HIV TESTING IN EDINBURGH AND THE LOTHIANS

A study of HIV testing behaviour among gay and bisexual men using the gay scene in Edinburgh

Steve O'Donnell Testing Barriers Project Gay Men's Health June 2003



INTRODUCTION AND ACKNOWLEDGEMENTS

This report has been produced by The Testing Barriers Project at Gay Men's Health, Edinburgh. The philosophy underpinning the project derives from research undertaken by Dr. Paul Flowers at Glasgow Caledonian University in 2000 and the subsequent publication, 'Testing Barriers' produced by Healthy Gay Scotland. The aim of the project is to tackle perceived and real stigma and discrimination on the commercial gay scene, and other barriers which prevent gay and bisexual men from having an HIV test thus enabling these men to make more informed personal choices about whether to have a test.

The report uses the same format and analyses used in Section 3 of the original "Testing Barriers" Report and is based on the results of a survey carried out in all the commercial gay venues in Edinburgh during September 2002. The questionnaire used in the survey was based on the original "Testing Barriers" research questionnaire and was developed in conjunction with Paul Flowers and Christina Knussen at Glasgow Caledonian University. Paul Flowers provided the overall design of the research and the analysis of questionnaire data was carried out by Christina Knussen. The questionnaire included questions on demographic information, HIV testing behaviour, perceived and actual HIV status, recent sexual behaviour, attitudes towards testing, attitudes to new treatments and factors which prompt or inhibit testing including real and perceived stigma and discrimination.

A team of volunteer researchers carried out the survey over 2 weekday and 2 weekend evenings between 8pm and midnight in each of the commercial gay venues in Edinburgh. In each venue, both customers and bar staff were approached but as there were only 17 responses from bar staff (6%) we have been unable to include this distinction in the analysis. Only gay and bisexual men were asked to complete the questionnaire. A team leader co-ordinated each session ensuring that response rates were monitored, that no man was approached twice on the same evening to complete the questionnaire and to provide information on HIV testing and services where required.

A total of 283 men took part in the survey which represented a response rate of 62% of all men approached. The majority of men completed the entire questionnaire but there were missing responses to some of the questions and so, in some instances, both percentages and the number of men answering each question is indicated.

Part A of the report summarises the information provided in the questionnaires, Part B examines the men's responses to the individual attitude questions including beliefs about and attitudes to real and perceived stigma and discrimination and finally in Part C we look at differences between testers and non-testers and which characteristics and attitudes are associated with men who intend to have an HIV test in the near future. Where there are significant changes from the data collected for the original 'Testing Barriers' research these are indicated in the report.

I would like to thank Paul Flowers and Christina Knussen of Glasgow Caledonian University for providing the overall design, data analysis of the questionnaire and guidance and support throughout the project. I would also like to thank all the gay venues in Edinburgh for allowing us to carry out the survey in their premises and the Gay Men's Health volunteers who conducted the survey and proof read the various drafts of this report.

Steve O'Donnell Testing Barriers Project Manager June 2003

¹ Flowers, Paul et al (2000) 'Testing Barriers' Healthy Gay Scotland

CONTENTS

Executive Summ Summary of Mai		4 5
Part A Survey	Results	
Section 1 Demographic Inf	formation	7
Section 2 Experience of H HIV testing histo Feelings about t Date of HIV tests Perceived HIV s Perceived HIV s	he HIV test s	9 9 10 10 11
	ur behaviour and perceived HIV status unknown HIV status	12 13 13
Section 4 Intention to take Reasons for hav	an HIV test in the near future ring an HIV test	14 15
Part B Men's	Attitudes to HIV Testing	
Attitudes toward The importance Benefits of HIV to Perceived discrin Costs of HIV tes Problems with the Attitudes about s	d values relating to HIV s new treatments of treatments in leading to testing testing mination against men with HIV	16 16 16 17 18 18 19 20 21 22
Part C Compa	risons	
	ers" and "non-testers" who intend to take an HIV test and those who do not	24 25
Conclusions		26
Table of Figure	s	
Figure 1 Figure 2 Figure 3 Figure 4 Figure 5 Figure 6 Figure 7 Figure 8 Figure 9 Figure 10 Figure 11	Age groups Area of residence Educational attainment Educational attainment by age range Regret about having had an HIV test Year of last HIV test Perceived HIV status Perceived HIV status and testing Perceived HIV status compared with number of reported UAI partners Intention to take an HIV test in the near future Reasons for having an HIV test	7 7 8 8 9 10 11 11 13 14

EXECUTIVE SUMMARY

The survey was carried out over 2 years after the original 'Testing Barriers' research² and is Edinburgh specific where the original research was carried out in both Edinburgh and Glasgow. There was, however, very little attitudinal change described by the participants. Two exceptions to this emerged. Firstly, while in the original research men who had not had an HIV test were identified as perceiving higher incidences of discrimination against positive men on the gay scene, this survey indicated there was very little difference between men who had had a test and those who had not in this regard. Secondly, in the original research non-testers appeared more likely to assume that other gay men were HIV negative while this survey again indicated no difference between testers and non-testers in relation to this assumption.

The percentage of those who had had an HIV test had risen from 55% in 1999 to 62% in 2002. This increase was also reflected in the MRC survey of 2002³ which noted an increase in reported testing from 52% in 1999 to 60% in 2002. Those who expressed an intention to test in the near future remained approximately the same, the percentage rising slightly from 45% to 48%. More detailed questions were included in this research relating to HIV stigma and discrimination including perceived discrimination on the gay scene, by bar staff, by other gay men and by potential sex partners. With the exception of bar staff, where only 10% agreed that HIV positive men are discriminated against by staff in gay bars, the percentages of men who believed HIV positive men were not discriminated against in various contexts were very low with only 13% disagreeing that HIV positive men are discriminated against by potential sex partners.

Psychological influences upon HIV testing

There was little difference in the importance of psychological influences on testing decisions identified by the respondents. Many participants described seeking an HIV test in order to put their minds at ease but, if the result of a test was likely to be positive, living with an uncertain HIV status could be preferable to actually knowing one was positive. Fear of a positive result emerged as a key reason why gay men do not seek HIV testing. Higher perceived likelihood of positive status was associated with greater fear and avoiding testing.

Sexual influences upon HIV testing

Engaging in HIV risk-related sexual behaviour was understood to be a key reason why HIV testing is sought, but 'risky' sex did not solely address unprotected anal intercourse (UAI) but included low risk sexual activity e.g. oral sex with HIV positive men. A large number of men indicated that they thought if a gay man found out any of his sexual partners were HIV positive, he would go for an HIV test.

