

**Michigan Persons Living with HIV/AIDS
Needs Assessment Results and
Recommended Intervention and Evaluation Activities**

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Executive Summary

A needs assessment was conducted with 326 persons living with HIV/AIDS (PLWH/A) throughout the State of Michigan to determine: specific information regarding how, when, and where they believe they became infected, factors that contributed to their infection, risk behaviors that they have engaged in and challenges they have faced since their infection, and services they would find useful. An effort was made to conduct a purposive sample by race and risk factors based on current epidemiological data. The factors most commonly indicated as contributing to their infection include: not knowing they were at risk, being under the influence of drugs or alcohol, not knowing about, liking, or having access to tools for practicing safer sex, and not feeling assertive enough for safer sex.

Many of the respondents report engaging in unprotected sexual behaviors. This indicates a need for prevention activities targeted toward PLWH/A. The data indicate significant portion of the sample report having engaged in unprotected anal, vaginal, and oral sex, since they learned of their infection, but most (58.4%) believe they have not infected anyone else since their infection.

There are some clear areas of need reported by the participants in this study. First, is an obvious need for enhanced communication skills. Many respondents report difficulties communicating with sex partners, families, and friends about their HIV status and about safer-sex options. Second, there are a number of psycho-social challenges reported by respondents including feeling hopeless about or fearful of intimate relationships. Indeed, many respondents reported a need for counseling and support for dealing with HIV and expressed a desire for counseling for their sex partners. Most (95.8%) also expressed a need to meet others with HIV. Additionally, a significant number of participants reported that they have had difficulty practicing and maintaining safer sex. Any interventions designed for this population should address these needs.

Recommendations for Intervention Design

Based on the needs assessment data as well as a review of the relevant literature, it is recommended that an intervention targets communication skills and socially normative behaviors around talking about safer sex options. The intervention should be modeled around the best practices (e.g. LA's Living and Loving Fully with HIV and the empowerment project) and based in behavioral theory (e.g. the Theory of Reasoned Action; Fishbein & Ajzen, 1975). The intervention should target HIV positive MSM (men who have sex with men) given the high behavioral risk of this group in Michigan. The intervention should be peer-based (to facilitate the social normative component), and include group-level seminar series combined with individual level client-centered risk reduction/referral sessions and formal outreach.

Outcome Evaluation

The design of the outcome evaluation will be driven, in part, by the format of the intervention. The intervention will be developed based on a combination of two social psychological theories. Thus, the hypotheses for the outcome evaluation will also be based on the variables in this model. The design for the evaluation will include a quasi experimental pre-test/post-test comparison group design. The pretest will take place immediately prior to the intervention and the post-test will occur immediately following

and 6 weeks later to assess any longer term effects of the intervention. Participants will include a convenience sample of PLWH/A in the metro Detroit area. Scales will be self-administered via questionnaire in order to elicit accurate information and to protect the anonymity of the respondents. All data will be analyzed via the Statistical Package for the Social Sciences (SPSS) and content analysis with multiple coders to ensure intercoder reliability.

Michigan Persons Living with HIV/AIDS Needs Assessment Results and Recommended Evaluation Activities

A needs assessment was conducted with persons living with HIV or AIDS (PLWH/A) in the state of Michigan to determine: specific information regarding how, when, and where they believe they became infected, factors that contributed to their infection, risk behaviors in which they have engaged, challenges they have faced since their infection, services they would find useful, and basic demographic information about participants. These data were collected via self-administered questionnaire supplemented by focus groups. The results reported below include primarily the survey data. The informal nature of the focus groups made generalizations across groups difficult. All respondents were informed of the anonymous and voluntary nature of the questionnaire.

Method

Survey Participants

Participants were sampled via a purposive nonprobability sample from PLWH/A gatherings, support groups, and case management clients throughout the State of Michigan. The purposive sampling method was chosen in order to approximately represent risk and racial groups based on the State Epidemiological Profile. Participants in the survey were asked to participate in a one hour focus group to seek additional information about the survey questions. The participants in the needs assessment included 326 PLWH/A in Michigan. Participants were primarily male (75%) with an average age of 40.05 (SD = 8.29; Range = 17-63). Eight of the respondents (2.5%) were transgendered. The racial/ethnic background reported by respondents included 56% African-American, 36% White, 2.8% Hispanic/Latina/o, 1.6% Native American, and 3.5% self-identified as having a racial or ethnic background other than those listed above. Half of respondents identified as being men having sex with men (MSM), 38% identified as heterosexual, and 11% reported as bi-sexual. The respondents reported being from a wide range of counties in Michigan (35 counties were represented in the sample), but the majority of the respondents were from counties in the metro-Detroit area including Wayne (59%), Washtenaw (4.9%), and Oakland (4.6%). This pattern is representative of the pattern of the epidemic in Michigan.

