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## The HIV Antibody Test: Why Gay and Bisexual Men Want or Do Not Want To Know Their Results

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### Synopsis .....

*Beginning in the latter part of 1985, 2,047 gay and bisexual men who were enrolled in the Pitt*

*Men's Study, the Pittsburgh cohort of the Multicenter AIDS Cohort Study (MACS), were invited by mail to learn the results of their antibody test for HIV infection—human immunodeficiency virus infection. Participants were asked to complete and return a questionnaire designed to assess the factors influencing their (a) decision about learning the results, (b) recent sexual behavior, (c) knowledge about acquired immunodeficiency syndrome (AIDS), and (d) attitudes toward AIDS risk reduction. Of those men, 1,251 (61 percent) accepted the invitation, 188 (9 percent) declined, and 608 (30 percent) failed to respond. Fifty-four percent of the cohort subsequently learned their results.*

*There were no significant differences in demographic, behavioral, and attitudinal characteristics or HIV seroprevalence between the men who accepted and those who declined. However, significant demographic differences were noted between the men who responded to the invitation versus those who did not; the latter group was composed of a greater proportion of men who were younger, nonwhite, and less educated. The most frequently cited reason (90 percent) why men wanted their test results was to determine if they had been infected with HIV. Of those who declined, 30 percent cited concerns about the psychological impact of learning about a positive result as being the most important factor for their decision. The two most frequently selected reasons for declining were the belief that the test is not predictive of the development of AIDS (48 percent) and concern about the worry that a positive result would produce (48 percent). These findings are discussed in the context of a nationwide, voluntary HIV screening program for gay and bisexual men.*

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**T**HE PUBLIC HEALTH SERVICE has recommended that strategies to control acquired immunodeficiency syndrome (AIDS) should incorporate voluntary counseling and testing for persons at risk of infection with the human immunodeficiency virus (HIV) (1). The screening test to be used is an enzyme immunoassay (EIA) procedure developed to detect antibody to HIV. The EIA test is technically well suited for screening purposes,

especially for blood banking agencies (2). It has a demonstrated high degree of sensitivity (99 percent) and specificity (99.75 percent), as well as a very good correlation with immunoblot analysis (98.8 percent)—the standard confirmatory test (3). Clinically, the test has also proven beneficial for resolving the often complex differential diagnoses associated with HIV-related disease and has also been used by the Centers for Disease Control to

increase the specificity of the AIDS case definition (4).

Despite the many beneficial applications of this new test, there may be negative consequences to its use as a screening tool. Certain States have instituted mandatory reporting of a positive HIV serostatus (5), and some Federal officials have proposed mandatory testing. The possibility that this practice might become widespread could impede participation in screening programs, partly because of the tremendous social stigma and discrimination associated with infection with this virus. Because homosexual and bisexual men account for nearly two-thirds of all AIDS cases in the United States (6), there is concern among risk group members that such testing could unwittingly abet discrimination in employment, housing, and health services, including medical insurance coverage. The lower than anticipated demand for antibody testing at alternate test sites may be related to these very concerns (7).

Because individual knowledge of HIV serostatus may play an important role in promoting AIDS risk reduction, it is important to study the factors that influence the decision to learn HIV results. What follows is a report of such an analysis of a large cohort of gay and bisexual men enrolled in a prospective study of the natural history of HIV infection.

## Methods

These data were collected from the 2,047 gay and bisexual male participants of the Pitt Men's Study (PMS), an 8-year prospective study of the natural history of HIV infection. This program, funded by the National Institutes of Health, is a portion of the Multicenter AIDS Cohort Study (MACS) (8). Volunteers were recruited for the PMS within a 100-mile radius of Pittsburgh, PA, between April 1984 and May 1987, with the use of a wide variety of recruitment techniques (9). The majority of this cohort had enrolled in the study before the development and licensing of the HIV-EIA test. A component of the recruitment process was the assurance of maximal confidentiality as provided by an elaborate confidentiality protocol and by the Certificate of Confidentiality (No. DA-84-10) awarded to the PMS by the Department of Health and Human Services. This certificate prohibits access by any authority, agency, or court of law to all personal identifying information collected during the course of the study without the written consent of the participant.