Status-related influences upon HIV testing

The impacts of a positive diagnosis, both psychological and material, were identified as a reason not to test for HIV. Attitudes to known HIV positive people on the commercial gay scene were also identified as reasons to avoid testing, i.e. stigma and discrimination could be avoided by not testing. Many negative and untested men assumed that HIV positive sexual partners would and should disclose their HIV status during sexual interactions and believed that HIV positive men should bear greater responsibility for sexual safety than untested or negative men.

Procedural influences upon HIV testing

The majority of men either agreed or were uncertain that gay men avoid testing because of waiting times for results. Responses to other questions about procedural influences produced high levels of 'uncertain' answers, perhaps due to the fact that more than one third of the sample had never had an HIV test and therefore may be unaware of clinic procedures, attitudes and opening times.

² Flowers, Paul et al (2000) Testing Barriers. Healthy Gay Scotland

³ MRC Survey (2002) Gay Men's Sexual Health, HIV Testing in Edinburgh

SUMMARY OF MAIN FINDINGS

- Most men who took part in the survey were in their 20's or 30's. Sixty eight percent lived
 in the Edinburgh postcode area, 12% had other Scottish postcodes and 20% either failed
 to give a postcode or lived outside Scotland.
- The sample was fairly well educated. Forty three percent had degrees and only 4% reported having no qualifications.
- The majority of men (62%) had had an HIV test. Of these, 82% reported a negative result, 7% a positive result and 11% were either unsure of the result or failed to provide this information.
- Of the men who had had a test, most (78%) reported having had only one test, 13% were repeat testers and 9% did not give details.
- Of the men who had tested, 79% indicated they did not regret having a test. Of those who
 reported testing positive, 46% said they had some regret.
- In terms of participants' perceptions of their own status, 57% said they were definitely negative and a further 24% said they were probably negative. Only 2 men said they were probably positive and 11 men (4%) said they were definitely positive.
- There was a discrepancy between men's perceived status and their testing history. Some
 men who felt certain of their HIV status had never had a test and equally some men who
 had received test results in the past currently do not know their status. Thus perceived
 status often will not reflect actual status.
- In terms of sexual behaviour, 32% of respondents reported having between 2 and 5 sexual partners in the last year although 21% reported having 6 or more. Forty three percent of men had had one or more UAI partner in the past year (compared to 37% in the 1999 survey) and 55% reported at least one UAI partner in the last 5 years.
- There was a discrepancy between men's perceived HIV status and their reported risk behaviour. Of the men who believed their status to be definitely negative, 38% had had at least one unprotected anal intercourse partner in the past year and, of the men who thought they were probably HIV negative, 48% reported at least one UAI partner in the past year. Almost one third (63%) of men who did not know their status reported at least one UAI partner in the past year as did 18% of men who described their status as definitely or probably positive.
- Almost one quarter (23%) of men reported having UAI with a partner of unknown status, 64% of whom believed they had put themselves at risk.
- Almost half the men said they intended to have an HIV test in the future but, of the men
 who had never had a test, 38% said it was unlikely or highly unlikely that they would have
 a test in the future and 46% of these men were unsure.
- Very few men (17%) reported taking more risks sexually now than they had done in the past.
- Over half (53%) of the sample said they were unsure if their friends had had an HIV test
 indicating that testing is seen more as an individual decision rather than a gay community
 issue. There appears to be stigma attached to testing itself.

- In terms of optimism about new treatments, respondents were in general quite pessimistic. Very few men agreed that HIV / AIDS is less of a threat because of new treatments or that treatments take the worry out of sex. Eighty eight percent, however, said they would take treatments if they were diagnosed HIV positive.
- Most men did not think that treatments were the main reason why gay men should seek testing. Only 11% agreed that there would be no point in testing if there were no treatments.
- The participants tended to agree that there were many benefits to testing with over 70%
 agreeing that having an HIV test can put your mind at rest and 55% agreeing that having
 a test can help you plan your life.
- Although 26% of men acknowledged that fear of a positive result is a reason to avoid or delay testing, only 9% agreed that it is better to live with uncertainty than to know you are HIV positive.
- Respondents readily acknowledged the high levels of stigma and discrimination
 experienced by people with HIV and 44% agreed that discrimination against people with
 HIV occurred on the gay scene. In general, percentages of men who thought people with
 HIV were discriminated against in various contexts were very high.
- In general, respondents were reasonably happy with clinic opening times and testing procedures.
- The majority of men would not have anal or oral sex with someone they knew to be HIV
 positive. There was evidence of sexual exclusion of men who are HIV positive. Thirty
 seven percent of men always assumed their sexual partners to be HIV negative.
- The vast majority of men (84%) believed that, if a person is HIV positive, it is that person's responsibility to ensure that they and their partners have safer sex.
- Paradoxically, the respondents tended to believe that safer sex responsibility was shared irrespective of HIV status, but also that men who are HIV positive bore a greater responsibility in making sure safer sex occurred.
- Comparing 'testers' to 'non-testers': non- testers were less likely to have negative attitudes to having sex with HIV positive men, less likely to perceive themselves as being at risk and less likely to see benefits of testing. They perceived more barriers to testing and more problems with clinics, seemed more aware of treatment / testing arguments and were more optimistic about new treatments. Non-testers had not avoided testing simply because they had never engaged in risky sexual behaviour: many non-testers have engaged in risky sexual behaviour and have high levels of fear of a positive test result. Higher perceived likelihood of positive status was associated with greater fear and avoiding having a test.
- Comparing men who intend to test in the near future to those who do not: those with a
 stronger intention to test were significantly more likely to have had a previous test and
 were less likely to have regrets about previous tests. They perceived many more benefits
 of testing and had much less fear of a positive result.
- Psychological factors such as perceived benefits of testing and fear of positive results appear to be central in shaping men's future testing decisions.

1. Demographic Information

Age

The mean age of the sample was 30.8, ranging from 16 - 65. As shown in Figure 1, most men were in their 20's or 30's with significantly fewer men aged under 20 or over 40.