Procedures

Following verbal consent to participate, each participants received a copy of the survey instrument containing 25 closed and open-ended items. Although the survey was self administered, participants were offered verbal administration to mitigate literacy issues. The survey took approximately twenty minutes to complete. Participants were not reimbursed for their participation. The entire survey instrument is presented in Appendix A.

Measurement

The development of the survey items, particularly the checklists, was accomplished in collaboration with the Michigan's PLWH/A Task Force. These items asked specific information regarding how, when, and where they believe they became infected, factors that contributed to their infection, risk behaviors in which they have engaged, challenges they have faced since their infection, services they would find useful, and basic demographic information about participants.

Results

Factors Associated with HIV Acquisition

Risk Behaviors. The respondents were asked to report all of the behaviors that they believe led to them becoming infected with HIV. Many respondents reported that receptive anal sex without a condom (50.3%), unprotected insertive anal sex (36.8%), fellatio (35.6%), or rimming (13.8%) may have led to their infection with HIV. Several respondents believed that they became HIV positive due to insertive anal sex with a condom (12.6%) or receptive anal sex with a condom (10.2%). Approximately 39.9% of the respondents indicated that vaginal sex without a condom may have led to their becoming HIV positive. Exposure via blood transfusion or receipt of blood products was mentioned by 7% of respondents. Additionally, some reported that sharing needles for drug use (16.3%) or sharing other drug paraphernalia (8%) may have contributed to their infection. Few respondents indicated that vaginal sex with a condom (4.9%), cunnilingus (10.1%), or other behaviors (8%) such as occupational exposure led to their infection. The responses of those participants who listed "other" are included, along with all comments and responses to open-ended questions, in Appendix B.

Transmitting Partner Participants were also asked if they knew the person from whom they acquired their infection and if so, what their relationship was with that person at the time. Thirty-six percent of respondents could not identify the person from whom they acquired the HIV virus. Some thought they could guess who the person might be (19%) or were fairly certain of the identity of that person (15%). Twenty-nine percent of respondents knew for certain the person from whom they acquired HIV. Although many reported that they could not identify the person, only 16.2% could not remember their relationship with the person from whom they acquired HIV. This discrepancy could be due to consistent sexual behaviors on the part of respondents at the time of their infection (e.g. always having sex with casual sex partners). Many reported the relationship with the person they believe infected them as casual acquaintance/casual sex partner (36.8%) or spouse/significant other (24.1%). Fewer respondents indicated the person from whom they acquired the infection was a long time friend (11.7%), commercial sex worker (3.2%) or other person (7.9%).

Location and Timeline of HIV Infection

The majority of the respondents acquired HIV either in the Detroit Metro area (54.7%) or while living outside of Michigan (MI; 23%). Analysis of the open-ended

responses indicated that those who believed they had been infected out of state most commonly listed California, New York, or Florida. The most frequently reported year in which they acquired their HIV infection was 1987. For those participants who had received an AIDS diagnosis, most reported being diagnosed in 1996 (See Table 1).

Table 1. History of Diagnoses (in Years) including Number of Participants Reporting, Minimum, Maximum, Mean (Standard Deviation), and Mode.

	N	Min.	Max.	Mean (S)	Mode
When did you learn you were infected with HIV?	292	1979	2000	1990 (5.17)	1987
When did you learn you were positive?	306	1980	2001	1992 (4.58)	1989, 1996
When did you receive an AIDS diagnosis?	153	1984	2000	1994 (3.96)	1996

Additional Factors Contributing to Transmission

Participants were also asked to report the factors that might have impacted their becoming HIV positive. The most commonly reported factors include being drunk or high (37.3%), not thinking that they were at risk for HIV (44%), being “in love” at the time (24.1%), and not feeling assertive enough for safer sex (22%). Several indicated that they were depressed at the time they engaged in risk behaviors that may have led to their infection (19.8%). Additionally, a number of people indicated that either they (26.2%) or their partner (24.7%) didn’t like condoms or didn’t have a condom (20.4%), so they did not use a condom at the time they were infected. Less frequently, people indicated that the other person looked “clean” (19.4%), told them that they were HIV negative (11%), or indicated that they were monogamous (14.5%).

