Positive health: Method and sample

Author:
Prestage, Garrett; Song, Angela; Grierson, Jeffrey; Race, Kane; Grulich, Andrew; Kippax, Susan

Publication details:
Report No. Monograph 1/2001
1875978399 (ISBN)

Publication Date:
2001

DOI:
https://doi.org/10.26190/unsworks/98

pH positive HEALTH

Method and Sample

1998 – 1999

Garrett **PRESTAGE** [2]
Angela **SONG** [1]
Jeffrey **GRIERSON** [3]
Kane **RACE** [1]
Andrew **GRULICH** [2]
Susan **KIPPAX** [1]

[1] National Centre in HIV Social Research
[2] National Centre in HIV Epidemiology and Clinical Research
[3] Australian Research Centre in Sex, Health and Society

Monograph 1/2001

NCHSR
National Centre in HIV Social Research

Copies of this monograph or any other publications from this project may be obtained by contacting:

National Centre in HIV Social Research
Level 2, Webster Building
The University of New South Wales
Sydney NSW 2052 Australia
Telephone (61 2) 9385 6776
Fax (61 2) 9385 6455
nchsr@unsw.edu.au
www.arts.unsw.edu.au/nchsr/

ISBN 1-875978-39-9

Garrett Prestage
National Centre in HIV Epidemiology and Clinical Research
The University of New South Wales

Angela Song
National Centre in HIV Social Research
The University of New South Wales

Jeffrey Grierson
Australian Research Centre in Sex, Health and Society
La Trobe University

Kane Race
National Centre in HIV Social Research
The University of New South Wales

Andrew Grulich
National Centre in HIV Epidemiology and Clinical Research
The University of New South Wales

Susan Kippax
National Centre in HIV Social Research
The University of New South Wales

CONTENTS

ACKNOWLEDGEMENTS

We would like to acknowledge the following individuals and organisations for contributing to the success of this project:

pH Participants

The 425 HIV-positive people who have given several hours of their time to ensure that the study is fully inclusive of their own circumstances and experiences.

Project Committee

David Austin, Jeffrey Grierson, Andrew Grulich, Sue Kippax, Dean Murphy, Garrett Prestage, Kane Race, Angela Song, Jo Watson, Michael Woodhouse.

NEW SOUTH WALES

Interviewers

David Abello, Daniel Alderman, Matthew Calvert, Lara Cassar, Tony Creighton, Olympia Hendry, David Mackay, Peter Mitchell, Greg Reading, Astrid Rogaz.

National Centre in HIV Epidemiology and Clinical Research Staff

Interviewer Counselling & Support:
Olympia Hendry

Computer Support:
Regina Linich, Terry Sharkey, Charles Tran.

Administrative Support:
Matthew Calvert, Yvette Toole.

AIDS Council of NSW Staff & Volunteers:

Community Liaison:

Anthony Adams, Brent Allan, Amelia McLaughlin, Vivien Munro, Kevin Orrel.

Other Organisations (Staff & Volunteers)

Albion Street Centre, Blackout, Bobby Goldsmith Foundation, Bridge House, Eora Centre, Gender Centre, Holdsworth House General Practice, Leather Pride, Luncheon Club, Mid Western Area Health Service, Multicultural HIV Service, Nepean Hospital, New England Area Health Service, New South Wales Users and AIDS Association, NorthAIDS, Northern Rivers Area Health Service, Northern Sydney Area Health Service, Parramatta Sexual Health Clinic, Positive Heterosexuals, Positive Living Centre, Royal North Shore Hospital Clinic 16, Sex Workers Outreach Project, SHAIDS, South-East Sydney Area Health Service, Sydney Gay and Lesbian Mardi Gras Association, Taylor Square Clinic, The Tree, Thrifty Car Rentals (Lismore).

VICTORIA

Interviewers

Gregory Horn, Michelle Humphreys, Mel Irenyi, Karalyn McDonald, Anton Mischewski, Katrina Newnham, Richard de Visser.

Australian Research Centre in Sex, Health and Society (La Trobe University) Staff

Mel Irenyi (Victorian Project Coordinator)

Other Organisations (Staff and Volunteers)

Alfred Hospital Access Information Centre, Alfred Hospital Haemophilia Treatment Centre, Alfred Hospital Infectious Diseases Unit, Alternative Therapists Group, Carlton Clinic, Country AIDS Network, Joy Melbourne, McLean House, Melbourne Sexual Health Centre, PLWHA (Victoria), Positive Attitude, Positive Living Centre, Positive People Victoria, Positive Women, Prahran Central Clinic, Prahran Market Clinic, Rosehaven Supported Accommodation, Royal Melbourne Hospital, Royal Women's Hospital, Straight Arrows, VAGMA, Victorian AIDS Council/Gay Men's Health Centre, VICAIDS.

The National Centre in HIV Social Research (NCHSR) and the National Centre in HIV Epidemiology and Clinical Research (NCHECR), both affiliated with the University of New South Wales, are funded by the Commonwealth Department of Health and Aged Care.

The Australian Research Centre in Sex, Health and Society (ARCSHS) is a collaborating centre to the National Centre in HIV Social Research funded by the Commonwealth Department of Health and Aged Care.

We thank the Commonwealth Department of Health and Aged Care, and the NSW Department of Health for funding the project.

LIST OF TABLES

LIST OF FIGURES

DESCRIPTION OF THE STUDY

The Positive Health (pH) project is a cohort study of HIV positive people. The aim of the study is to monitor responses to HIV and treatments over time, particularly in relation to engagement with health care services, health beliefs, preventive behaviour and medication use. The main focus of the study is on positive people's health management strategies and the impact of HIV on their lives.

Participants were recruited through two research centres: one in NSW and one in Victoria. The criterion for entry into the study was being HIV positive.

The project is administered collaboratively through the National Centre in HIV Social Research (NCHSR), the National Centre in HIV Epidemiology and Clinical Research (NCHECR), the Australian Research Centre in Sex, Health and Society (ARCSHS), the National Association of People Living with HIV/AIDS (NAPWA) and the Australian Federation of AIDS Organisations (AFAO).

A description of the sample of 425 participants is contained in this report. Detailed analyses of the data will be published as they are completed. The descriptions of the data presented here are not final and further analyses may require some reinterpretation of the findings.