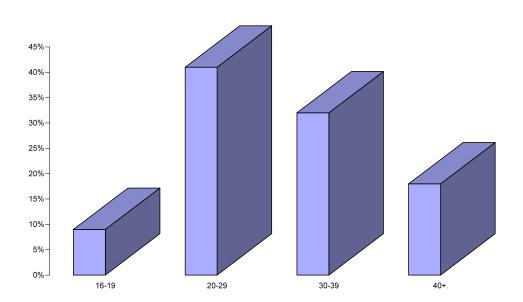


Fig. 1 Age Groups

Area of Residence

As Figure 2 shows, 67.5% of the respondents had an Edinburgh postcode, 2.5% a Glasgow postcode and 10% other Scottish. One fifth of the sample were resident outside Scotland or failed to indicate a postcode. One hundred and sixty men indicated their place of residence to be within the City of Edinburgh (postcodes EH1 – EH17) and 32 indicated their place of residence to be outside the city but within the Lothians (other EH codes) There was no significant age difference between those living in the City of Edinburgh and those living elsewhere.

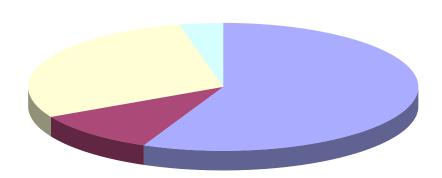


Fig 2 Place of Residence

Men were asked to indicate their highest level of educational attainment: 3.5% of men had no qualifications, 20.6% had "O" grades or equivalent, 31.9% had Highers or equivalent, 42.6% had a degree and 1.4% indicated that they had "other" qualifications.

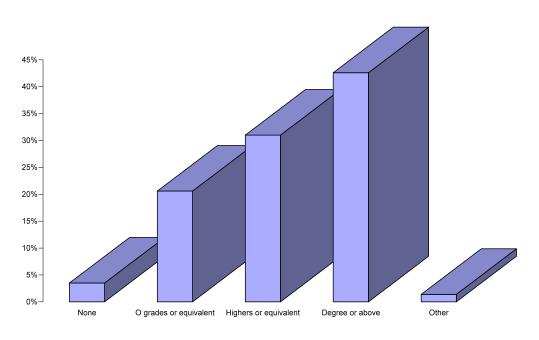


Fig. 3 Educational Attainment

Age was significantly related to educational achievement. As shown in Figure 4, older men were less likely to have higher level qualifications such as a degree. The average age with no qualifications or 'O' grades was 33, the average age of those with Highers was 28 and the average age of those with a degree was 32.

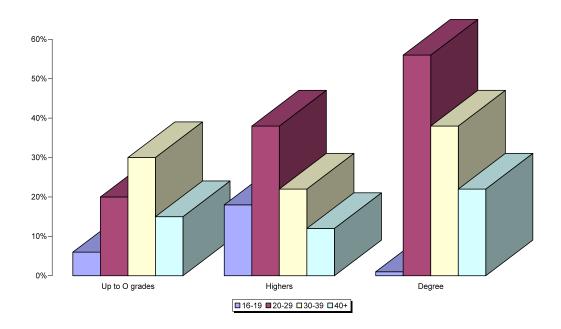


Fig. 4 Educational Attainment by Age Range

2. HIV testing and perceived HIV status

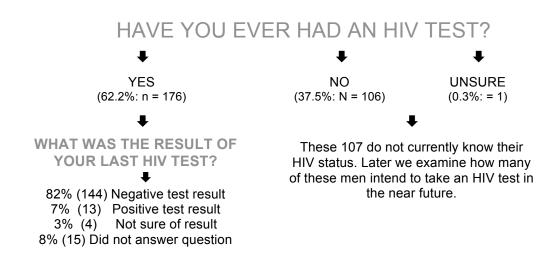
Experience of HIV testing

Men were asked if they had ever had an HIV test, and those who had were also asked the result of their last test. Sixty two percent (n = 176) of the sample had already had an HIV test, 37.5% (n = 106) had not had a test and one respondent was unsure whether he had tested. Of those who indicated that they had had an HIV test, 15 (8%) failed to provide further details of the test(s) and test results.

Of the remaining 161 testers, most had been given a negative test result (82%: n = 144), 7% (n = 13) had been diagnosed positive and 4 people didn't know which HIV status results they had been given.

Considering the sample as a whole, 49% of bar going gay men had been given a negative test result, 5% had been diagnosed HIV positive, 8% did not provide details of test results and 38% had never taken a test or were unsure if they had.

In the final section of this report we explore the differences between testers and non-testers in more detail, including their recently reported risk behaviours and their attitudes towards HIV testing and intentions to test in the near future. We shall see that there are significant differences between testers and non-testers in these areas.



HIV testing history

Some respondents reported having taken more than one HIV test in their lifetime. For each test, results and date of the test were requested. We coded all men who tested at least twice as repeat testers and those who only tested once as single testers. This suggested that among the men who had taken an HIV test, most (78%: n = 138) were single testers and relatively few (13%: n = 24) were repeat testers. Nine percent of respondents (n = 15) did not provide details. All repeat testers reported their HIV status to be negative. Of the repeat testers, 6 men had tested twice and 18 reported at least 3 tests. We only coded up to 3 tests so those reporting 3 tests may have had more.

There were no significant differences between testers and non-testers in terms of area of residence (EH1 – 17 or other postcodes).

Feelings about the HIV test

Respondents who had taken a test were asked to rate the extent to which they regretted having a test. Of the men who had taken a test, the majority (79%) indicated they did not regret having had a test i.e. they either disagreed or disagreed strongly with the statement "I regret having had an HIV test". Of the 14 respondents who indicated they were HIV positive, 7 strongly disagreed that they had regret, 3 disagreed, 2 were uncertain and only 1 strongly agreed that they regretted taking the test. The remaining person who can be identified as HIV positive did not respond to this question.

In all, 39 men indicated that they had regret over a taking an HIV test (i.e. they responded 'uncertain', 'agree', or 'strongly agree' with the statement "I regret having had an HIV test"). Only 8 gave reasons for this regret and most of these were related to not having had a choice e.g. in relation to insurance. Almost half (46%) of men who reported being HIV positive had some regret over testing compared to 33% of men reporting HIV negative status.