*'The majority of men who chose to learn their results apparently believed that knowing whether they had been exposed to the HIV would be of benefit to them. Many were concerned about their responsibility to sexual partners and believed that knowing their results would enable them to change to less risky sexual practices.'*

PMS participants are seen at 6-month intervals and are asked to provide serum for testing and for storage in a freezer repository. In addition, detailed medical and sexual behavior data are obtained. Funding provided by the Centers for Disease Control has permitted the collection of additional data relating to knowledge and attitudes about AIDS and AIDS risk reduction for the purpose of assessing the efficacy of a predisclosure educational session called the AIDS Prevention Project.

In August 1985, testing for HIV antibodies was begun on the repository samples. From September 1985 through May 1987, as the testing of samples was completed, each participant was sent an invitation to learn his results. With this letter was a "decision form" that participants were asked to complete, sign, and return within 1 week in a prepaid envelope. In addition to being a record of the volunteer's decision, this form was designed to assess his reasons for making that decision. Participants who decided to learn the results were asked to check one or more options from a list of six reasons for their decision and to indicate which of the six was the most important factor influencing their decision. Those who declined could check from a list of 12 options, with the same instructions. Both groups were given the option to write other reasons as well.

Also with the invitation was a 75-item questionnaire designed to assess the participant's recent sexual practice history, level of knowledge about HIV, and attitudes about AIDS risk reduction (10). Knowledge about HIV was assessed with the use of 18 multiple choice questions. Attitudes were assessed with the use of a 45-item questionnaire requesting participants to respond to a variety of statements about AIDS and AIDS risk reduction. Responses were assessed on a 5-point Likert scale,

Table 1. Demographic comparison of volunteers in the Pitt Men's Study, University of Pittsburgh, by desire to learn their HIV serostatus, September 1985–May 1987

Characteristics	Yes group (N = 1,251)	No group (N = 188)	No response (N = 608)
Mean age (years).....	33.3	33.5	<sup>1</sup> 31.3
Race:			
White (percent).....	96.5	96.8	<sup>2</sup> 92.3
Other (percent).....	3.5	3.2	<sup>2</sup> 6.7
Education: Percent with college degree.....	62.2	59.6	<sup>2</sup> 51.5
Percent HIV antibody positive.....	19.8	19.9	17.4
Sexual practices:			
Percent engaging in receptive anal intercourse in previous 6 months....	60.3	58.9	<sup>3</sup> NA

<sup>1</sup> Differences significant at  $P < .05$  level using Duncan's new multiple range test.

<sup>2</sup> Differences significant at  $P < .05$  level using chi-square analysis.

<sup>3</sup> Concurrent data not available.

Table 2. Reasons why men wished to learn their HIV serostatus (N = 1,251)

Options	Men selecting option as a reason		Men selecting option as most important reason <sup>1</sup>	
	Number	Percent	Number	Percent
To learn if they had been infected.....	1,120	90	484	39
To cope better with fear of AIDS.....	581	46	163	13
To promote change in sexual behavior.....	504	40	124	10
To confirm a perceived negative status.....	505	40	166	13
To confirm a perceived positive status.....	269	22	70	6
To clarify the cause of current symptoms.....	124	10	51	4
For other reasons.....	178	14	152	12

<sup>1</sup> 3 percent of respondents failed to indicate the most important reason.

SOURCE: Pitt Men's Study, University of Pittsburgh, September 1985–May 1987.

with options ranging from "strongly agree" to "strongly disagree."

Before the results were disclosed, the men who chose to learn the results were asked to attend a 1 1/2-hour group counseling session conducted by the AIDS Prevention Project (10). At this peer-led session, the mechanism of HIV transmission, AIDS risk reduction, and interpretation of HIV antibody results were discussed. Men who refused to attend this session were offered individual predisclosure counseling. At the end of the counseling, they were scheduled for an individual

appointment with a study clinician to learn their test results. The men also were informed that local resources for postdisclosure counseling support were available should they require it.

During the 20 months after the initial invitations were distributed, three general newsletters were sent to each of the PMS participants. The newsletters contained articles that encouraged the men to make a decision about learning the results of their tests if they had not already done so. Similar articles also had been published in the local newspaper for gays. Further, during clinic visits, members of the study staff encouraged the participants to learn their test results.

## Results

Of the 2,047 active PMS participants, 1,251 (61 percent) had accepted the invitation by May 11, 1987 (the Yes group), 188 (9 percent) had formally declined the invitation (the No group), and 608 (30 percent) had failed to respond to multiple invitations (the No Response group). Of those in the Yes group, 142 (7 percent of the total cohort) failed to attend a result disclosure meeting with the clinician, even though they had indicated a desire to learn the results. Therefore, 54 percent of the cohort had actually learned their results by May 1987. Only 37 persons in the Yes group requested individual rather than group predisclosure education.

