They want community. We are very privileged to have a trans community in real life.” Another participant added, “It feels good to be able to provide support for people that don’t have community.”



CONCLUSIONS AND RECOMMENDATIONS

Data from this needs assessment suggest that risk for HIV infection was low among the transgendered persons surveyed. Overall respondents seemed to be very aware of health issues, possibly because of the perception of greater potential risk within the transgender community. As a whole, respondents were well educated, and appear to have access to healthcare, housing and employment. However, issues related to stigma, and the availability of trans-friendly and trans-specific services and information are ongoing concerns.

It is important to note that other national studies show higher risk in this population and the focus groups participants perceived higher risk within the overall transgender community in Maine. This needs assessment may be biased due to the way the information was gathered (through people connected with trans-friendly organizations) and therefore may not be reflective of the larger population. Further study focusing on younger people (who in this needs assessment reported more partners and sexual encounters) is recommended.

The respondents to the written survey showed very low overall sexual or needle sharing HIV-related risk. As in the earlier CPG 2002 – 2003 Needs Assessment, respondents were considered to have overall risk *if*:

1. they engaged in one or more of the following activities: receptive anal sex without a condom, insertive anal sex without a condom, receptive vaginal sex without a condom, sharing needles; *and*
2. if in addition to their “main partner” they had other sexual partners during the 6 months prior to the survey.

When looked at in the aggregate, only one (1) of the survey respondents had elevated risk due to using a condom “sometimes” during insertive anal intercourse with a main partner and also having casual oral sex partners.

It appears that some of the risk that was discussed in focus groups was related to what people felt that they might do in the future, whereas the written survey looked at risk over the previous six months. In the written survey, 10 people (35%) had not had any type of during the preceding 6 months. Although the respondents that are sexually active appear to be taking good care of themselves, the focus group data suggest that some would be willing to engage in riskier behavior if they could find partners that validated their identity and were interested in having sex with them (see Insights on page 22 and 24). This potential for risk is important to bear in mind when doing prevention work with the transgender population.

Many respondents used needles (for hormones, 1 for street drugs) so there is greater potential for risk in this area as well. Of those people who had some risk (including greater number of partners, more types of partners such as casual and paying partners,

injection drug use, and drug use during sex) most were younger, so interventions might focus on youth and young adults. Additionally, there appears to be a greater potential for risk during and immediately following transitioning, with hormones and eagerness to experiment with ones new body playing a role. One focus group member mentioned that it was “like going through second adolescence.”

Due to the overall low risk of the entire sample; difficulty in distinguishing how to classify people who identified as “GenderQueer;” and small sample size when the responses to the risk behavior questions were separated into female to male (FTM) and male to female (MTF) categories, it was not possible to determine any differences in risk between FTM and MTF transgendered persons. This could also be an area for future study.

Recommendations from focus group participants for delivery of HIV prevention services to this population are listed below.

➤ **FOCUS GROUP RECOMMENDATIONS**

Focus group participants were asked for suggestions on the best way to get trans-specific HIV/AIDS information to the transgendered community. Some of the ideas included:

- “We should see the word “transgendered,” “transsexual,” and/or the trans symbol.”
- “Having a picture of someone who was “clearly” trans would be negative because the breadth of the continuum could turn some on and repel others.”
- “I would use a ‘group’ of photos of different types of appearing transgendered folks, of FTM, MTF, different races, and ages, transsexuals, cross-dressers, gender-benders, etc.”
- A person in a different group stated, “Actually the info needs to be both general info and aimed at specific ID’s. Brochure design would be quite varied, multiple designs would be needed. The cover design might be specific to a group while the internal information is the same.”
- The literature ought to be targeting younger folks because trans folks are coming out earlier and earlier.”