METHODOLOGY

- A questionnaire was developed over many months, in consultation with community organisations and service providers.
- The questionnaire covered a broad range of issues, including the use of treatments, access to services, and community and personal relationships.
- Recruitment occurred both directly, by staff members on-site at community events and venues, and indirectly through promotional and informational material.
- Participants were recruited through a wide variety of community venues, events, organisations and clinical settings.
- In some cases promotional material was distributed and volunteers were encouraged to contact a project office.
- About 20% of participants were enrolled through the pre-existing SMASH cohort study.
- Each interview was conducted at a time and place that suited the participant; most interviews were carried out at the project offices, AIDS Council offices, or in the participant's own home.
- A small number of interviews were conducted in languages other than English with the assistance of the NSW Multicultural HIV/AIDS Service.

SAMPLE SELECTION

Although testing for HIV antibodies has been relatively widespread in Australia, without universal testing it is difficult to know the true extent of the epidemic or its distribution throughout the population. Obtaining a representative sample of HIV positive people is therefore quite difficult. Indeed, the limited demographic details collected through surveillance of HIV and AIDS are not sufficient to provide a complete demographic profile of 'people living with HIV/AIDS' (PLWHA). HIV positive people do not represent a clearly identifiable section of the general population and so cannot be located simply on the basis of geography or by the use of particular services. Some sub-populations are inevitably under-represented in studies of this kind. These include people who are not socially attached to the gay community or to HIV positive organisations, young people, women, people from minority cultural backgrounds and people who do not have a history of accessing treatments.

A national registry of HIV infections is kept in Australia. Data from this registry provide a limited means of assessing the distribution of HIV within various populations but, as this is an anonymous database, it does not provide a means of recruiting HIV positive people into a cohort.

Issues associated with confidentiality and anonymity may also influence the composition of a sample in a study of this type. The pH study is longitudinal in design, which requires participants to make a long-term commitment to the study and to provide research staff with personal contact details. This means that participants are not anonymous within the research project, but anonymity is assured outside the project. The recorded survey responses of all participants are confidential. Given the potential for discrimination against HIV positive people, it is plausible that some potential respondents may have been concerned about disclosing their sero-status due to the nature of the research and consequently may have chosen not to participate.

Given these constraints, pH is primarily a study of those people who are most likely to be in contact with HIV-related services and support networks, especially those who exist within the gay community. Nonetheless, special efforts were made to include women, young people, people from non English-speaking backgrounds, Indigenous people and Torres Strait Islanders, as well as HIV positive people who live outside the inner-city areas of Sydney and Melbourne.

Participants were enrolled into the study via: direct recruitment by a staff member at an event; filling out a volunteer form at a social or community venue; or telephoning the project office. In the latter case, appointments for interviews were made immediately. People who were recruited at an event or who filled out a volunteer form were later contacted by a staff member, at which time appointments were made.

The first round of data was obtained through face-to-face structured interviews. Follow-up interviews will be conducted annually. Interviews were conducted at the participant's convenience. Most participants preferred to complete their initial interview at the project offices in Sydney or Melbourne, while others preferred to have the interviewer come to their home. A small number of interviews were conducted at the participant's workplace, or at an AIDS Council office.

Interviews were almost always conducted in the English language. Speakers of other languages were made available through the Multicultural HIV/AIDS Service in Sydney, but these services were used in only a few cases.

RECRUITMENT AND PARTICIPATION

Recruitment strategies included:

1 Appeals through the HIV and gay media inviting volunteers to phone.
2 Distribution of flyers and reply-paid contact cards at venues and events. These attracted a substantial number of HIV positive people.
3 Production and distribution of a project newsletter explaining the purpose of the project and encouraging participants to develop an ongoing personal commitment to the project.
4 Distribution of newsletters and cards to medical practitioners with large HIV caseloads.
5 Direct recruitment from participants in other relevant studies.
6 Personal networking.
7 Direct recruitment through community organisations, social groups, events and venues.
8 'Snowballing' through friends and acquaintances of participants.
9 Inviting HIV positive participants from SMASH to enrol in the project.
10 Direct referrals from medical practitioners.

Channels of recruitment are listed in the following table.

Table 1 : Channels of recruitment

	Frequency	Percentage (%)
SMASH participant	96	22.6
Gay community event	47	11.1
Doctor's clinic	43	10.1
HIV positive organisation	33	7.8
HIV positive social function	32	7.5
AIDS Council	30	7.0
Other community organisation	18	4.2
Friends	15	3.5
Through other studies	15	3.5
HIV positive publication	12	2.8
Referred through SMASH	11	2.6
Gay press	10	2.3
Gay organisation	5	1.2
Health centre	5	1.2
Other	49	11.5
Unsure/No response	4	0.9
Total	**425**	**100**

With regard to the participants recruited through the SMASH study, the methods of recruitment used in that study were similarly broad ranging (Prestage et al, 1995). Overall, the pH cohort drew participants from a wide variety of sources.

THE QUESTIONNAIRE

The initial questionnaire used in the study was the product of many months of deliberation and consultation. It was adapted from instruments used in previous studies, particularly the questionnaire used in the SMASH study. In developing this questionnaire, the pH project team consulted with a variety of HIV organisations and medical practitioners.

The final version of the questionnaire was 74 pages long and contained about 1000 items. Questionnaires were administered in face-to-face interviews and took between ninety minutes and two hours to complete. Although the interview was necessarily complex, there were relatively few difficulties with its administration and very few complaints from the participants.

Major areas covered in the interview were:

1 Demographic details (46 items)
2 Contact with HIV positive people and organisations (44 items)
3 Disclosure of serostatus (21 items)
4 Use of health and support services (138 items)
5 Personal health and serological testing (178 items)
6 Use of alternative/natural therapies (47 items)
7 Use of anti-retrovirals (255 items)
8 Use of other medical treatments (49 items)
9 Recreational drug use (47 items)
10 Relationships with service providers (39 items)
11 Clinical trials (7 items)
12 Beliefs about medicine and HIV (34 items)
13 Involvement in community subcultures (17 items)

STUDY PARTICIPATION

At the end of the initial twelve months (September 1998 – September 1999) of recruitment, 425 HIV positive people had been interviewed, including 56 people in Victoria. These participants form the initial cohort sample. Of these 425 participants, 98% have consented to follow-up interviews. Further annual intakes will occur in future years as a way of boosting the number of participants.