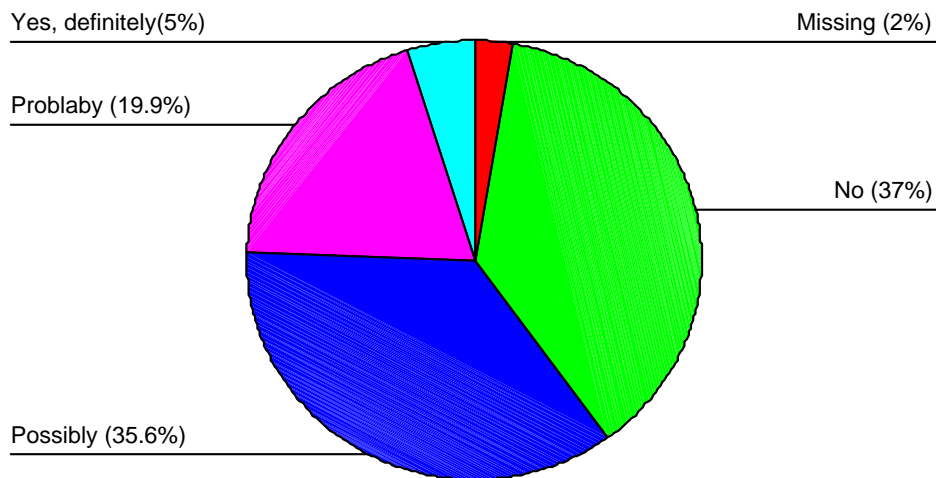
Analysis of the other factors listed by respondents as contributing to their infection included: HIV/AIDS was unknown at the time (N=17), didn’t think I was at risk/denied my risk (N=7), thought I was safe because I used protection/asked partner about status (N=8), and I was “loose” sexually or a “slut”/ “freak” (N=7).

Current Behaviors

Participants were asked to report the types of risk behaviors they have engaged in since learning of their HIV infection. Seventy-two percent of respondents indicated that they had *protected* oral, anal or vaginal sex with someone who knew the respondent was HIV positive. Similarly, 50.3% indicated that they had *unprotected* sex with some who knew that the respondent was positive. Many participants also said they had engaged protected (43.6%) or unprotected (36%) oral, anal or vaginal sex without disclosing that they were HIV positive. Participants indicated that they had had unprotected anal or vaginal (39%) or oral (46%) sex with someone whose HIV status the respondent didn’t know. Many respondents also reported avoiding sex, choosing not to have sex, or shutting down sexually (36%). Several people indicated sharing needles or works with either someone who knew they were positive (6%) or someone who did not know the respondent’s serostatus (4%).

Some of the participants responded to questions about preferences for relationship partners. Of those who are currently in a relationship (N=109), most said their current partner is HIV positive (46.8%), some indicated their current partner is negative (30.3%), and others indicated they do not know the status of their current partner (22.9%). Of those who reported they were not in a relationship at that time, they indicated future partners who are HIV positive (67.4%) rather than negative (16.3%) or unknown (16.3%) would be preferred. Finally, participants (N = 172) were asked to indicate their partner preferences regardless of their current relationship status. Participants overwhelmingly would prefer to be involved with someone who is positive (61.6%) than negative (24.4%) or of unknown serostatus (12.8%).

Before learning of your infection, did you infect anyone else with HIV?



The chart above indicates that many respondents believe they may have infected someone else with HIV before they learned of their infection. Similarly, respondents were asked to indicate whether or not they believe they have infected another with HIV since they learned of their infection. Most indicated they had not (58.4%), but some reported they possibly (26.5%) or probably (12.9%) had infected others. Only 2.2% believed they have definitely infected another.

Challenges and Needs

Participants were also provided a checklist of problems commonly faced by those living with HIV or AIDS and asked to indicate which of these challenges they had faced since becoming HIV positive. The percentages and number of participants (N) who checked each challenge are provided in Table 2 below. Clearly, many participants believe telling friends and family and sex partners about their HIV status is an important challenge. Practicing safer sex and feeling hopeless about intimate relationships were also reported as challenges.

Table 2. Percent and Number of Participants (N) who Reported Experiencing Each Challenge Since Learning of Their HIV Infection.

Challenges Since HIV Diagnosis	Valid Percent	N
Practicing safer sex	47.8	154
Feeling hopeless about intimate relationships	47.2	152
Using clean needles/works	4.7	15
Fear of intimate relationships	43.2	139
Alcohol/Other drug use	34.8	112
Having no sex drive	33.5	108
Feeling confident I won't infect others	35.4	114
Feeling unworthy of intimate relationships	30.7	99
Telling sex partners about my HIV status	57.1	184
Feeling I am dirty or contaminated	38.8	125
Feeling that I am trapped, damned, or doomed	38.2	123
Telling friends/family about my HIV status	49.4	159
Other (see Appendix B)	5.4	17

The final question asked participants to indicate the usefulness/helpfulness of a number services regardless of which services are currently available. This was accomplished by asking respondents to check each service that was useful and rate the most important services. It should be noted that many respondents did not accurately complete this question. Many participants ranked every service (as opposed to only the top 5) and often ranked all services as “1” (very important). All responses are included in the data provided in Table 3 below. The services most commonly checked by respondents include counseling and/or support to help make decisions about living with HIV (82.2%), opportunities to socialize with other HIV positive people (95.8%), and information about safer sex practices (59%). These three issues were also ranked highly by participants. The “other” services commonly listed by participants as important included: counseling and support for disclosing your HIV status

Table 3. Rankings of Services.