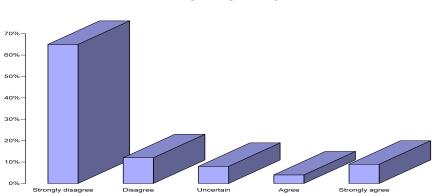
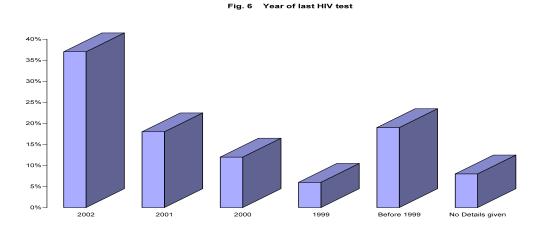


Fig.5 I regret having had an HIV test

Date of HIV tests

Of the 176 men (62.2%) who reported having had an HIV test, 138 (78%) reported having had only one test, 6 (3%) reported two tests and 18 (10%) reported having had three or more tests. Most men had had their last test in 2002 (37%) with 18% reporting their last in 2001, 12% in 2000 and 6% in 1999.

Of men who have had an HIV test, as shown in Figure 6, over half (62%) took their last test in the 9 months preceding the survey. (Figures for 2002 are incomplete as the survey was carried out in September 2002 thus data only represents the first 8 months of that year). Seventy eight percent of respondents reported only having had one test and the chart shows a significant increase in testing since 1999



10

Perceived HIV status

All respondents were asked the question "What do you believe your HIV status to be?" 268 men answered this question. More than half of them (57.1% n=153) said they were definitely HIV negative and a further 23.9% (n=64) said they were probably negative. Only 2 men said they were probably positive and 11 men (4.1%) said they were definitely HIV positive. Fourteen percent (n=38) responded "don't know" to this question.

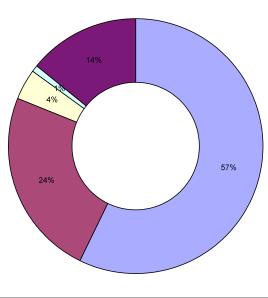


Fig. 7 Perceived HIV Status

□ Definitely negative □ Probably negative □ Definitely positive □ Probably positive ■ Don't know

Perceived HIV status and HIV testing

Of the 176 men who had had an HIV test, 164 indicated that they definitely knew their status (to be either negative or positive). The relationship between perceived status and testing is not straightforward.

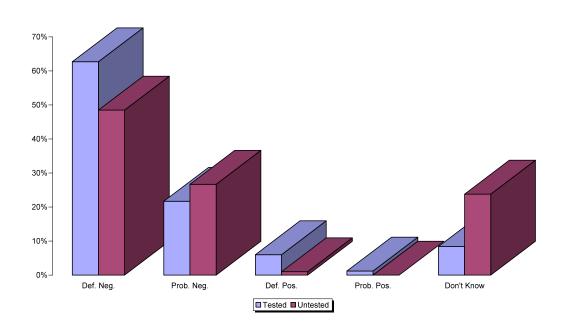


Fig. 8 Perceived status and testing

Almost half (49%) of those who had not had an HIV test indicated their perceived status to be definitely negative. One person said he was definitely positive but he indicated that he had not had a test. Twenty seven percent of those not tested perceived their status to be probably negative and 24% didn't know.

Of those who had had a test: 63% indicated their status to be definitely negative; 22% said they were probably negative; 6% said they were definitely positive; 2 people said they were probably positive and 8% didn't know.

There are, then some men who have been given HIV test results yet still feel unsure of their status (they may have tested years ago and had UAI since then) and some men who feel certain of their HIV status yet have never taken an HIV test.

To understand how men's HIV risk behaviour relates to their perceived HIV status and HIV testing behaviour it is important also to consider men's recent sexual behaviour.

3. Sexual Behaviour

Men were asked to report the number of anal sex partners they had had in the past year, how many of these were unprotected (no condom) and how many unprotected anal sex partners they had had in the past five years. The number of UAI partners in the last year is usually used as a basic measure of HIV risk-related behaviour.

Number of anal sex partners in the last year (n=280):

None	53 (19%)
One	78 (28%)
Two – Five	91 (32%)
Six +	58 (21%)

Only 19% (n=53) of men reported having had no anal partners in the last year while 28% (N=78) reported one contact and 32% (n=91) reported having anal sex with between 2 and 5 partners. A further 21% (n=58) reported more than 5 anal contacts in the last year.

Number of UAI partners in the last year (n=280):

None	158 (56%)
One	81 (29%)
Two – Five	32 (11%)
Six +	9 (3%)

When asked how many of their anal contacts in the last year were unprotected (no condom) the majority of men (56%) reported no unprotected anal intercourse within the last 12 months, 29% reported 1 unprotected contact and 14% reported 2 or more.

Number of UAI partners in the past 5 years (n=280):

None	125 (45%)
One	64 (23%)
Two – Five	67 (24%)
Six +	21 (8%)

When extending this question to the past 5 years less than half the men (45%) reported no UAI, 23% reported one UAI partner and 32% reported 2 or more.

HIV risk-related behaviour and perceived HIV status

Figure 9 shows how HIV risk related behaviour compares with men's perceived HIV status.

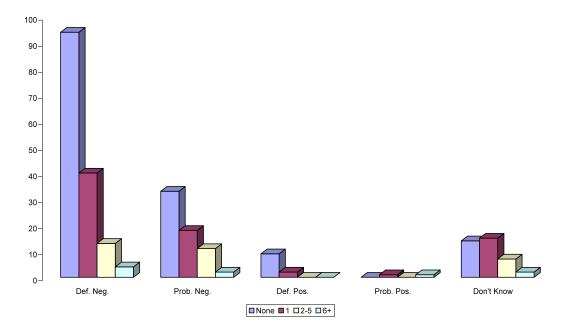


Fig 9 Perceived HIV status compared with number of reported UAI partners in the last year

There is some discrepancy between men's perceived HIV status and their reported HIV risk behaviour within the last year. Of the men who believed they were definitely HIV negative 38% had had at least one UAI partner in the last year and, of the men who thought they were probably HIV negative 48% reported at least one UAI partner in the last year. Almost two thirds (63%) of men who did not know their status reported at least one UAI partner in the last year as did 18% of men who described their status as definitely positive or probably positive.

Sex with men of unknown HIV status

Men were asked to report on whether, in the past year, they had had UAI with men of unknown HIV status, or whether they only had UAI with a partner who they knew to be the same status as themselves. Men were also asked if they thought this put them at risk of HIV infection.

Of the 275 men who responded, 64 men (23%) reported having UAI with a partner of unknown status, 200 (73%) said this had not occurred and 11 (4%) were unsure. When asked whether they thought their sexual activity over the past year had put them at risk of HIV infection, 72 men (26%) thought it had, 173 (62%) thought it had not and 33 (12%) were unsure.