DEMOGRAPHIC PROFILE

- Participants lived predominantly in private accommodation in urban areas.
- Although many lived alone, a third lived with their regular partner.
- The mean age of participants was 41 and most participants were male.
- The majority of participants were from an Anglo-Celtic background and about 50% held a religious belief.
- About half the participants were in receipt of social security, and a similar proportion received an income of less than $15,000 a year.
- Of those who were employed, over half were in professional or managerial occupations.
- About a third of participants had received some tertiary education.
- Half the participants were in a relationship at the time of the interview and almost 20% were parents.

AGE AND GENDER

Ninety-five percent of the 425 participants were men and 5% were women. There was one transgender male-to-female and one participant whose gender was not reported.

The participants ranged in age between 22 and 69, with the mean age being 41 (see Figure 1).

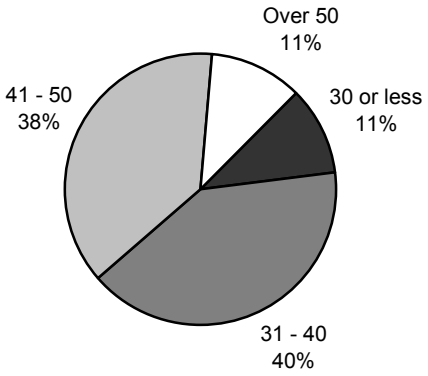

Figure 1 Age

COUNTRY OF BIRTH AND ETHNICITY

Most of the participants were born in Anglophone countries: Australia, New Zealand, the United Kingdom or North America. Very few were born in non English-speaking countries (see Figure 2).

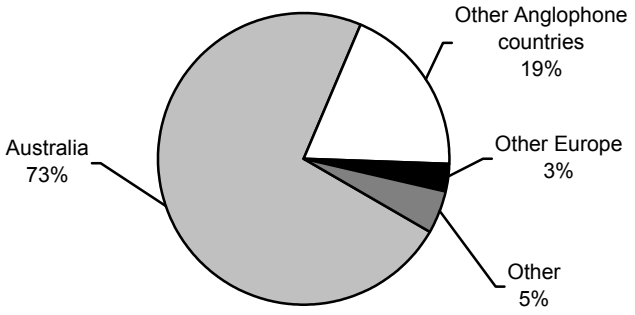

Figure 2 Country of birth

With regard to ethnic or cultural background, 81% of participants said that they were Anglo-Celtic and 10% said that they came from another European background. Among the 36 (9%) non-Europeans, 5 identified as Arabic, 10 as Asian, 12 as Aboriginal and Torres Strait Islanders and 9 as other ethnicities. (see Figure 3)

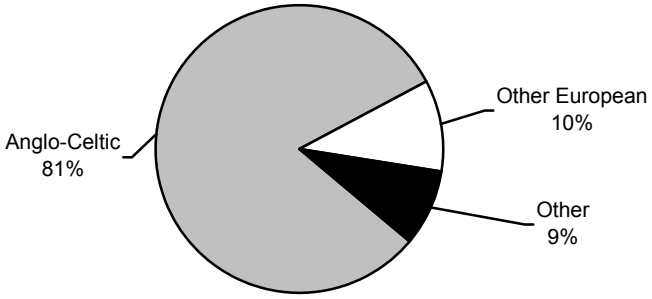

Figure 3 Ethnicity

RELIGION

About half of all participants held no religious beliefs. Twenty-eight percent of the sample reported that they were Christians, and a further 25% held a range of other non-Christian religious beliefs, including Buddhism (see Figure 4).

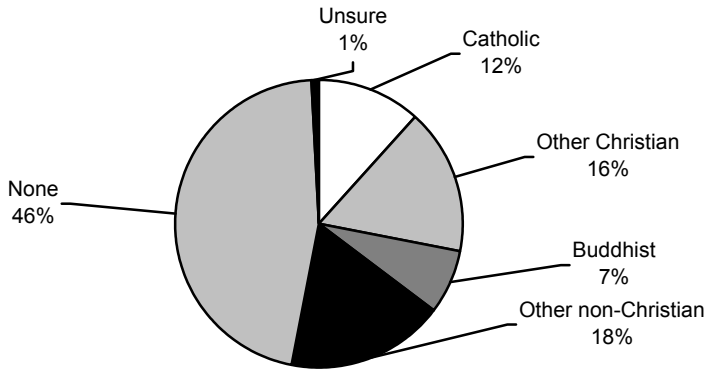

Figure 4 Religious affiliation

INCOME

About half the sample received an income of $15,000 or less per year, and one in five received an income of more than $40,000 per year (see Table 2).

Table 2 : Income

	Frequency	Percentage (%)
Up to $9,000	69	16.3
$9,001—$15,000	139	32.9
$15,001—$26,000	49	11.6
$26,001—$40,000	75	17.7
$40,001—$60,000	51	12.1
Over $60,000	32	7.5
Unsure/No response	8	1.9
Total	**423**	**100**

Note: Data were missing on this item for 2 participants.

LABOUR FORCE PARTICIPATION

Less than half the participants were employed and about a quarter were in full-time employment (see Table 3). Many were on a pension of some sort. Few participants were students or registered as unemployed.

Table 3 : Employment status

	Frequency	Percentage (%)
Full time employed	113	26.6
Part time employed	73	17.2
Unemployed	19	4.5
Student	13	3.1
Pensioner/Social security	188	44.2
Other	19	4.5
Total	**425**	**100**

OCCUPATION

Over half the participants who were employed or had been employed in the previous 12 months were in professional or managerial occupations (see Figure 5). A further 33% were white-collar workers, while 12% were blue-collar workers. Given the large proportion of gay men in the sample it is not surprising that the employment status of respondents is similar to other study samples of gay men (Prestage et al, 1994).