Service	Percent Indicating Useful (N)	Percent Ranked #1
Information of safer sex	67 (204)	50.8
Information on safer injecting practices	51.6 (157)	36.4
Counseling/support to help make decisions about living with HIV	82.2 (250)	52.4
Assistance adhering to drug regimens	65 (196)	41
Counseling/support to help practice safer sex	69.3 (210)	42.6
Counseling/support for sex partners	64.5(195)	34.5
Alcohol and/or drug treatment services	64.6 (196)	40.3
Easy access to clean needles/works	49.5 (150)	23.4
Easy access to condoms	69.1(210)	53.3
Opportunities to socialize with other HIV positive people	95.8(282)	62.5
Other	43.5 (142)	n/a

Conclusions

The results of this needs assessment indicate several things about a sample of the population of persons living with HIV/AIDS in the State of Michigan. First, most believe that they were infected either by a casual sexual partner or a long time partner as opposed to by a friend or sex-worker. This combined with the data on current practices suggests many of the respondents have a history of casual sex and sex without communicating about safer sex options. These data suggest that any intervention should account for the possibility that many PLWH/A engage in sex (either oral, vaginal or anal) with people that they may not know well and with whom they may not have discussed safer sex options.

Most respondents believe they were infected while either in the metro-Detroit area or while living outside of Michigan. The factors most commonly indicated as contributing to their infection include: not knowing they were at risk, being under the influence of drugs or alcohol, not knowing about, liking, or having access to tools for practicing safer sex, and not feeling assertive enough for safer sex.

One important limitation of these data is that these participants were asked to recall this information from the time they were infected. Some of the respondents report becoming infected in the early 1980's. Although some factors, such as where and by whom they were infected with HIV, are likely to be accurately recalled, other factors might not be as accurately recalled (e.g. emotional state at the time of believed infection). Similarly, response to these questions should not be treated as proxy for current needs,

but as important background information for understanding the experience of PLWH/A in Michigan.

Another significant finding of the current study is the fact that many of the respondents report engaging in unprotected sexual behaviors. This finding highlights the importance of prevention activities targeted toward PLWH/A. Additionally, there is a lack of correspondence between the number of people reporting they engage in behaviors that might put others at risk for HIV (e.g. engaging in unprotected sex without disclosing their status or knowing the others' status) and the number who believe they have actually infected others with HIV. That is, a significant portion of the sample report that they have engaged in unprotected anal, vaginal, and oral sex, since they learned of their infection, but most (58.4%) believe they have not infected anyone else since their infection.

Based on these findings and the challenges and needs for service reported by respondents, there are some clear areas of need for PLWH/A in Michigan. First, is an obvious need for enhanced communication skills. Many respondents report difficulties communicating with sex partners, family, and friends about their HIV status and, as described above, indicated that they engaged in both protected and unprotected sex without disclosing their status or discussing the status of their partner. Second, there are a number of psycho-social challenges reported by respondents including feeling hopeless about or fearful of intimate relationships. Indeed, 82.2% of respondents reported a need for counseling and support for dealing with HIV and 64.5% expressed a desire for counseling for their sex partners. Many also expressed a need to meet others with HIV, perhaps for support from these individuals or for a desire to be around others facing issues similar to their own. This desire to meet others who are positive speaks to the power of social norms in the positive community. Importantly, a significant number of participants also reported that they have had difficulty practicing and maintaining safer sex. Any interventions designed for this population should address these needs.

Recommended Activities

Based on the results of the needs assessment, several recommendations can be made for intervention content and design of an outcome evaluation around the intervention.