Venues mentioned for distributing information included: support groups, peer groups, homeless shelters, drug treatment centers, doctors offices, clinics, therapists offices, etc. Someone from the youth group commented, “Schools safer sex programs should incorporate information for all identities or at least make it available.” Another member of the group said, “Outreach in bars is important, aim for reaching community leaders, community groups, not just about MSM [males who have sex with males] issues. Outreach to queer community because it already has its ears open, this would create a network.”

In conclusion, health professionals and service providers need to be better trained to understand and be sensitive to transgender persons including issues related to transitioning, the difference between gender identification and sexual orientation, and stigma and confidentiality concerns. This training should be incorporated into all Standards of Care and Quality Assurance measures. In addition:

- It is very important that forms and questions used by agencies and healthcare providers to classify people include transgender-specific categories.
- Trainings for service delivery such as those for Counseling, Testing and Referral (CTR) should include role plays or scenarios that include transgender examples.
- Trans-specific healthcare literature that addresses the needs and concerns of the transgender community should be developed or purchased and made easily available.

As one focus group member stated, “Don’t just try to remove the risk, but go for the cause of the behavior. Provide positive experiences for people, safe, positive experience.”

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APPENDIX A

Survey Tool

CPG Survey

TRANSGENDER BEHAVIORAL RISK ASSESSMENT

Here's your chance to contribute to the health and well-being of people like yourself living in Maine. The information in this survey is being collected to better understand how to decrease HIV and AIDS among transgender people living in Maine. The group collecting and using this information is the Maine HIV Prevention Community Planning Group (CPG), a community group that plans HIV prevention for Maine.

This is not a test! There are no right or wrong answers. The only "right" answer is the one that is honest for you. Your answers to these questions are very important and are strictly confidential – no one will know what you said. For that reason please don't write your name anywhere on this survey.

Please be aware that this survey contains some explicit language. This is to help make sure that everyone understands the questions.

If you'd like to know more about this survey or the work of the CPG, call Christine Agronick at 1-800-427-7566, extension 233 or visit our website at <http://www.mehivcpg.org>.

Do yourself and your friends a favor – complete this form.

BACKGROUND INFORMATION

1. What sex were you assigned at birth?
 - Male
 - Female
 - Intersexed
2. Which gender do you identify with?
 - Masculine
 - Feminine
 - Other _____
 - Transgender: Male to Female
 - Transgender: Female to Male
3. What is your race? (Check all that most apply)
 - African American/Black
 - Caucasian/White
 - Native American/Alaskan Native
 - Asian
 - Pacific Islander
 - More than one race
 - Other
4. What is your ethnicity?
 - Hispanic
 - Franco-American
 - Non-Hispanic
5. How old are you? _____
6. Where do you currently live? (Check **ALL** that apply)
 - House or apartment
 - In a friend or family member's home or apartment
 - On the streets, in a park, a car, etc. (specify) _____
 - Single room occupancy hotel room
 - Halfway house or drug/alcohol program
 - Shelter (specify) _____
 - Hospital
 - Jail
 - Other: _____

7. Where did you get your health care in the past year? (*This does not include hormone therapy*) (Check **ALL** that apply)

- Private doctor, or HMO
- Veterans Administration ~ military
- Hospital emergency room
- Public clinic/health center (like Portland Public Health or Auburn STD Clinic)
- Alternative/complementary care
- Other (specify) _____
- None (haven't received any care in the past year)

8. In the past year did you take cross-gender hormones?

- Yes (Continue to question 9)
- No (Skip to Question 10)

9. Where did you get your *hormonal* health care in the past year? (Check **ALL** that apply)

- Private doctor, or HMO
- Veterans Administration ~ military
- Hospital emergency room
- Public clinic/health center (like Portland Public Health or Auburn STD Clinic)
- Other (specify) _____
- Alternative/complimentary care
- Get hormones off streets
- Get hormones from friends
- Internet

10. What region of the state do you currently live in?

- Northern Maine:** Aroostook, Hancock, Penobscot, Piscataquis, and Washington Counties
- Central Maine:** Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset and Waldo Counties
- Southern Maine:** Cumberland and York Counties