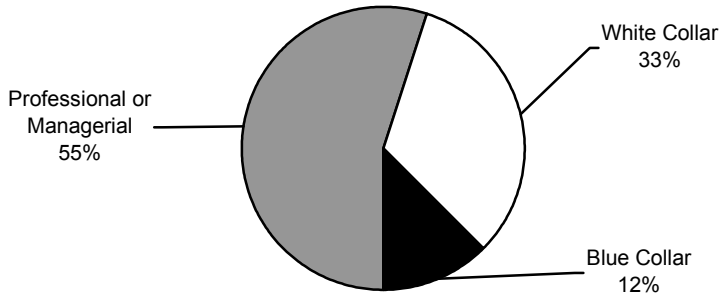

Figure 5 Occupation

EDUCATION

Although the sample was relatively well educated, it was less so than is commonly found in other samples of gay men (Prestage et al, 1994). There was, however, little difference in levels of education between the gay or homosexual men in the sample and the other participants. Over two thirds of all participants had proceeded beyond Year 10 of high school: over one in five had received a trade certificate or diploma, and one third had received some university education (see Figure 6).

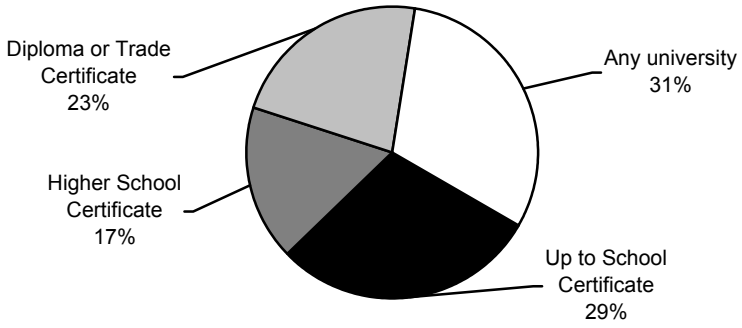

Figure 6 Education

RESIDENTIAL DISTRIBUTION OF THE SAMPLE

Recruitment of the sample was carried out from two sites: one in Sydney (87% of the sample) and one in Melbourne (13% of the sample). With regard to participants' residential distribution, 85% were living in NSW, 14% in Victoria, and 1% in other states of Australia (see Figure 7).

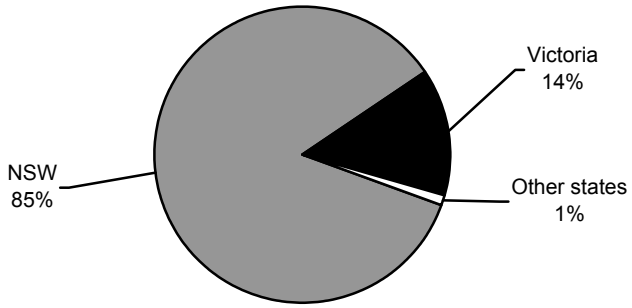

Figure 7 Residential distribution of the sample

The NSW sample was drawn primarily from the inner metropolitan areas of Sydney – the Eastern Suburbs, Inner City and the Inner West – which broadly correspond to the geographic concentrations of the epidemic and of the gay community. Among those 67 NSW participants who lived outside Sydney, over half lived on the North Coast of New South Wales (see Figure 8).[1]

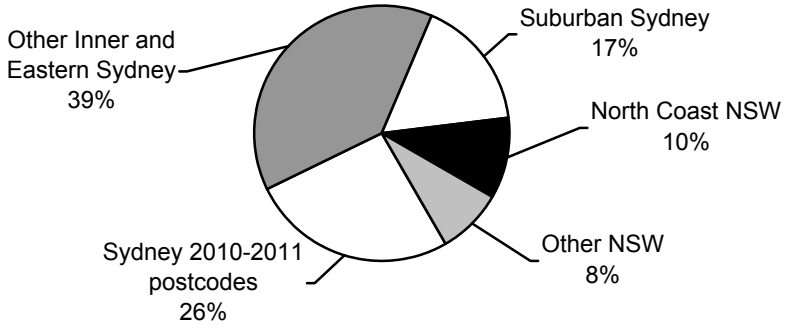

Figure 8 Place of residence of NSW respondents

LIVING SITUATION

The types of housing in which people lived included both private and government assisted rental accommodation and privately owned homes (see Table 4).

Table 4 : Housing

	Frequency	Percentage (%)
Own home	116	27.3
Private rental	140	32.9
Public rental	57	13.4
Government-assisted	87	20.5
Other	25	5.8
Total	**425**	**100**

[1] This was as much a consequence of the targeted recruitment as it was of the fact that there is a concentration of HIV positive people in that area.

Forty-one percent of the participants lived alone, a third lived with a regular partner (29% with a male partner and 3% with a female partner), 18% lived with friends and a small number (3%) lived with their parents or other family members (see Figure 9).

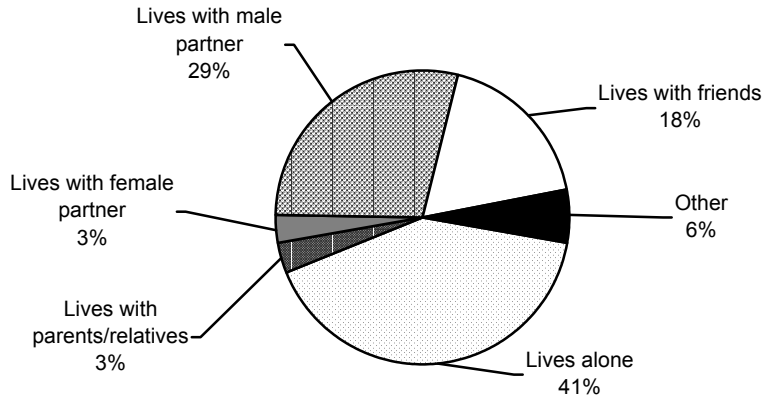

Figure 9 Living situation

Twenty-two percent of the sample lived with at least one other HIV positive person (in some cases their sexual partner) and 50% shared accommodation with gay, lesbian or bisexual person(s).

RELATIONSHIPS AND CHILDREN

Forty-six percent of the participants were in a sexual relationship with a regular partner (male or female) at the time of the interview.

The HIV status of regular partners was as likely to be HIV negative as HIV positive, with only a handful of participants being unaware or unsure of their partner's sero-status (see Table 5).