Recommendations for Intervention Design and Content

Intervention will be designed with the knowledge that:

- Individual specific psycho-social issues are a continuous issue for PLWH/A
- Evidence suggests PLWH/A are engaging in episodic vs. serial risk behaviors

Intervention will be:

- Peer Based-to facilitate perceptions of normative behaviors and interaction with other positives
- Theory-based: Theory of Reasoned Action Accounts for the impact of social norms on subsequent behaviors

- Focus on MSM (age, how long positive to be specified)
- Include Group Level (½ community building, ½ seminar) combined with Individual Level Client-Centered Risk Reduction/Referral Sessions And Formal Outreach to HIV+MSM
- Referral to existing services strong part of program – participants will received “PRIDE” card to track referral completion with unique identifier – card provides “custom” services

Overview of 3 Proposed Program Components

1. Group Level Intervention (GLI)

- Focus: Relationship building and communication with significant others
Via 5 GLI Seminars, will also include a community-building component to provide participants the opportunity to meet other members of the positive community.
- Curriculum will include interactive discussion and role-play exercises (NOTE: all content is specifically for those who are HIV positive):
 1. Information on STDs/HIV
 - Risk reduction behaviors that work
 - Transmission
 - Relationship between meds and behaviors
 2. Substance use and prevention
 3. Communication with family, friends
 4. Communication with long term and casual sex partners about safer sex options including disclosure as one possible option
- Outcomes
 - Increased knowledge
 - Changes in Attitudes, Behavioral Intent, and Behaviors around Communication About Safer Sex,
 - Decrease in number of self-reported unprotected sexual behaviors (oral, anal, vaginal)
 - Changes in normative perceptions
 - Skills around talking about safer

2. Individual Level Intervention (ILI)

- Focus: individual level counseling client-centered counseling around issues raised in GLI. Referral component will include “PRIDE” card to provide access to special services and allow for tracking of referrals.

- Outcomes
 - Personalized RR plan
 - Additional skills
 - Referral to services (and tracking of completion)

3. Formal Outreach

- Focus: Bar parties designed to address social norms, provide opportunity for socializing with other positives, market other components of intervention
- Outcomes
 - Increased awareness of the project
 - Changes in normative perceptions about communication about safer sex and status disclosure among PLWH/A and MSM community at large

Provider Training

Peers will be trained on GLI curriculum, outreach, and facilitation/client-centered risk reduction counseling with content specific for positives

Curriculum Development

The curriculum will be developed using best practices and behavioral theory by a consortium of health education professionals and community members.

Pilot

The initial phase of the project will include piloting with approximately four agencies centered in the metro-Detroit area.

Outcome Evaluation

Outcome evaluation is essential for understanding the effectiveness of a given intervention in changing targeted attitudes, beliefs, and behaviors. Ideally, outcome evaluation should be considered in the planning phase of implementing an intervention. Thus, the design of the outcome evaluation will be driven, in part, by the format of the intervention. The intervention will be developed based on a combination of two social psychological theories. Thus, the hypotheses for the outcome evaluation will also be based on the variables in this model. The design for the evaluation will include a quasi experimental pre-test/post-test comparison group design. The pretest will take place immediately prior to the intervention and the post-test will occur immediately following and 6 weeks later to assess any longer term effects of the intervention. Participants will include a convenience sample of PLWH/A in the metro Detroit area. Scales will be self-administered via questionnaire in order to elicit accurate information and to protect the anonymity of the respondents. All data will be analyzed via the Statistical Package for the Social Sciences (SPSS) and content analysis with multiple coders to ensure intercoder reliability.

Appendix A.
MIDWEST AIDS PREVENTION PROJECT
CONTINUING PREVENTION PROGRAM

SURVEY ON PREVENTION NEEDS FOR PERSONS
LIVING WITH HIV/AIDS

PARTICIPANT SURVEY

This survey is being conducted to help us better understand the HIV prevention needs of persons living with HIV/AIDS. The results will be used to help us make recommendations for prevention interventions targeting persons living with HIV/AIDS.

Thank you for assisting us in this important effort

1) Which of the following behaviors *do YOU believe* led to you becoming HIV positive? (*Check ALL that apply*)

- | | |
|---|--|
| <input type="checkbox"/> Vaginal (penis-vagina) sex <i>without</i> a condom | <input type="checkbox"/> Oral sex (mouth-penis/fellatio) |
| <input type="checkbox"/> Vaginal (penis-vagina) sex <i>with</i> a condom | <input type="checkbox"/> Oral sex (mouth-vagina/cunninglingus) |
| <input type="checkbox"/> Anal sex without a condom (you are insertive/top) | <input type="checkbox"/> Oral sex (mouth-anus/rimming) |
| <input type="checkbox"/> Anal sex <i>with</i> a condom (you are insertive/top) | <input type="checkbox"/> Sharing needles for drug use |
| <input type="checkbox"/> Anal sex without a condom (you are receptive/bottom) | <input type="checkbox"/> Sharing other works (i.e. cottons) for injecting drug use |
| <input type="checkbox"/> Anal sex <i>with</i> a condom (you are receptive/bottom) | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Blood transfusion/receipt of blood products | |

2) Do you know the person(s) from whom you acquired your infection? (*Check ONE only*)