When applying this only to the men who reported having UAI with men of unknown status, 64% thought it had put them at risk of HIV infection, 14% were unsure and 22% did not think it had put them at risk.

There are then a number of men who are having UAI with men of unknown status. Many of these men do not know their own status and some of them do not believe their sexual behaviour is putting them at risk of HIV infection.

4. Intention to take an HIV test in the near future

We asked all the men taking part in the survey how likely it was that they would take an HIV test in the near future. Responses were mixed: almost half (48%) said they had decided to test in the near future but 28% were undecided and 24% said it was unlikely or highly unlikely.

The diagram below shows that men who had previously taken an HIV test are more likely to say that they intend to take a test in the near future (70%) than men who had never tested (16%) Almost half of the non-testers said they were unsure about whether they would have a test in the near future and 38% said it was unlikely or highly unlikely.

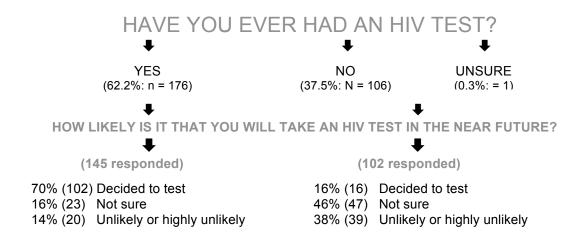
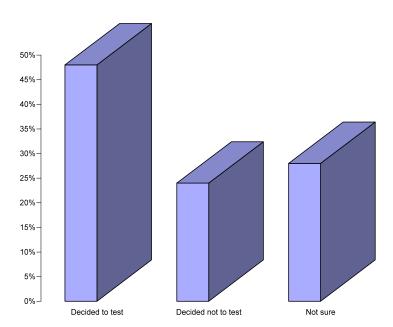


Fig. 10 Intention to test



Reasons for having an HIV test

Men who indicated they intended to have an HIV test were asked their reasons for this decision. Some men gave more than one reason so up to two reasons per person were recorded. Ninety seven men gave reasons and 117 reasons were given altogether.

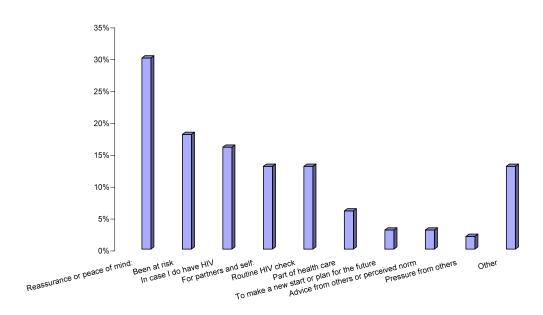


Fig 11 Reasons for having an HIV test

PART B

Men's attitudes to HIV testing

KEY ISSUES

We measured attitudes that related to eight key issues:

- General attitudes towards HIV testing
- Social norms and values relating to HIV testing
- Attitudes towards new treatments for HIV
- Statements about the importance of treatments in leading to testing (the testing / treatment argument)
- Costs and benefits of HIV testing
- Problems associated with the HIV testing process
- Attitudes about sex with men diagnosed HIV positive
- Attitudes about HIV status of sexual partners and sexual risk taking

Within the questionnaire, men were presented with a list of attitude statements and asked how far they agreed/disagreed with each statement on a 5-point scale. Instead of simply using single statements, we ensured that, wherever possible, multiple statements were provided to get a better measure of underlying attitudes.

To allow men to address each question individually and try to reduce any bias, statements were not grouped under the "Key Issues" above but were presented at random. The statements and results have now been regrouped under the "Key Issues" headings and we have merged the results to show only how many men 'agreed', were 'uncertain' or who 'disagreed'. We begin this part of the report with an item by item presentation of the findings before going on to present the more complex analysis of multi-item attitudinal measures.

Changing attitudes towards HIV

HIV is less of threat because the epidemic is in decline	5%	13%	82%
	agreed	uncertain	disagreed
I take more HIV risks than I used to	17%	8%	75%
	agreed	uncertain	disagreed

Men were asked 2 general questions about their attitudes to HIV and risk. Most men (82%) did not agree that HIV was less of a threat because the epidemic was in decline. Participants also tended to disagree that they personally take more HIV risks now than they used to (only 17% agreed, whilst 75% disagreed with this statement).

Social norms and values relating to HIV testing

It is my responsibility as a gay man to have an HIV test	61%	14%	25%
	agreed	uncertain	disagreed
Most of my gay friends have had an HIV test	26%	53%	21%
	agreed	uncertain	disagreed
I wouldn't tell anyone if I was going for an HIV test	35%	18%	47%
	agreed	uncertain	disagreed

We asked specific questions about HIV testing within the gay community to try to assess the social norms or values surrounding HIV testing, for example whether it is part of a gay man's responsibility to seek an HIV test. These are shown in the table above. Over 60% thought it was their responsibility as a gay man to have an HIV test compared with 51% in the 1999 research⁴.

Interestingly, in terms of the norms surrounding testing, when asked if their gay friends had taken an HIV test, more than half the sample (53%) were uncertain suggesting a certain lack of disclosure regarding even going for HIV tests. Twenty six percent said that most of their gay friends had taken a test (representing a slight increase on the 1999 data) and 21% did not think that most of their gay friends had had an HIV test. Given that we reported earlier that 62% of gay men in this sample had taken an HIV test, it appears possible a large number of men are choosing not to tell their friends they have had a test. Less than half of the men (47%) said they would tell others they were seeking testing.

Attitudes towards new treatments for HIV - "treatment optimism"

HIV / AIDS is less serious than it used to be because of new treatments	10%	17%	73%
	agreed	uncertain	disagreed
New treatments take the worry out of sex	16%	25%	59%
	agreed	uncertain	disagreed
If I was diagnosed HIV positive I would be willing to go on new treatments	88%	9%	3%
	agreed	uncertain	disagreed
If every HIV positive person took the new treatments, the AIDS epidemic would be over	4%	20%	76%
	agreed	uncertain	disagreed
People with undetectable viral loads do not need to worry so much about infecting others with HIV	4%	36%	60%
	agreed	uncertain	disagreed

A set of questions were designed to measure men's attitudes to new treatments for HIV and the extent to which they were seen as a 'cure' or an end to the epidemic. Most men (73%) disagreed with the statement "HIV / AIDS is less serious than it used to be because of new treatments". Neither did men believe that new treatments would take the worry out of sex (only 16% agreed, representing a slight increase from 13% in the 1999 data) ³

The vast majority of men (88%) agreed that if they were diagnosed HIV positive they would be willing to go on new treatments but far fewer men (4%) agreed that if every HIV positive person took new treatments, the AIDS epidemic would be over: indeed 32% strongly disagreed with this statement. Similarly, few men (4%) agreed that people with undetectable viral loads do not need to worry so much about infecting others with HIV: 60% disagreed and 36% were uncertain.