Table 5 : HIV status of regular partner

	Frequency	Percentage (%)
HIV positive	95	48.0
HIV negative	98	50.0
Unknown HIV status	2	1.0
Some positive and some negative	2	1.0
Total	**197**	**100**

Note: Includes only those who were in a regular relationship. (N=197)

Nearly one in six participants were parents, with the majority of their children aged 18 years and over. (see Table 6).

Table 6 : Children

	Frequency	Percentage (%)
Children under 18 years	15	3.6
Children 18 years or older	51	11.9
No children	359	84.5
Total	**425**	**100**

SEXUAL IDENTITY AND COMMUNITY

- As would be expected from the nature of the epidemic in Australia, most participants were homosexual men who identified as gay.
- Gender and sexuality were perceived as more important aspects of self-identity than HIV status
- Participation in gay community subcultures was fairly widespread and, although participation in HIV positive functions was less common, most participants saw themselves as being part of a 'positive community'.
- Most participants had extensive contact with the HIV/AIDS epidemic and had had close relationships with people who had died from AIDS.

SEXUAL IDENTITY

Sixty-three percent of the sample identified as gay or lesbian (see Table 7). A further 17% identified as homosexual but did not specify the terms gay or lesbian. The remaining participants identified as heterosexual (8%), bisexual (5%), queer (3%) and unspecified (5%).

The following table provides an overview of sexual identity broken down by gender.

Table 7 : Gender and sexuality

	Frequency	Percentage (%)
Male		
Gay	266	62.6
Homosexual	72	16.9
Queer	12	2.8
Bisexual	18	4.2
Heterosexual	17	4.0
Other	19	5.0
Female		
Lesbian	2	0.5
Heterosexual	15	3.5
Bisexual	2	0.5
Other	1	0.2
Transgender male to female		
Gay/lesbian	1	0.2
Total	**425**	**100**

There were considerable differences in the importance attributed to various aspects of participants' self-identity. While over half considered their gender (57%) and their sexuality (57%) to be very important, only about a third (37%) attached such importance to their HIV sero-status and fewer than one in six (15%) said their cultural background was very important (see Figure 10).

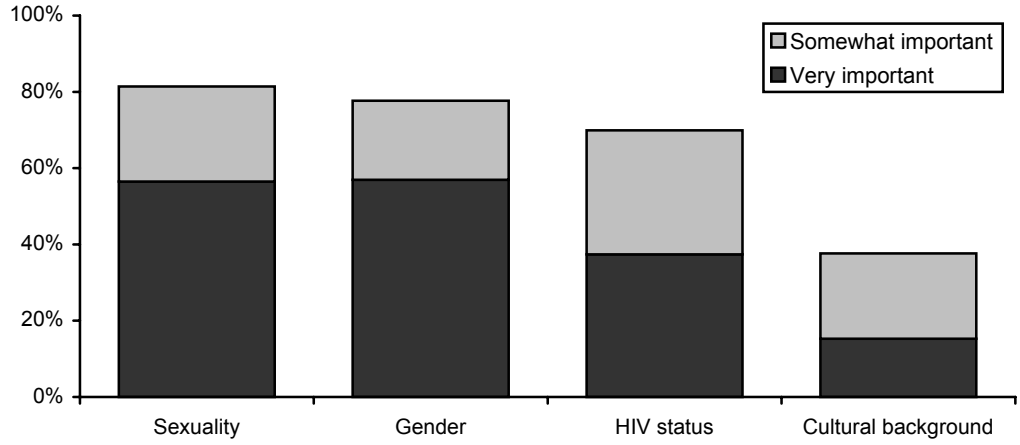

Figure 10 Importance of certain aspects in self-identify

POSITIVE COMMUNITY AND CONTACT WITH EPIDEMIC

Most participants considered themselves to be part of a 'positive community', and half indicated that they participated in that community. However, one in six reported that they avoided the positive community and one in ten did not believe there was such a thing as a positive community.

Over two thirds of the participants (69%) knew more than ten other HIV positive people, and nearly as many (63%) had known at least one person who had died of AIDS in the previous twelve months. A quarter (25%) of the participants had nursed someone with AIDS who had been sick during that time.

Most participants had close relationships with at least some other positive people, and nearly two thirds had a current or former partner with HIV, while less than one in ten had a partner who had died of AIDS in the twelve months prior to the interview (see Table 8).

Table 8 : Contact with people with HIV/AIDS

	Frequency	Percentage (%)
Friend/relative has HIV	381	90.1
Current/former sex partner has HIV	266	62.8
A regular partner died from AIDS in past year	36	8.5

PARTICIPATION IN SUBCULTURES

A series of questions was asked about participation in various subcultures. Some of these subcultures were associated with the gay community and some were not. When asked about the gay 'scene',[2] 44% reported that they participated 'very much' or 'somewhat', 30% participated 'a little' and 25% said they did not participate at all in this subculture. In contrast to the gay 'scene', participants were also asked about their participation in the gay 'non-scene'[3]. Fewer participants had participated in this subculture, 35% participated 'very much' or 'somewhat', 22% participated 'a little' and 42% said they did not participate in it at all.

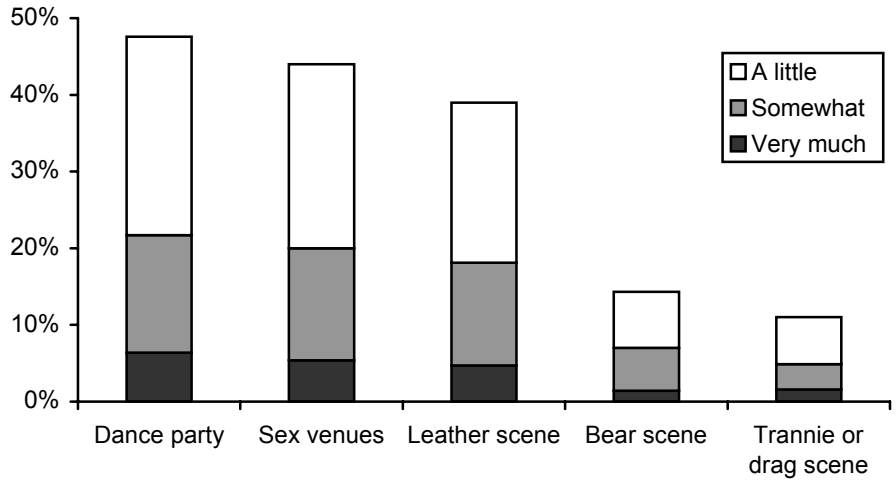

Figure 11 Participation in various gay community scenes

A number of other subcultures associated with the gay community were nominated (see Figure 11). These included the 'dance party scene',[4] the 'sex venues scene',[5] the 'leather scene',[6] the 'bear scene',[7] and the 'Trannie or drag scene'.[8]

---

[2] The term 'gay scene' refers to gay commercial subcultures such as those associated with gay nightclubs and similar venues. Some would argue that this term also has a geographic association with the Oxford Street area in Sydney or the Commercial Road area in Melbourne.