11. During the past year, what were your sources of income? (Check **ALL** that apply)

- Full-time employment
- General Assistance
- Part-time employment
- Selling drugs
- Other: _____
- Sex work
- SSI
- SSDI
- TANF/AFDC

12. What is your highest level of schooling?

- Grade school / elementary school
- Middle school
- Some high school
- High school graduate / received GED
- Trade, technical, or vocational school
- Other (specify) _____
- Some college education (including an AA)
- Received college degree
- Some graduate school
- Received graduate degree

13. What is your current sexual orientation? (check only **ONE**)

- Lesbian
- Gay (male)
- Bisexual
- Other (specify) _____
- Heterosexual (straight)
- Queer

The following questions are about sexual behaviors. A few of these questions may seem personal, but it is important to gather this type of data so that we can plan appropriate prevention health services for the transgender community. Please be honest and accurate. Remember, your name does not appear on this form!

SEXUAL RISK ASSESSMENT

14. In the past 6 months, have you had any type of sex with? (check **ALL** that apply)

- | | | | |
|------------------------------|------------------------------|------------------------------|------------------------------|
| 14a.Males | 14b.Females | 14c.Trans People | 14d.Intersexed People |
| <input type="checkbox"/> Yes | <input type="checkbox"/> Yes | <input type="checkbox"/> Yes | <input type="checkbox"/> Yes |
| <input type="checkbox"/> No | <input type="checkbox"/> No | <input type="checkbox"/> No | <input type="checkbox"/> No |

Note: If you answered NO to all of the above, skip to Question 34.

15. How many different people have you had sex with over the past 6 months?

(Indicate number of partners)

_____ Male partner(s)	_____ Trans partner(s)
_____ Female partner(s)	_____ Intersexed partner(s)

The next few questions ask about three different types of sex partners. The first type is a *main partner*, which is someone with whom you have a close, intimate relationship ~ more than anyone else. The second type is a *casual partner* which is someone you have sex with, but do not consider your main partner. The third type is a *paying partner*, which is someone with whom you exchange sex for money, drugs, shelter or food.

For Questions 16 – 29 answer each question for all three types of partners (main, casual or paying).

16. In the past 6 months did you have sex where you used dildos, sex toys, penile prosthesis, butt plugs etc?

16a. Main Partner	16b. Casual Partner(s)	16c. Paying Partner(s)
<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes
<input type="checkbox"/> No	<input type="checkbox"/> No	<input type="checkbox"/> No
How many times?	How many times?	How many times?

17. In the past 6 months, have you had **any type of sex** with the following types of sex partners? (Check **ALL** that apply)

17a. Main Partner	17b. Casual Partner(s)	17c. Paying Partner(s)
<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes
<input type="checkbox"/> No	<input type="checkbox"/> No	<input type="checkbox"/> No
How many times?	How many times?	How many times?

Note: If you answered NO to all of the above, skip to Question 34.

18. In the past 6 months, did you have the type of **sex where someone put their penis in your butt?**

18a. Main Partner	18b. Casual Partner(s)	18c. Paying Partner(s)
<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes
<input type="checkbox"/> No	<input type="checkbox"/> No	<input type="checkbox"/> No
How many times?	How many times?	How many times?
<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply

19. When you have this type of sex how often was a condom used?

19a. Main Partner	19b. Casual Partner(s)	19c. Paying Partner(s)
<input type="checkbox"/> Always	<input type="checkbox"/> Always	<input type="checkbox"/> Always
<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes
<input type="checkbox"/> Never	<input type="checkbox"/> Never	<input type="checkbox"/> Never

20. In the past 6 months, did you have the type of **sex where someone put their penis in your vagina?**

20a. Main Partner	20b. Casual Partner(s)	20c. Paying Partner(s)
<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes
<input type="checkbox"/> No	<input type="checkbox"/> No	<input type="checkbox"/> No
How many times?	How many times?	How many times?
<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply

21. When you have this type of sex how often was a condom used?

21a. Main Partner	21b. Casual Partner(s)	21c. Paying Partner(s)
<input type="checkbox"/> Always	<input type="checkbox"/> Always	<input type="checkbox"/> Always
<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes
<input type="checkbox"/> Never	<input type="checkbox"/> Never	<input type="checkbox"/> Never

22. In the past 6 months, did you have the type of **sex where you put your penis in someone's butt?**

22a. Main Partner	22b. Casual Partner(s)	22c. Paying Partner(s)
<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes
<input type="checkbox"/> No	<input type="checkbox"/> No	<input type="checkbox"/> No
How many times?	How many times?	How many times?
<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply

23. When you have this type of sex how often was a condom used?

23a. Main Partner	23b. Casual Partner(s)	23c. Paying Partner(s)
<input type="checkbox"/> Always	<input type="checkbox"/> Always	<input type="checkbox"/> Always
<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes
<input type="checkbox"/> Never	<input type="checkbox"/> Never	<input type="checkbox"/> Never

24. In the past 6 months did you have the type of **sex where you put your penis in someone's vagina?**

24a. Main Partner	24b. Casual Partner(s)	24c. Paying Partner(s)
<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes
<input type="checkbox"/> No	<input type="checkbox"/> No	<input type="checkbox"/> No
How many times?	How many times?	How many times?
<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply

25. When you have this type of sex how often was a condom used?

25a. Main Partner	25b. Casual Partner(s)	25c. Paying Partner(s)
<input type="checkbox"/> Always	<input type="checkbox"/> Always	<input type="checkbox"/> Always
<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes
<input type="checkbox"/> Never	<input type="checkbox"/> Never	<input type="checkbox"/> Never

26. In the past 6 months did you have the type of **sex where you put your mouth on someone's penis?**

26a. Main Partner	26b. Casual Partner(s)	26c. Paying Partner(s)
<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes
<input type="checkbox"/> No	<input type="checkbox"/> No	<input type="checkbox"/> No
How many times?	How many times?	How many times?
<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply

27. When you have this type of sex how often was a condom used?

27a. Main Partner	27b. Casual Partner(s)	27c. Paying Partner(s)
<input type="checkbox"/> Always	<input type="checkbox"/> Always	<input type="checkbox"/> Always
<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes
<input type="checkbox"/> Never	<input type="checkbox"/> Never	<input type="checkbox"/> Never

28. In the past 6 months did you have the type of **sex where you put your mouth on someone's vagina?**

28a. Main Partner	28b. Casual Partner(s)	28c. Paying Partner(s)
<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes
<input type="checkbox"/> No	<input type="checkbox"/> No	<input type="checkbox"/> No
How many times?	How many times?	How many times?
<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply	<input type="checkbox"/> Does not apply

29. When you have this type of sex how often was a dental dam or other barrier used?

29a. Main Partner	29b. Casual Partner(s)	29c. Paying Partner(s)
<input type="checkbox"/> Always	<input type="checkbox"/> Always	<input type="checkbox"/> Always
<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes
<input type="checkbox"/> Never	<input type="checkbox"/> Never	<input type="checkbox"/> Never

30. In the past 12 months, has a doctor or a clinic diagnosed you with or treated you for a Sexually Transmitted Infection?