The high levels of uncertainty reported for some questions about new treatments may reflect the ongoing medical uncertainty regarding many of these issues.

-

⁴ Flowers, Paul et al (2000) Testing Barriers. Healthy Gay Scotland

If there were no new treatments there would be no point having an HIV test	11%	14%	75%
	agreed	uncertain	disagreed
If there were no HIV treatments available I would probably not have an HIV test	19%	16%	65%
	agreed	uncertain	disagreed
I would not rush to get HIV tested because it doesn't matter when you start treatment	8% agreed	14% uncertain	78% disagreed
Despite new treatments, HIV testing should be avoided	5%	9%	86%
	agreed	uncertain	disagreed
HIV treatments are a new reason to go for an HIV test	49%	31%	20%
	agreed	uncertain	disagreed

One of the major impacts of HAART has been the idea that men should test early to get the most out of available treatments. This is known as the 'testing-treatment' argument. Despite both national and international debate concerning the appropriateness of when to start treatment (and thus when is the optimum time to test positive), it is still important to assess how important gay men think treatments are as a reason to seek HIV testing. The table above indicates that most men (75%) felt that there were benefits to HIV testing even without new treatments. Accordingly, when asked about themselves, only 19% agreed that they would not have a test if there were no new treatments. A further 16% were uncertain and a total of 65% disagreed.

Similarly, few men (8%) agreed with the statement that they would 'not rush to get tested because it doesn't matter when you start treatments' and even less (5%) agreed that 'despite new treatments HIV testing should be avoided'. There is very little difference in these percentages from the 1999 data⁵.

Benefits of HIV testing

Having an HIV test puts your mind at rest	71%	16%	13%
	agreed	uncertain	disagreed
Having an HIV test can help you plan your life	55%	23%	22%
	agreed	uncertain	disagreed
If more people had an HIV test there would be less new HIV infections	59%	20%	21%
	agreed	uncertain	disagreed

A set of questions was included which related to some of the benefits of HIV testing. These are shown in the table above. Most men (71%) agreed that having an HIV test could bring peace of mind. Similarly, over half the men felt that having an HIV test could help to plan one's life. Men tended to agree (59%) that an increase in HIV testing would lead to fewer new infections while 20% were uncertain and 21% disagreed. Again, there is very little difference here from the 1999 data⁶.

⁶ Flowers, Paul et al (2000) Testing Barriers. Healthy Gay Scotland

⁵ Flowers, Paul et al (2000) Testing Barriers. Healthy Gay Scotland

HIV positive men are discriminated against on the gay scene	44%	34%	22%
	agreed	uncertain	disagreed
HIV positive men are discriminated against by bar staff on the gay scene	10%	36%	54%
	agreed	uncertain	disagreed
HIV positive men are discriminated against by other gay men	44%	34%	22%
	agreed	uncertain	disagreed
HIV positive men are discriminated against by potential sex partners	51%	36%	13%
	agreed	uncertain	disagreed
HIV positive men are discriminated against in employment	35%	46%	19%
	agreed	uncertain	disagreed
HIV positive men are discriminated against financially	56%	30%	14%
	agreed	uncertain	disagreed
HIV positive men are discriminated against by the law	30%	43%	27%
	agreed	uncertain	disagreed
If I was diagnosed HIV positive I would get negative reactions from sex partners	43%	40%	17%
	agreed	uncertain	disagreed
If I was diagnosed HIV positive I would get negative reactions from family	34%	28%	38%
	agreed	uncertain	disagreed
If I was diagnosed HIV positive I would get negative reactions from friends	20%	38%	42%
	agreed	uncertain	disagreed
If I was diagnosed HIV positive I would get negative reactions from work colleagues	38%	37%	25%
	agreed	uncertain	disagreed

The "Testing Barriers" report produced in 2000 highlighted the importance of perceived stigma and the psychological impact of positive diagnoses in affecting men's decision-making regarding having an HIV test. We felt it was important to address these issues in the questionnaire and added several statements to those included in the original "Testing Barriers" research.

The table above shows the responses to this set of statements. Forty four percent of men believed that discrimination against men with HIV occurred on the gay scene, 34% were uncertain and only 22% believed that men with HIV were not discriminated against on the scene. When asked if they thought that HIV positive men were discriminated against by other gay men exactly the same percentages applied. This may reflect the fact that the survey was carried out in gay bars and not with gay men who don't use the commercial scene. When asked whether they

Ξ

⁷ Flowers, Paul et al (2000) Testing Barriers. Healthy Gay Scotland

believed that HIV positive men were discriminated against by bar staff, only 10% believed they were, 36% were uncertain and 54% believed they were not discriminated against by bar staff.

When asked whether they considered HIV positive men to be discriminated against by potential sex partners, over half the men agreed that they were and 36% were uncertain. Only 13% disagreed that HIV positive men were discriminated against by potential sex partners. When asked about themselves, 43% believed they would get negative reactions from sex partners if they were diagnosed HIV positive and 40% were uncertain. Only 17% believed they would not get negative reactions from sex partners if they were diagnosed HIV positive.

In general the percentages of men who believed HIV positive men were discriminated against in various contexts were very high. The only instances where the number of men who believed they would not get negative reactions to an HIV diagnosis was higher than those who believed they would were when men were asked about themselves in relation to family and friends. However, with fairly high levels of uncertainty, perceived stigma and discrimination emerged as very significant factor when considering the implications of a positive diagnosis.

When asked about reactions from family, 38% of men believed they would not get negative reactions while 28% were uncertain and 34% believed they would get negative reactions from their families. Forty two percent believed they would not get negative reactions from friends while 38% were uncertain and only one in five believed they would get negative reactions.

Similarly high levels of uncertainty were expressed in relation to discrimination by the law, in employment and in terms of finance. When asked whether HIV positive men were discriminated against in employment, 35% agreed while 46% were uncertain and only 19% disagreed. When asked about themselves 38% agreed that they would get negative reactions from work colleagues if they were diagnosed HIV positive while 37% were uncertain and 25% disagreed.