There were no significant differences in age, race, educational level, HIV serostatus, and recent sexual behavior between the men who accepted the invitation and those who declined (table 1). The men who failed to respond differed significantly ( $P < .05$ ) from men who formally declined or accepted; the No Response group contained a higher proportion of men who were younger, nonwhite, and less educated. However, there were no significant differences in HIV seroprevalence (17–20 percent) among the three groups. Although concurrent sexual practice data on the No Response group were not available for comparison, the recent practices of the Yes and No groups were quite similar, with nearly 60 percent of both groups reporting receptive anal intercourse with one or more partners in the previous 6 months. The mean number of partners with whom they had practiced receptive anal sex in that period was 2 for both groups.

The majority (90 percent) of the 1,251 men who wanted results indicated that among their reasons for learning their HIV serostatus was to determine

Table 3. Reasons why men did not wish to learn their HIV serostatus (N = 188)

Options	Men selecting option as a reason		Men selecting option as most important reason <sup>1</sup>	
	Number	Percent	Number	Percent
Because test is not predictive of AIDS.....	91	48	30	16
Because if positive, they would be too worried about developing AIDS.....	90	48	30	16
Because they would be unable to cope with a positive result....	58	31	25	13
Because if their results were positive, they would be afraid to have sex.....	52	28	2	1
Because the test is inaccurate.....	34	18	4	2
Because they did not have the time to schedule an appointment	34	18	14	7
Because of concerns about confidentiality.....	35	19	2	1
Because they believe their results would be positive and do not wish to know for certain.....	19	10	4	2
Because they are not "promiscuous" and therefore believe they have not been exposed.....	16	9	6	3
Because they would not change their sexual practices no matter what the test showed.....	15	8	6	3
Because they already knew results from an alternate test site....	8	4	5	3
For other reasons.....	45	24	25	13

<sup>1</sup> 20 percent of respondents failed to indicate the most important reason.

SOURCE: Pitt Men's Study, University of Pittsburgh, September 1985-May 1987.

if they had ever been exposed to HIV. This was also described as the most important reason by 39 percent of the Yes group. Forty-six percent believed that knowledge of their serostatus would help them cope with their fears about AIDS, and 40 percent believed it would help to promote a change in their sexual behavior. The frequencies of the remaining motives for learning results are shown in table 2. The majority of write-in reasons in the "other" category related to concerns about the men's responsibility to their sexual partners and to themselves (8 percent). Additional write-in reasons included the desire to confirm results obtained elsewhere (1 percent), to be screened prior to a physical examination for employment or insurance (1 percent), and to obtain additional information on the HIV screening procedure and AIDS (2 percent).

The most frequent reason chosen by 48 percent of the 188 men who declined results was the belief that the test is not predictive of AIDS (table 3). This was also the most important reason for 16 percent of these men. The next three most commonly cited reasons reflect concern about the potentially harmful psychological impact if the antibody results were positive. Forty-eight percent indicated that a positive test result would be "too worrisome," 31 percent felt they would be "unable to cope" with a positive result, and 28 percent believed that if their results were positive they would be "afraid to have sex." Eighteen percent

of the men believed the test was inaccurate and 19 percent were concerned about confidentiality. Nine percent declined because they were "not promiscuous" and believed, therefore, that they were not exposed to HIV. Eighteen percent did not have the time to schedule an appointment, and 8 percent stated that they would not change their sexual practices regardless of their serostatus and therefore declined. Only 8 men (4 percent) declined results because they had already been tested elsewhere.

Twenty-four percent of the men who declined also listed an "other" reason for not wanting results that often was similar to one of the listed options. Included in these write-in reasons were additional concerns by 8 percent of the No group about their inability to cope with a positive result. Two percent expressed the desire not to know about a result prior to applying for insurance or employment. Three percent also questioned the validity of the test.