Yes

No

31. Where do you go to hang out, socialize and/or meet potential sexual partners? (Check **ALL** that apply)

- | | |
|---|--|
| <input type="checkbox"/> The workplace | <input type="checkbox"/> GLBT organizations |
| <input type="checkbox"/> Community events | <input type="checkbox"/> Public bath/sauna |
| <input type="checkbox"/> Sporting events | <input type="checkbox"/> Personal ads |
| <input type="checkbox"/> Movie theaters | <input type="checkbox"/> Camping/hunting trips |
| <input type="checkbox"/> Public park | <input type="checkbox"/> Parties and social gatherings |
| <input type="checkbox"/> Bars | <input type="checkbox"/> The gym |
| <input type="checkbox"/> Hiking trails | <input type="checkbox"/> Museum or gallery |
| <input type="checkbox"/> Dating/escort service | <input type="checkbox"/> Adult book store/theater |
| <input type="checkbox"/> School | <input type="checkbox"/> Rest areas |
| <input type="checkbox"/> Club meetings | <input type="checkbox"/> Night clubs/discos/raves |
| <input type="checkbox"/> Beach or pool | <input type="checkbox"/> The Internet |
| <input type="checkbox"/> Other places (please name) _____ | |

32. If you had casual sex partners in the past 6 months, where did you go to pick them up? _____

33. If you had sex with paying partners in the past 6 months, where did you go to pick up dates or tricks? _____

HORMONE USE

34. In the past 6 months, have you **injected** any hormones?

- Yes (Continue to question 35)
 No (Skip to Question 39)

35. In the past 6 months, how many times have you injected hormones? _____

36. In the past 6 months, where did you get the syringes you use to inject hormones? (Check **ALL** that apply)

- From a clinic, health center or private doctor
 From a pharmacy (with or without a prescription)
 Off the streets (*dealer / black market*)
 Off the streets (*find needles*)
 From a lover, sex partner or friend (*specify where they get them*) _____
 From a needle exchange site (*specify the site*) _____
 From someone who gets needles at needle exchange sites
 From a diabetic
 From the Internet
 Other (*specify*) _____

37. When you injected *hormones* in the past 6 months, how many times did you use a needle that someone else had used before you (including your family, friends, and partners)?
_____ (# of times)

(Note: if "0 times" skip to Question 39)

38. In the past 6 months, when you used *hormone needles or syringes* that someone else had used, how often did you clean them with bleach before using?

- Always
- Sometimes
- Never

39. In the past 6 months have you received silicone injections? Yes No

40. From what source did you get the silicone? _____

The following questions are about alcohol and drug use NOT including injectable hormones. Remember your answers are strictly confidential and there is no way to connect your answers to your name.

ALCOHOL AND DRUG USE

41. In the past 6 months have you injected any type of street drugs?

- Yes (Continue to question 42)
- No (Skip to Question 46)

42. In the past 6 months, about how many times did you inject any type of street drugs?
_____ (# of times)

43. When you **injected street drugs** in the past 6 months, how many times did you use a needle that someone else had used before you (including family, friends, partners)?
_____ (# of times)

(Note: if "0 times" skip to Question 46)

44. In the past 6 months, when you used needles or syringes that someone else had used, how often did you clean the needles or syringes with bleach before you used them?

- Always
- Sometimes
- Never

45. In the past 6 months, where did you get the needles you use to inject street drugs? (Check **All** that apply)

- From a clinic, health center, or a private doctor
- From a pharmacy
- From a diabetic
- Off the streets (*dealer / black market*)
- Off the streets (*find needles*)
- From a lover, sex partner or friend (*specify where they get them*) _____
- From a needle exchange site (*specify the site*) _____
- From someone who goes to needle exchange sites
- From the Internet
- Other (specify) _____

46. In the past 6 months, did you have sex while you were high on any type of drugs or alcohol?

- Yes (continue to Question 47)
- No (skip to Question 48)

47. If yes, what drugs were you high on? (Check **ALL** that apply)

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> Alcohol | <input type="checkbox"/> Marijuana |
| <input type="checkbox"/> Cocaine | <input type="checkbox"/> Poppers / Amyl Nitrate |
| <input type="checkbox"/> Crack | <input type="checkbox"/> Special K |
| <input type="checkbox"/> Ecstasy / E | <input type="checkbox"/> Speed/Crystal Meth |
| <input type="checkbox"/> GHB | <input type="checkbox"/> Oxycontin |
| <input type="checkbox"/> Heroin | <input type="checkbox"/> Dilaudid |
| <input type="checkbox"/> LSD | |
| <input type="checkbox"/> Other _____ | |