When asked whether they believed that HIV positive men were discriminated against by the law, 30% agreed, 27% disagreed and 43% were uncertain. More than half the men (56%) agreed that HIV positive men are discriminated against financially, 30% were uncertain and 14% disagreed.

The costs of HIV testing

You shouldn't have an HIV test because you might have to tell people you fancy that you are HIV positive	8%	14%	78%
	agreed	uncertain	disagreed
Fear of a positive result puts me off testing	26%	17%	57%
	agreed	uncertain	disagreed
I would rather not know my status than risk being told I am HIV positive	15%	17%	68%
	agreed	uncertain	disagreed
I do not want to test because of the psychological consequences of a positive result	20%	23%	57%
	agreed	uncertain	disagreed
It's much better to live with an uncertain HIV status than to wake up every morning actually knowing you're HIV positive	9%	21%	70%
	agreed	uncertain	disagreed
I would rather get ill than find out I was HIV positive	9%	6%	85%
	agreed	uncertain	disagreed

Several statements related to the relative costs of HIV testing were included in the questionnaire. The table shows the responses to these statements. Very few men (8%) thought that testing should be avoided because of the possibility of having to tell people you fancy that you are HIV positive. However, only 13% of men did not think they would receive negative reactions from potential sex partners if they told them they were HIV positive suggesting that the majority of men see this as an acceptable cost of testing.

The remaining statements in this section focussed on men's fear of being diagnosed HIV positive and how this may discourage them from taking an HIV test. More than a quarter of the men (26%) agreed that "fear of a positive result puts me off testing" and 17% were uncertain. Few men (15%) agreed that they would rather not know their status than risk being told they were HIV positive and only one in five agreed that they did not want to test because of the psychological consequences of a positive result. Only 9% thought it was better to live with uncertainty than a positive diagnosis and 21% were uncertain. Most men (70%) disagreed that this was a reason to avoid testing and, similarly, few men (9%) reported that they would rather get ill than find out they were HIV positive.

Problems with the HIV testing process

Clinics don't open at the right times for gay men to get tested	18%	31%	51%
	agreed	uncertain	disagreed
The way staff treat people when they get tested puts them off having a test	10%	34%	56%
	agreed	uncertain	disagreed
If I wanted an HIV test I would have to travel a long way to the clinic	10%	15%	75%
	agreed	uncertain	disagreed
I would not go for an HIV test if I had to wait more than a day for the results	19%	9%	72%
	agreed	uncertain	disagreed
Gay men avoid testing because they can't bear waiting for the results	25%	37%	38%
	agreed	uncertain	disagreed

This category of statements, shown in the table above, aimed to investigate problems associated with HIV testing centres and waiting for test results. As with the 1999 'Testing Barriers' data⁸, this set of statements produced high levels of 'uncertain' answers, possibly due to the fact that more than one third (compared with one half in 1999) of the sample had never had an HIV test and therefore may be unaware of clinic attitudes, procedures and opening times. The responses indicated that only 18% of men thought that clinics did not open at the right time for gay men to get tested and even fewer men (10%) felt the way staff at clinics treat people when they get tested puts them off having a test. Over 50% of men (compared with 40% in 1999) disagreed that these problems existed to any real extent and almost a third were uncertain.

Asked if they would have to travel a long way to have an HIV test, the majority of men (75%) disagreed but this may be expected as the survey was carried out in Edinburgh rather than rural or isolated areas. Men were asked two questions about waiting for test results to ascertain how far this was a barrier to testing. Most men (72%) disagreed that waiting more than a day for test results would put them off testing or that gay men avoid testing because they can't bear waiting for test results (38% of men disagreed with this statement while 37% were uncertain).

-

⁸ Flowers, Paul et al (2000) Testing Barriers. Healthy Gay Scotland

Attitudes about sex with HIV positive people

I wouldn't have anal sex with anyone I knew was HIV positive	52%	22%	26%
	agreed	uncertain	disagreed
I wouldn't have oral sex with anyone I knew was HIV positive	42%	29%	29%
	agreed	uncertain	disagreed
Nobody would want to have sex with me if they knew I was HIV positive	32%	38%	30%
	agreed	uncertain	disagreed
If a gay man found out any of his sexual partners were diagnosed HIV positive, he would go for an HIV test	63%	26%	11%
	agreed	uncertain	disagreed

The original 'Testing Barriers' research⁹ showed that the sexual, as well as social, exclusion of HIV positive men was commonplace. To explore this further three statements which addressed sex with partners known to be HIV positive were included in the survey, shown in the table above.

Since the vast majority of the sample are HIV negative or untested, it is clear that the responses to these statements do not represent the views of positive men talking about sex with other positive men. Just over half the men (52% compared with 65% in the 1999 data) said they would not have anal sex with anyone they knew to be HIV positive. A slightly lower percentage (42%) said they would not have oral sex with anyone they knew to be HIV positive. When asked to consider how their own lives might be affected by a positive diagnosis, 32% (compared to 37% in 1999) thought that "nobody would want to have sex with me if they knew I was HIV positive". However, a higher percentage (38%) were uncertain about this statement.

We also asked about how participants thought about risks of HIV transmission in situations in which they know a partner is HIV positive. Almost two thirds would seek an HIV test after finding out a sexual partner was HIV positive.

Attitudes about HIV status of sexual partners and sexual risk taking

Whatever your HIV status you are equally responsible for safer sex	90%	6%	4%
	agreed	uncertain	disagreed
I always assume my sexual partners are HIV negative	37%	23%	40%
	agreed	uncertain	disagreed
Unless someone told me they were HIV positive, I would assume they were HIV negative	38% agreed	24% uncertain	38% disagreed
If you are HIV positive it is your responsibility to make sure you and your partners have safer sex	84%	7%	9%
	agreed	uncertain	disagreed
If someone wants to have unprotected sex they are probably HIV negative	3%	21%	76%
	agreed	uncertain	disagreed

⁹ Flowers, Paul et al (2000) Testing Barriers. Healthy Gay Scotland

-

A number of statements were included to assess men's assumptions about the HIV status of their sexual partners. The responses to these statements are presented in the table above. Almost all men (90%) agreed that "whatever your HIV status, you are equally responsible for safer sex, with only 6% uncertain and 4% disagreeing with this statement.