[3] The term 'gay non-scene' refers to informal networks of friends and acquaintances who socialise outside the gay commercial subcultures.

[4] The 'dance party scene' refers to organised dance parties, such as the Sydney Gay and Lesbian Mardi Gras and Sleaze Ball parties.

[5] The 'sex venues scene' refers to commercial venues where sex occurs on the premises, such as saunas and sex clubs.

[6] The 'leather scene' refers to venues, events and personal networks in which leathersex is emphasised and leather is fetishised.

[7] The 'bear scene' refers to venues, events and personal networks where mature men, particularly those who are hirsute, are considered to be attractive.

[8] The 'trannie or drag scene' refers to venues, events and personal networks in which transgender persons are known to participate, particularly those wearing drag costume, in drag performance.

Each of these include aspects that may not be directly linked to the gay community, but in general, they are thought of as being gay community subcultures. Following are the percentages of people who reported some participation in these subcultures: dance party 48%, sex venues 44%, leather scene 39%, bear scene 14% and trannie or drag scene 11%.

A number of other subcultures that do not necessarily have an association with the gay community were also nominated. These included HIV positive social functions,[9] the 'street scene',[10] the 'women's subculture',[11] the 'drugs scene',[12] and the lesbian community.[13] Some of these, such as the street and drugs scenes and the women's subculture, are less formal or institutional than others and rely on informal networks, geographies or behaviours. Nonetheless, it was believed that the terms used would be recognisable to the majority, particularly those who participate in them. Of these subcultures, only HIV positive social functions appeared to attract a sizeable number of participants: 62% participated to some extent in such functions, 25% participated in the drugs scene and a similar proportion in the lesbian community. Few people participated in the women's subculture and the street scene (see Figure 12).

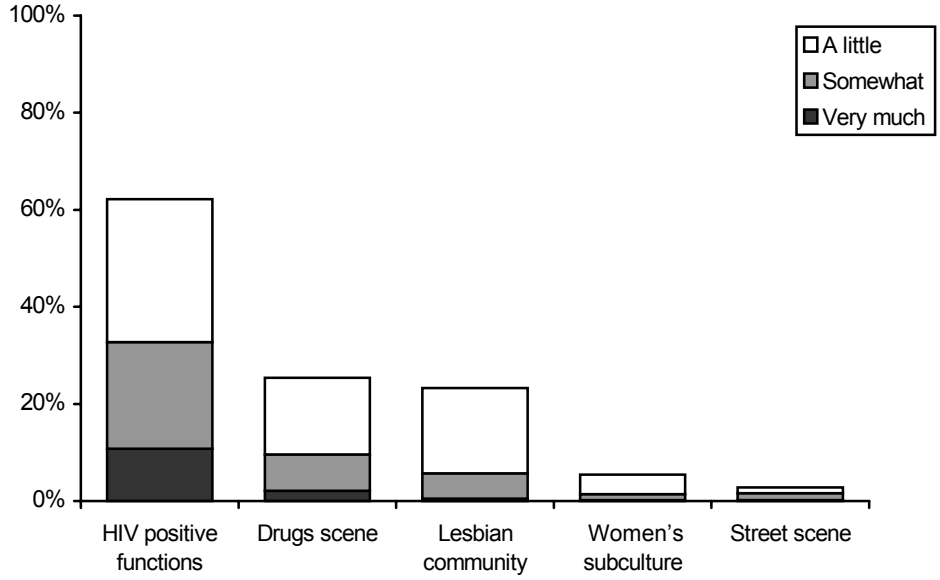

Figure 12 Participation in other subcultures

[9] This refers to social events organised specifically for HIV positive individuals and their friends.

[10] This refers to the informal networks of individuals who spend much of their social lives on or around the streets of the inner city, particularly the Kings Cross area of Sydney or the St. Kilda city centre area of Melbourne. It refers particularly to those people who are homeless.

[11] This refers to the events, places, and personal networks associated specifically with women's organisations and services and the women's movement.

[12] This refers to the events, places and personal networks associated with the use and availability of psychotropic drugs.

[13] This refers to the events, places and personal networks dedicated specifically to lesbians.

RECREATIONAL DRUG USE

- Half the participants were current tobacco smokers, a much higher proportion than is found in the general population.
- Nearly one in eight drank alcohol heavily (or binged) at least once a week, which is also higher than the general population.
- The use of other recreational drugs was considerably higher than that in the general population.
- Marijuana and amyl nitrate were the recreational drugs most commonly used in the preceding six months, followed by speed and ecstasy.
- One in six participants had injected recreational drugs (usually speed) in the previous six months.
- Although most participants were able to cite some therapeutic benefit from using recreational drugs (eg. to relieve stress), most also agreed that there were drawbacks (eg. that they damage one's health).

TOBACCO

Over half (53%) of the participants were current tobacco smokers while a quarter had never smoked. The proportion of smokers was at least twice that found in the general population (National Heart Foundation, 1989: 85), but was similar to that found in a national study conducted in a HIV position population (HIV Futures II, Grierson et al, 2000: 82).

Of those who smoked tobacco at the time of the interview, 42% smoked more than 20 cigarettes each day. This amount is higher than in the general population (the National Heart Foundation 1989: 87).

ALCOHOL

Eighty-seven percent of participants (87%) drank alcohol. This percentage is similar to the proportion found in the National Heart Foundation's Risk Factor Prevalence Study (1989:79) and similar to that found in HIV Futures II (Grierson et al, 2000:82).

Two-thirds of those who drank alcohol did so less frequently than once per week. About 15% of participants reported drinking alcohol every day. Most consumers of alcohol in the study would usually have fewer than 5 drinks on each occasion.