48. Do you know your HIV status?

- Positive
- Negative
- Don't know
- Don't want to say

49. If you are negative or don't know your status, how long has it been since your most recent HIV test?

- | | |
|---|--|
| <input type="checkbox"/> I haven't been tested | <input type="checkbox"/> Within the last 7 – 12 months |
| <input type="checkbox"/> Within the last 0 – 3 months | <input type="checkbox"/> It has been longer than 12 months |
| <input type="checkbox"/> Within the last 4 – 6 months | |

50. If you have not tested for HIV which of the following relate to your decision not to be tested? (Check **ALL** that apply)

- | | |
|---|--|
| <input type="checkbox"/> I don't worry about HIV | <input type="checkbox"/> I don't know where to go for testing |
| <input type="checkbox"/> I am at low risk for HIV | <input type="checkbox"/> Testing sites/hours are not convenient |
| <input type="checkbox"/> Privacy/confidentiality | <input type="checkbox"/> I don't have access to testing services |
| <input type="checkbox"/> I don't think I can get HIV | <input type="checkbox"/> I don't have the money |
| <input type="checkbox"/> I am afraid to learn the results | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> I have not been sexually active | |

51. If you did not return for your HIV test results, which of the following relate to your decision not to come back? (Check **ALL** that apply)

- | | |
|--|---|
| <input type="checkbox"/> I don't worry about HIV | <input type="checkbox"/> Testing sites/hours are not convenient |
| <input type="checkbox"/> I am at low risk for HIV | <input type="checkbox"/> I didn't have transportation to the testing site |
| <input type="checkbox"/> Privacy/confidentiality | <input type="checkbox"/> I didn't have the money |
| <input type="checkbox"/> I don't think I can get HIV | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> I was afraid to learn the results | |

52. In the past 12 months do you feel you have put yourself or your partner at risk for HIV infection or re-infection?

- Yes
- No
- Don't know

THANK YOU VERY MUCH FOR TAKING THE TIME TO ANSWER THESE QUESTIONS.

APPENDIX B

Focus Group Protocol Topic Areas for Discussion

PROTOCOL/GUIDELINES FOR TRANSGENDER FOCUS GROUPS

Facilitators: Please sign and return this form along with the surveys, audiotapes, meeting notes and summary report.

GOAL: To better understand the knowledge of, and attitudes about, HIV among transgender people in Maine and their risks for infection.

Supplies:

Consent Forms, Paper and Pencil Questionnaire, Discussion Questions, Pad of Paper, Pens, Incentives, Tape Recorder

Agenda:

0:00 Participants arrive.

0:05 Introduce yourself. Explain consent form. Participants review and sign.

- Emphasize purpose of the focus group (see goal above) and confidentiality.
- Review the purpose of the CPG and why we are here.
 - The HIV Prevention Community Planning Group (CPG) is a community group that plans HIV prevention for the State of Maine.
 - The CPG wants to learn more about the trans community in order to better understand the needs of transgender people regarding HIV and related issues. This is very important because there is very little information currently available.
- Review what participants will be doing today and what the next steps will be.
 - TODAY: Complete a paper and pencil survey & participate in a discussion led by a facilitator around certain topic areas. You will also be asked to take home additional surveys with postage paid envelopes to give out to other transgender people that you know. You will be given \$25.00 at the end to thank you for your participation.
 - NEXT STEPS: Additional focus groups will be completed, results of all surveys will be tabulated and a CPG report summarizing the results of the surveys and the focus groups will be written and distributed. All original documentation will be kept locked in the CPG office.

0:15 Participants complete the paper and pencil questionnaire

0:30 Focus Group begins

Thank people for coming.