One third of the men in the survey agreed that they assumed their sexual partners were HIV negative unless told otherwise. Three quarters of the sample thought that HIV positive men should disclose their status to sex partners and 84% said that HIV positive men were responsible for ensuring that safer sex occurs. Despite this, 76% of the sample disagreed that wanting unprotected sex was indicative of an HIV negative status.

PART C

1. Comparing "testers" and "non-testers"

By analysing the characteristics associated with men who either have, or have not, ever had an HIV test we can begin to understand some of the issues that are likely to be important in understanding testing decisions and, equally, isolate those factors which act as barriers to HIV testing. For example, we can see whether those who have never had a test have in actual fact never engaged in risky behaviour and thus may have no need to test. Of the sample, 62% reported they had had at least one HIV test. (This compares with 55% in the Glasgow / Edinburgh 'Testing Barriers' research of 2000¹⁰) In the following analyses we compare these men to the 38% of men who said they had never had an HIV test or were unsure. For simplicity, in the results below we refer to these groups as 'testers' and 'non-testers'.

As in the original 'Testing Barriers' research, we examined the key differences between testers and non-testers: thus it is possible to think of these factors shown below as barriers to testing.

Non-testers:

- were significantly younger than men who had taken an HIV test. In other words, as men got older they were more likely to have had an HIV test.
- were less likely to indicate an intention to test in the near future. Seventy percent of past testers had decided to take a test in the future compared to 16% of non-testers.
- saw significantly more problems with using clinics, such as opening times
- perceived more barriers to having a test such as problems with waiting for results
- · saw significantly fewer benefits to testing
- had significantly higher fear of a positive test result
- were more likely to endorse treatment optimism i.e. were more likely to believe that treatments presented a key reason to test
- had more negative attitudes towards having sex with someone who was HIV positive. In other words they were less likely to have oral or anal sex with someone they knew to be positive

Unlike the original 'Testing Barriers' research this survey showed very little difference between testers and non-testers in terms of perceived discrimination towards HIV positive men or in assumptions that other gay men are negative. However, it must be remembered that, in this section, different measures were used with many more items included in this survey. There were no differences in terms of area of residence or perceived negative reactions from others if diagnosed HIV positive.

Non-testers were more fearful of getting a positive result. They were more likely to have negative attitudes towards sex with HIV positive men, less likely to perceive themselves at risk and less likely to see benefits of testing. They perceived more barriers to testing and more problems with clinics, seemed more aware of treatment/testing arguments and were more optimistic about new treatments. They were less likely to have had two or more anal sex partners in the past year and less likely to have had two or more unprotected anal sex partners in the past five years. However, non-testers had not avoided testing simply because they had never engaged in risky sexual behaviour. Many non-testers have engaged in risky sexual behaviour and have high levels of fear of a positive test result.

-

¹⁰ Flowers, Paul et al (2000) Testing Barriers. Healthy Gay Scotland

2. Comparing men who intend to take an HIV test and those who do not.

Those intending to have an HIV test in the near future:

- were more likely to have already had an HIV test
- were more likely to have had two or more anal sex partners in the past year and two or more unprotected anal sex partners in the last 5 years
- were less likely to have regrets about previous tests
- were more likely to say they would take treatments if diagnosed positive
- · perceived more benefits to testing, e.g. giving peace of mind
- had less fear of a positive result
- perceived fewer barriers to testing
- perceived themselves to be more at risk

In this analysis we examined factors associated with intending to have an HIV test in the near future. We compared those men (48%) who said they had decided to test with those who said they were not sure or it was unlikely or highly unlikely that they would have a test in the near future.

The analysis found that those with a stronger intention to test were significantly more likely to have had a previous test, were less likely to have regrets about previous tests, perceived many more benefits to testing and had much less fear of a positive result.

Psychological factors such as perceived benefits of testing and fear of positive HIV test results appear to be central in shaping men's future testing behaviour.

Keeping in mind that the original 'Testing Barriers' research was conducted in both Edinburgh and Glasgow, comparing data collected for that report suggests aggregate levels of unprotected anal intercourse (UAI) have increased from 37% in 2000 to 43% in 2002. There was a similar increase when the Testing Barriers data was compared with data collected for the Gay Men's Task Force (Hart et al, 1999) which reported 32% in 1996. As in 2000, gay men engaging in UAI with partners of unknown status were aware of what they were doing in terms of personal risk taking. Those at most risk are likely to say they take more risks now than they used to.

There is evidence for change in terms of increases in levels of HIV testing from an average of 55% in 2000 (Flowers et al, 2000) to 62% in 2002. This represents a continuing trend with 51% reported by GMTF in 1996 (Hart et al, 1999). The impact of new treatments has undoubtedly contributed to this trend but not all recent developments reinforce the advantages of testing. Recent studies on increases in drug resistant strains of HIV and the psychosocial impacts of the Stephen Kelly court judgement put greater burdens and responsibilities on HIV positive people.

Only 5% (14 men) self-reported a positive HIV status indicating that seroprevalence remains quite low. However, in the light of the findings above, the importance of testing is highlighted for the group of gay men who are HIV positive but who do not know it. For some of these men there would be clear medical advantages in knowing their status and accessing appropriate medical care. There are clearly a number of men who have had UAI with people of unknown status in the past 5 years who have not had a test. They perceive barriers to testing, the most common of which is fear of a positive result associated with beliefs about what it means to be positive.

One of the key issues associated with what it means to be HIV positive was the very high level of HIV stigma and discrimination towards positive people. HIV positive status is widely understood to bring with it stigma and discrimination, associated physical and mental health problems and sexual problems (e.g. dealing with disclosure issues, responsibility for condom use, lack of sexual partners). The stigma associated with HIV positive status extends to the testing process itself and, as the report has shown, HIV testing remains a personal issue with a large number of men choosing not to tell their friends if they have had a test. More than half (53%) of the sample said they were unsure if their friends had had a test and it appears that gay men anticipate and avoid the issue of status disclosure even when considering whether to have a test.

This research underlines the complexity of gay men's responses to HIV and the importance of psychosocial factors in contributing to gay men's testing decisions. The Testing Barriers Project has adopted a community development approach to dealing with barriers to testing including information and training for volunteers and bar staff on the commercial gay scene, peer education initiatives, involving gay men with HIV in developing strategies to tackle HIV stigma and discrimination and organising various health promotion events in gay venues. The findings of this report support these methods of intervention rather than any specifically pro-testing campaign at this time.

Steve O'Donnell Testing Barriers Project Manager May 2003