The National Heart Foundation has classified the range of alcohol consumption from 'no risk' to 'very high risk' according to both frequency and quantity consumed, where risk relates to several

possible health outcomes (see Appendix A for a classification table). According to this classification, the major difference between the pH sample and the National Heart Foundation's findings is that there are about three times as many high risk drinkers in the pH study, albeit the number is relatively small (see Figure 13).

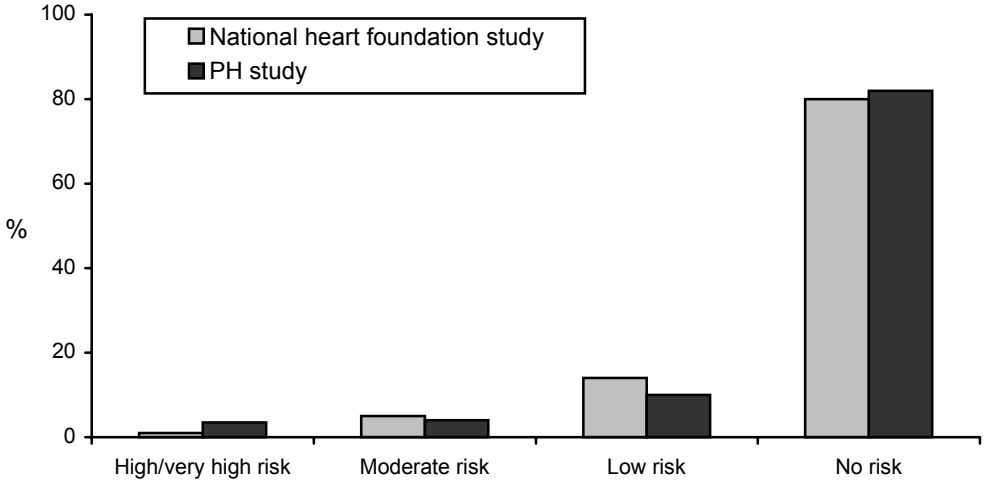

Figure 13 Alcohol consumption compared to the general population

Half the participants reported 'getting drunk' at some time during the preceding six months, with a few doing so regularly. About one in eight participants 'got drunk' at least once a week (see Table 9).

Table 9 : Frequency of getting drunk in previous six months

	Frequency	Percentage (%)
Never	170	40.0
Once or twice (six months)	108	25.4
Once a month	58	13.6
Once a week	28	6.6
More than once a week	21	4.9
Unsure/No response	40	9.4
Total	**425**	**100**

OTHER RECREATIONAL DRUGS

Most participants (82%) had used drugs recreationally during the preceding six months and almost half (49%) had used so-called 'party drugs', such as ecstasy, speed and cocaine, in that time. These levels are considerably higher than was found in the 1993 National Drug Household Survey (Commonwealth Department of Health, Housing, Local Government and Community Services, 1993: 34), in which fewer than 10% had ever used party drugs. The proportions of participants in

this cohort who used the various types of recreational drugs were higher than found in Futures II (Grierson et al, 2000: 82). The percentages of people who used different types of recreational drugs are presented in Figure 14.

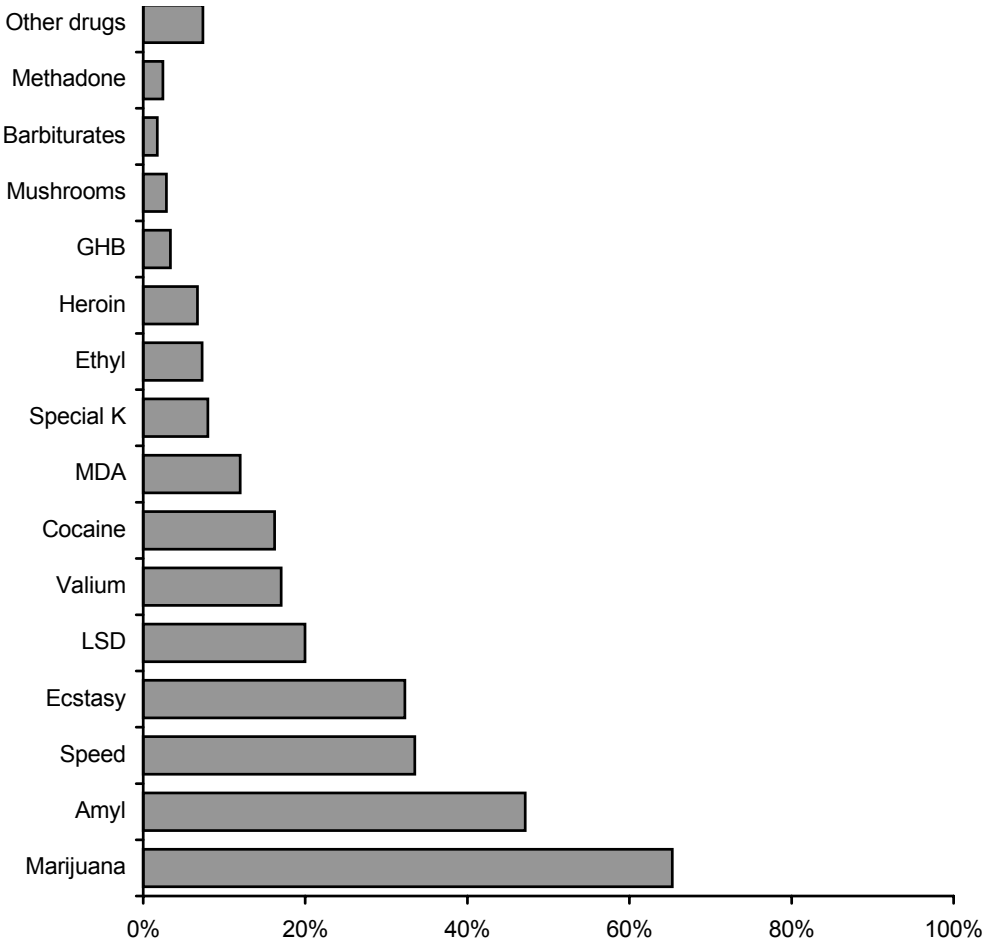

Figure 14 Recreational drugs used in previous six months

One in six participants (17%) had injected recreational drugs in the preceding 6 months. This was very similar to that found in HIV Futures II (Grierson et al, 2000: 83). The drug most commonly injected by participants was speed; 12% of participants reported injecting speed in the preceding 6 months.