- | | | | |
|-----------------------------|--|---|--|
| <input type="checkbox"/> No | <input type="checkbox"/> Unsure, but could guess | <input type="checkbox"/> Fairly certain | <input type="checkbox"/> Yes, definitely |
|-----------------------------|--|---|--|

3) What was your relationship, at the time you became infected, with the person from whom you acquired your infection? (*Check ONE only*)

- Spouse, husband/wife, partner, significant other
- Non-spouse, but long time friend
- Casual acquaintance, casual sex partner
- Sex-worker, prostitute
- Other: _____
- Don't know/remember

4) If you are currently in a relationship, is your partner:

- HIV positive HIV negative HIV status unknown

5) If you are *not* currently in a relationship, would you prefer your next partner to be:

- HIV positive HIV negative HIV status unknown

6) Regardless of your current relationship status, would you prefer your partner to be:

- HIV positive HIV negative HIV status unknown

7) Where do you think you became infected with HIV? (*Check ONE only*)

- In the Detroit metro area
 In the Lansing metro area
 In the Flint metro area
 In the Kalamazoo/Battle Creek metro area
 In the Grand Rapids metro area
 In Michigan, but outside of one of the metro areas: list county/city _____
 While I was *living* out of state: specify city/state/country _____

While I was *visiting* out of state (e.g. on business, vacation, etc.) Specify city/state/country: _____

I don't know where I became infected with HIV

8) Using your best guess, in what year did you become infected with HIV? _____

9) When did you first learn you were HIV positive? Month _____ Year _____

10. If you have had an AIDS diagnosis, when did you receive this? Month _____ Year _____ I have not received an AIDS diagnosis.

11. There are a number of issues which might be factors in HIV transmission. Which of the following statements were true for you when you became HIV infected? (*Check ALL that apply*)

- | | |
|---|---|
| <input type="checkbox"/> I didn't think I was at risk | <input type="checkbox"/> I was trying to get a partner |
| <input type="checkbox"/> I didn't know about safer sex | <input type="checkbox"/> I was trying to keep a partner |
| <input type="checkbox"/> I didn't know about clean needles/works | <input type="checkbox"/> I/we didn't have a condom |
| <input type="checkbox"/> I didn't feel assertive enough for safer sex | <input type="checkbox"/> I didn't have clean needles/works |
| <input type="checkbox"/> I needed money, drugs or something else | <input type="checkbox"/> I wanted to become infected |
| <input type="checkbox"/> I don't like condoms, so I didn't use them | <input type="checkbox"/> S/he was really clean looking |
| <input type="checkbox"/> My partner didn't like condoms | <input type="checkbox"/> My partner refused safer sex |
| <input type="checkbox"/> I was inside a prison/correctional facility | <input type="checkbox"/> The person told me s/he was HIV negative |
| <input type="checkbox"/> None of my friends practiced safer sex | <input type="checkbox"/> I thought my partner was monogamous |
| <input type="checkbox"/> I was drunk or high | <input type="checkbox"/> I was in love |
| <input type="checkbox"/> I was feeling depressed | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> I really needed to get high | <input type="checkbox"/> Other: _____ |

12. Since you learned of your infection, which of the following have you experienced, *even once*?
(Check **ALL** that apply) Please remember that all of your answers are **ANONYMOUS**.

- I have had protected sex (anal, vaginal, oral) with someone who knew I am HIV positive.
- I have had *unprotected* sex (anal, vaginal, oral) with someone who knew that I am HIV positive.
- I have had protected sex (anal, vaginal, oral) without disclosing my HIV status.
- I have had *unprotected* sex (anal, vaginal, oral) without disclosing my HIV status.
- I have had *unprotected* sex (anal, vaginal, oral) with someone who's HIV status I didn't know.
- I have had *unprotected oral* sex with someone who's HIV status I didn't know.
- I have avoided sex, chose not to have sex, or shut down sexually.
- I have shared needles or other works with someone who knew I am HIV positive.
- I have shared needles or other works with someone without disclosing my HIV status.
- I have shared needles or other works with someone whose HIV status I did not know.
- I have engaged in other risk activities that could pass on HIV: _____

13. Since you became infected, *but before you learned of your infection*, did you infect anyone else with HIV? (Check **ONE** only)

- No
- Possibly, but not sure
- Probably, but not sure
- Yes, definitely

14. Since you learned of your infection, have you infected anyone else with HIV? (Check **ONE** only)

- No
- Possibly, but not sure
- Probably, but not sure
- Yes, definitely

15. Since you were diagnosed, which of the following have been challenges for you? (Check **ALL** that apply)

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

16. An individual being treated with combination therapy for HIV/AIDS is less able to spread the infection to someone else.

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree

17. Regardless of the services currently available, please rate the extent to which you might find each of the following services useful or not useful.