- Introduction of yourself (the facilitator) and the note taker
- Get OK to tape record session
 - Emphasize confidentiality ~ don't use last names
- Explain how the meeting will proceed and how members can contribute.
- Set ground rules. Bring in list and ask if there are others

- Encourage open participation.
- Set the tone by asking an opening question and making sure all opinions on that question are heard.
- Ask further questions in the same general manner (try to get everyone to participate).
- When all your questions have been asked, ask if anyone has any other comments to make.
- Thank the group for coming!

2:00 Focus Group ends

- Participants are thanked
- Participants are asked if they would like to distribute the paper and pencil questionnaires (with SASE) to other transgender people that they know. Emphasize the importance of hearing from as many transgender people as possible.
- Focus group participants are given \$25.00 incentives.
- Facilitators provide support and/or referrals to participants if needed.

Other Issues

Time: The time for the focus group should be 1.5 hours. In order to complete all of the discussion questions, try to limit answers to about 5 minutes per participant apiece. Begin with the first question and continue until time is up. If there are still questions remaining at the end of 1.5 hours and if everyone agrees to continue, than the session can continue.

Eligibility: No more than 12 people (6 Male to Female, and 6 Female to Male) should be invited to attend each focus group session. A minimum of 6 are required in order to conduct the focus group. The CPG is interested in gathering information from people whose behaviors put them at risk for HIV. Priority should therefore be given to those who are at highest risk. Use your best judgment.

Incentive: A \$25.00 incentive will be given to all participants who complete the survey and participate in the focus group session. These incentives are to be paid by the contractor.

Number of focus groups: A total of 2 focus groups will be held by each contractor.

Audiotaping/Notetaking: The focus group should be audio taped AND someone should be taking extensive notes during the focus group session. The notes are important as tape recordings are often unclear. The running of the tape recorder should be handled by the note taker.

Provide written summary of the focus group: In addition the facilitator and note taker will supply a supplemental report that should include insights about the non-verbal dynamics of the group that may not be apparent on the tapes or in the notes.

I agree to conduct the focus groups according to the above protocol.

Date

Date

TRANSGENDER FOCUS GROUP

TOPIC AREAS FOR DISCUSSION

Goal: To better understand the knowledge of, and attitudes about, HIV among transgender people in Maine and their risks for infection.

Trans Identity

Help participants feel comfortable and listened to

- When you talk about stuff, talk about yourself, do not use names of other people
- Can you take 2 or 3 minutes and tell us something about your self - Describe your gender identity

Access/Barriers

Where do they get information, how best to give information, what are the barriers to info/services?

- Where have you gotten any information about HIV/AIDS?
- Have you gotten any trans specific information about HIV/AIDS? If so, where?

Explore possible answer ~ do they not need or want information?

- What are the best ways to get HIV/AIDS trans-specific information to the trans community? Brainstorm . . .
- What is your personal experience around getting HIV/AIDS services ~ both positive/negative?

Risk Behaviors

Identify their perceptions of risk behavior in the trans community

- How much of a problem do you think HIV/AIDS is in the transgender community?
- How much do you think about HIV/AIDS in your personal life?
- What do you think is going on in the transgender community that puts people at risk for HIV? Brainstorm ~ reminder not to use specific names of people
 - What kind of sex – what is risky?
 - What about sex work?

- What about needle sharing? (drugs and hormones)
- Tell me about alcohol and drug use in the trans community.
- What type of services would help with these behaviors?

Social Support

Do they have it, what is it, is it needed?

- If you woke up tomorrow feeling “really... [bad]” about your gender ID do you have someone or a group you would reach out to first?
- What is relationship/friendship to you?
- Anything else you need to say about transgender people and HIV that hasn't been discussed that you feel is important?

Conclusion ~ Wrap Up

- Reminder of what the information will be used for
 - The focus group discussion and survey answers will be summarized into a report by the CPG Transgender Focus Group Committee. The final report will be distributed to the Community Planning Group members for use in HIV prevention planning and to other interested parties upon request. The summary will NOT contain any information that could identify any individual person that participated in the focus group.
- Thank participants for their participation!

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