The two groups that responded were also compared with respect to their knowledge and attitudes about AIDS before the counseling session. Both groups demonstrated an equally high level of knowledge about HIV test result interpretation, local HIV seroprevalence, and risk reduction practices: the percentages of the 18 knowledge questions that were answered correctly by the Yes and No groups were 85 percent and 87 percent, respectively. There were no significant differences

Table 4. Comparison of responses to the statement, "I believe that I have already been infected with the AIDS virus" with actual HIV serostatus in the Yes and No groups<sup>1</sup>

Category	Yes group (N = 1,251)		No group (N = 188)		Total (N = 1,439)	
	Number of respondents seropositive	Percent of respondents seropositive	Number of respondents seropositive	Percent of respondents seropositive	Number of respondents seropositive	Percent of respondents seropositive
Agreed with statement (N = 183) . . . . .	66 of 159	42	10 of 24	42	76 of 183	42
Had mixed feelings about statement (N = 455) . . . . .	87 of 387	23	20 of 68	30	107 of 455	24
Disagreed with statement (N = 801) . . . . .	87 of 705	12	8 of 96	8	95 of 801	12

<sup>1</sup> The Yes group of men accepted the invitation to learn their HIV serostatus; the No group formally declined the invitation.

SOURCE: Pitt Men's Study, University of Pittsburgh, September 1985–May 1987.

noted between the two groups in their responses to any of the 45 attitudinal statements. For example, 79 percent of the men who accepted and 74 percent of the men who declined strongly agreed with the statement, "I believe that it is my responsibility to avoid transmitting the AIDS virus to my sexual partners." No one in the Yes group and only 2 percent in the No group strongly disagreed with that belief.

Finally, the men in both groups were asked to respond to the statement, "I believe that I have already been infected with AIDS virus." Only 13 percent of the members of both groups agreed with the statement, while 56 percent of the Yes group and 51 percent of the No group disagreed; the remaining men in both groups had mixed feelings about the statement. However, in the combined group of respondents, when a participant's response to this statement was compared with his actual HIV serostatus, only 42 percent of the men who agreed with this statement (N=183) were correct, while 88 percent of those who did not believe they were exposed (N=801) were accurate (table 4). In the group of men who were undecided about this statement (N=455), 24 percent were HIV seropositive. There were no significant differences in the accuracy of this perception between the Yes and No groups.

## Discussion

Obviously, for any voluntary screening program to be successful, it must be made acceptable to high-risk persons. Our findings indicate that even in a setting where confidentiality is maximized and psychosocial support is available, both before and after disclosure of the results, only slightly more than half (54 percent) of the gay and bisexual men who were already tested chose to participate in

prediscovery counseling and subsequently learned their HIV antibody results.

The majority of men who chose to learn their results apparently believed that knowing whether they had been exposed to the HIV would be of benefit to them. Many were concerned about their responsibility to sexual partners and believed that knowing their results would enable them to change to less risky sexual practices. An analysis of followup data concerning the sexual practices is planned to determine if this outcome actually was achieved.

Perhaps more important to the success of an education and screening program for gay and bisexual men is an analysis of the reasons why they choose not to learn their results. The majority of men in our study who did not learn their HIV status (30 percent) chose not to give us the reasons for the decision or were too ambivalent about the testing to make any decision. While these men gave information that helped us to identify differences in demographic characteristics, they did not provide concurrent data on their attitudes, knowledge, and sexual behavior. However, with a HIV seroprevalence similar to that of the Yes and No groups, it is unlikely that there are significant differences in risky sexual practices among the three groups. Efforts are underway to learn more about this group and especially about those members who are nonwhite or have a lower educational level.

Although they may not be entirely representative of the men who failed to learn their results, the 188 men who formally declined our invitation may contribute to our understanding. We found that one of the most frequently cited reasons for declining was the belief that HIV testing does not predict who will develop AIDS. This perception may arise in part from the valid emphasis by

health officials and leaders of gay organizations that this test is not a test for AIDS. This fact may imply that the test is of no clinical value. The situation may be compounded by the fact that, traditionally, screening programs have been instituted to identify persons who could benefit from treatment. Perhaps the message that there is no cure or treatment for AIDS has contributed to the notion among members of risk groups that antibody screening therefore is worthless. More emphasis needs to be placed on the value of the test vis-a-vis the health of the at-risk person rather than viewing it as a means of infection control only. For example, the screening of the 2,047 participants has identified 406 HIV seropositive men, 6 of whom were found, upon further clinical assessment, to have significant asymptomatic thrombocytopenia. More indepth clinical evaluation could also lead to earlier identification of persons who are at the greatest risk of progressing to AIDS (11) and who might benefit from newly developed anti-HIV therapies.