	1	2	3	4	5
Information on safer sex practices	Very Useful				Not Useful
Information on safer injecting practices	Very Useful				Not Useful
Counseling and/or support to help you make decisions about living with HIV (e.g. whether to have sex, have a baby, have sex with other HIV+)	Very Useful				Not Useful
Assistance in adhering to drug regimens	Very Useful				Not Useful
Counseling/support to help you practice safer sex	Very Useful				Not Useful
Counseling/support for your sex partner(s)	Very Useful				Not Useful
Alcohol and/or drug treatment services	Very Useful				Not Useful
Easy access to clean needles/works	Very Useful				Not Useful
Easy access to condoms	Very Useful				Not Useful
Opportunities to socialize with other HIV+ people	Very Useful				Not Useful
Counseling/support for making decisions about disclosing your HIV status	Very Useful				Not Useful
Other: _____	Very Useful				Not Useful
Other: _____	Very Useful				Not Useful

18. Are you:

- Male
 Female
 Transgendered

19. Which one of the following **best** describes your racial/ethnic background?

- White
 African American
 Native American
 Hispanic/Latino/a
 Arab
 Other: _____

20. How would you describe your sexual identity? (Check **ONE** only)

MSM/Gay

WSW/Lesbian

Bisexual

Heterosexual

Other: _____

21. Your age: _____

22. In which Michigan county do you live? _____

23. Do you have any comments or suggestions about this questionnaire or about addressing the HIV prevention needs of HIV+ people?

Appendix B.
Partial Recording of Open-Ended Responses

QUESTION 1: What behaviors do you believe led to you becoming positive?

ID: 20

Occupational hazard

ID: 25

Immaculate Infection

ID: 40

Needle stick in health care setting

ID: 59

I know I was infected from sex, but I don't know which act or when it occurred.

ID: 89

Crack pipes

ID: 96

Poked by needles while testing people for HIV in the early 80's.

ID: 115

(EDITORIAL NOTE: Checked "Blood transfusion/blood products) Taking care of HIV+ partner.

QUESTION 3: What was your relationship with the person from whom you acquired your infection?

ID: 27

One night stand

ID: 32

One night stand

ID: 37

Forced relationship –blackmailed sex not to expose in military

ID: 87

Friend/Co-Worker

ID: 92

Contracted thru work-hemodialysis

ID: 96

Hospital Patients

QUESTION 4: Where do you think you became infected?

ID:4

NYCity

ID:5

Atlanta, GA

ID:10

Saginaw

ID: 11

Miami, FL

ID: 12

Fort Wayne, Texas

ID: 14
Manila, Philippines
ID: 15
Carbondale, IL
ID: 19
Kentucky
ID: 20
Texas while in the Army
ID: 21
Chicago, Il
ID: 24
New Orleans or L.A.
ID: 26
NY,NY
ID: 27
Oakland County
ID: 30
San Francisco
ID: 32
Chicago or NYC
ID: 33
Houston, TX
ID: 37
Philadelphia, PA
ID: 39
Toledo, OH
ID: 40
St Joseph
ID: 42
San Diego, CA
ID: 49
Fort Lauderdale, FL
ID: 52
Inkster, Wayne County
ID: 53
Freemont, Indiana (visiting)
ID: 55
Colorado Springs, CO
ID: 57
Ann Arbor/Ypsilanti Area
ID: 59
Dade County, Florida
ID: 61
L.A.
ID: 64
Jackson, Prison

ID: 69
LA, CA
ID: 70
Denver, CO/Palm Springs, CA
ID: 71
Albuquerque, NM
ID: 78
Mason County
ID: 79
Muskegon
ID: 83
Florida
ID: 87
San Francisco, CA
ID: 90
Homer, Ypsilanti
ID: 91
Ypsilanti
ID: 92
LA, California
ID: 95
Bay City
ID: 99
San Francisco
ID: 100
Washtenaw/Ann Arbor
ID: 103
San Francisco
ID: 105
New York, New York
ID: 111
Chicago, IL Cook County
ID: 113
New York City
ID: 117
Orlando, FL
ID: 119
Cleveland, OH
ID: 125
Chicago, IL
ID: 127
Berrien, Waterviliet
ID: 128
Salinas, Puerto Rico
ID: 135
Atlanta, GA

ID: 137
Berlin, West Germany

QUESTION 8: What are the factors that led to you becoming infected?

ID:4
Plain old slut

Liked sex with strangers

ID: 7

Didn't know you could get it from a blood transfer

ID:10

-wanted to be loved

-cheated on/revenge

-self destructive behavior

ID:25

AIDS didn't "exist" yet-never heard about it. My partner moved here from Chicago in 1981. We met when I lived in Detroit, but didn't get intimate until 1982.

ID: 26

Thought it was inevitable

ID: 27

I was very loose sexually.

ID: 32

HIV was not yet introduced

ID: 33

No knowledge at the time

ID: 35

Thought I was practicing safe sex

ID: 36

I thought there was less risk

ID: 40

Medical care setting

ID: 44

Never thought about asking if positive or negative

ID: 59

I think I was infected before I knew about HIV because I have been practicing safe sex since 1985.

ID: 65

My partner knew he was infected and didn't disclose this until I became infected.

ID:66

Used protection and still became infected.

ID:71

Infected before the disease was identified.

ID: 78

Condom Broke

ID: 80

Very early in being "out"

ID: 84

Early in epidemic, transmission uncertain.

ID: 86

Freak

ID:88

-Love = Sex

-denial –it couldn't happen to me, I wasn't traveling to LA, NYC, etc.

ID: 90

At that time AIDS was unheard of. went into a monogamous relationship to avoid exposure.

ID: 92

Just didn't think about it.

ID: 96

No universal precautions where in effect; HIV/AIDS was still the “gay cancer” and I was the only nurse who would care for “these” people.

ID: 100

I didn't know he was bi-sexual.

ID: 101

I was in a hospital and had a transfusion.

ID: 104

Married men –thought it was safer.

ID: 105

Naïve

Low self-esteem

ID: 111

By the time anyone knew what to do not to get it, it was already too late

ID: 113

I didn't know what AIDS was at the time.

ID: 114

None of the above

ID: 115

Was not taking “universal precautions”

ID: 118

Use of condoms is not enough

Use of water-based lotion is not enough

Use of mynoxinal 9 not enough

ID: 128

My partner told me he was HIV negative but he knew he was positive and told me he was monogamous.

ID: 132

Thought perhaps I was marginally at risk.

QUESTION 9: Other activities that I engaged in that put me at risk for HIV...

ID: 25

anal-oral

ID: 104

Oral

ID: 132

(engaged in unprotected sex) “related to drug use” (protected sex) = “pull out method”
-gave blood for money

QUESTION 12: Since you were diagnosed, what are other challenges you faced?

ID: 12

-Not use any more

-abstain from sex

ID: 45

Trying to keep the condom from breaking, but at times during the course of sex some condom brands can not be felt broke until it's pulled out.

ID: 64

Telling employers if I had an accident at work.

ID:12

Not working, chronic health concerns

ID: 96

Major depression!!

Feeling very alone!!

ID: 100

Receiving positive support from my church/members

ID: 118

Feel life is really done and over.

Ideas from general public!

ID: 125

I was involved with the individual for economical reasons.

QUESTION 13: Other services that would be helpful.

ID: 24

HIV – being able to cope, talk, (their acceptance) and knowledge

ID: 36

Counseling and support for family

ID: 81

To educate other PWA's

ID: 100

-Support in the African-American community

-African-American churches –support/prevention/education

ID: 118

Let others know to wear two condoms.

Let others know not to have oral sex.

ID: 125

Community acceptance of HIV community

QUESTION 16: Sexual identity

ID: 57

Other: Confused, non-sexual for the last 12+ years (editorial comment: since learned of infection)

Comments/Suggestions for addressing prevention needs of HIV+ people

Keep up the good work

I think people need to be more aware of their drugs and how to take them.

That I need to step up/it has been a long tough fight and it is time to give back what has been given so freely to me –life.

There should be a greater concentration on the knowledge and responsibility of each of us not to transmit.

“up-play” the risk of oral infection

These conventions are the best for us and it brings us all together to share what we have learned and are still learning.

Yes, most of the HIV+ people that I know became infected as a result of sexual addiction- we never address this section of the HIV+ population –sexual addicts.

Better, more professional, caring case management, advocacy and primary care.

There is still a great need for education of those not infected and info articles reaching the public.

The idea that low or nondetectable status may not transmit HIV.

Better outreach to those living healthy with HIV will reduce spread. Better education of HIV- to reduce spread.

Transportation needs

We need more research on exactly how the virus is spread (EDITORIAL COMMENT: reports extensive unprotected sex w/o indicating that they may have exposed others–denial?)

I have facilitated two HIV+ groups which have dwindled because of lack of interest or whatever. I want to reach out but I don’t know how/where.

My rank of services now is totally different than when I first was diagnosed.

Retreats help me to meet people (sex partners) with HIV, reduces risk of giving HIV to another person.

Need more transportation to get to and from other places and for the insurance to cover more than just doctors appointment and meds and some dental.

Length of survey

Housing and better transportation and more seminars.

Invisibility fuels the epidemic.

Given my race and sexual preference and county of residence I feel I could easily be identified so this questionnaire does not feel very confidential to me.