Because the Yes and No groups did not differ significantly in their perceptions of the chances of their being HIV seropositive or of their actual serostatus (table 4), neither perceived risk of infection nor HIV-related symptomatology appeared to be a major factor distinguishing men in the two groups. However, what did seem to be important were differences in their perceived ability to cope with the news of a positive result. In fact, these concerns about the psychological consequences of a positive test, when combined, become the most frequently cited major reason for declining to learn the results by almost a third of the men. At least half of the participants indicated one of these concerns as a factor in their decision. This is especially noteworthy given the extensive predislosure and postdisclosure counseling services made available to them. Perhaps the men who chose to learn their results believed that they possessed adequate coping skills and support networks or did not appreciate the potential psychological impact of these findings. Certainly, any HIV screening program must include skilled psychosocial support. Even then, these issues may be a major deterrent to voluntary participation. Additional research needs to be performed to assess the psychological consequences of HIV screening and to develop methods to provide more effective support.

It is equally important to determine the psychological impact of not learning one's HIV serostatus, given the high levels of public concern

*'Testing agencies may also benefit, as we have, by the establishment of a gay community advisory board whose purpose is to provide guidance in the design of testing notification procedures and confidentiality protocols, as well as to serve as a liaison with the gay community.'*

about this epidemic. Eighty percent of the men in the No group were HIV seronegative, yet included in this group were men who incorrectly believed that they had been exposed to HIV and men who had mixed feelings about their risk of exposure. Many of these participants declined results out of fear of the emotional consequences of a positive test, yet many might have benefited psychologically from learning about their negative serostatus. Additional studies are needed in high-risk populations to assess the emotional consequences of living with the uncertainty of one's HIV serostatus, as well as the potentially positive benefits of screening.

Another reason people cite for declining the results is the concern about the test's accuracy. Testing sites need to evaluate their specific testing methods to afford clients the most accurate testing possible and educate members of risk groups that current methods are highly sensitive and specific, at least for established infection. However, because screening tests may not detect early or recent HIV infection (12), testing centers must be careful to counsel all men found to be seronegative to have the test repeated, especially if any high-risk sexual practice has occurred in the 6 months prior to the screening.

Nine percent of the men who declined the results believed that because they were not "promiscuous" they were not likely to have been exposed. This misconception appears to be very common among the men in our study. In fact, at least 13 of the 57 men in our study who seroconverted to HIV in the past 3 years appear to have been infected by a partner with whom they had begun a monogamous relationship (unpublished data). This misunderstanding is supported in part by the publication of risk reduction guidelines for gay and bisexual men that stress the importance of reducing the numbers of sexual partners and of

knowing one's partner rather than explicitly convey the urgency of modifying a specific sexual practice that is the major route of HIV transmission in gay men, namely, unprotected receptive anal intercourse (13). This message is especially important for urban gay male populations where the prevalence of HIV infection is already high.

Although 19 percent of the men who declined results were concerned about confidentiality, only two cited it as their most important concern. This finding implies that, with the strictest level of confidentiality, this deterrent to screening can be greatly reduced. An alternative to this high degree of confidentiality may be to test anonymously, an option we could not explore given the prospective nature of our study. Testing sites must closely evaluate the potentially negative effects of mandatory reporting, non-anonymous testing, and contact tracing on the overall goals of their screening program. Testing agencies may also benefit, as we have, by the establishment of a gay community advisory board whose purpose is to provide guidance in the design of testing notification procedures and confidentiality protocols, as well as to serve as a liaison with the gay community.

Seven percent of those who declined disclosure cited lack of time for a session and private appointment as the most important factor behind their decision. Certainly our response rate might have been higher if we had eliminated predisclosure counseling or had given results by telephone. However, these options were precluded by our study design and ethical concerns for their potential psychological impact and questionable public health efficacy.

Perhaps most significant is the fact that the efficacy, with respect to the reduction of HIV transmission, of testing high-risk persons outside of the blood donation system has not yet been adequately studied (14), especially when the testing is performed without adequate risk reduction education. Many education projects are stressing the adoption of safe sexual practices by all high-risk persons regardless of their antibody status. Some advise that screening is unnecessary. At least 8 percent of our No group declined results because they believed that knowing their serostatus would have no effect on their behavior. This group included both men who were practicing "safer sex" and men who were not. Even with extensive confidentiality protection and psychosocial supports, it is likely that a large number of people will not accept HIV antibody screening. Alternative voluntary education and prevention strategies

that are not linked to testing will therefore be necessary.

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