When asked about potential benefits to be derived from using recreational drugs, 75% of participants cited some benefit. One third of the participants said drugs relieved stress, and a quarter of the sample said that they took drugs for fun (see Table 10).

Table 10 : Perceived benefits of recreational drug use

	Frequency	Percentage (%)
None	93	22.1
Relieves stress	128	30.4
Fun	107	25.4
Other	74	17.6
Unsure/No response	19	4.5
Total	**421**	**100**

Note: Data were missing on this item for 4 participants.

Most participants identified some potential drawbacks from using recreational drugs, such as damaged health (32.5%), 'downer' effects (18.5%) and addiction (13%) (see Table 11).

Table 11 : Belief of drawbacks of recreational drug use

	Frequency	Percentage (%)
None	30	7.1
Damages health	137	32.5
Has downer effect	78	18.5
Addiction	55	13.1
Affects judgement	12	2.9
Other	88	20.9
Unsure/No response	21	5.0
Total	**421**	**100**

Note: Data were missing on this item for 4 participants.

Eighty-one percent of participants who were on anti-retroviral drugs had also used recreational drugs in the preceding 6 months. These same people were asked about their concerns regarding the interaction between antiretroviral drugs and recreational drugs; 31% indicated no concern about possible drug interactions, 35% said they needed more information, 35% worked their recreational drug use around taking their antivirals while 17% did the reverse (see Table 12).

Table 12 : Attitude to interaction between recreational drugs and antivirals (n=272)

	Frequency	Percentage (%)
Unconcerned about interactions	85	31.3
Need information about interactions	96	35.3
I try to work my recreational drug use around my antivirals	95	34.9
I try to work my antivirals around my recreational drug use	46	16.9

Note: Items are not mutually exclusive. Includes only those who were on anti-retrovirals at the time of the interview and had taken any recreational drugs in the previous 6 months.

PERSONAL SUPPORT SERVICES AND INFORMATION

- Most participants had disclosed their HIV status to a wide range of people.
- The major source of emotional support for people in a relationship was their partner.
- Other important sources of emotional support included people with whom the participants lived, friends and pets.
- Most participants had some HIV negative friends and some HIV positive friends, although 10% of participants had no positive friends.
- Most participants had access to some HIV-related publications, the most common of which were Talkabout and Positive Living.
- Many participants were actively involved in HIV organisations, with nearly a third having some involvement in an AIDS Council.

PERSONAL SUPPORT NETWORKS

Most participants had disclosed their HIV status to a wide variety of friends, relatives and other personal contacts. Nearly every participant had disclosed their status to their doctor. About 15% of the people who were in a relationship at the time of the interview had not disclosed their HIV status to their regular partners (see Figure 15).

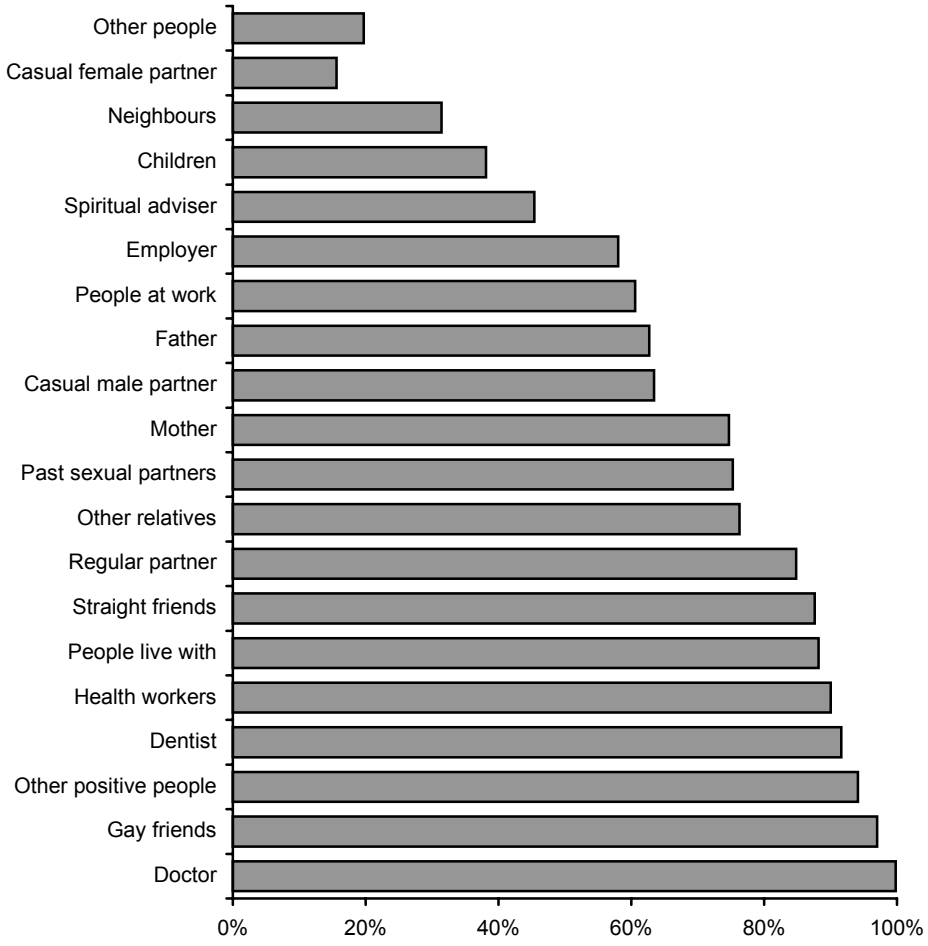

Figure 15 Disclosure of HIV status

Note: Percentages were calculated by including only those participants for whom the nominated person(s) in each item existed.

Among those with a regular partner, the partner was the most likely source of emotional support. Other important sources of such support were people with whom the participant lived, doctors, gay friends and pets. A similar proportion of participants nominated HIV negative friends and HIV positive friends as sources of emotional support (see Figure 16).

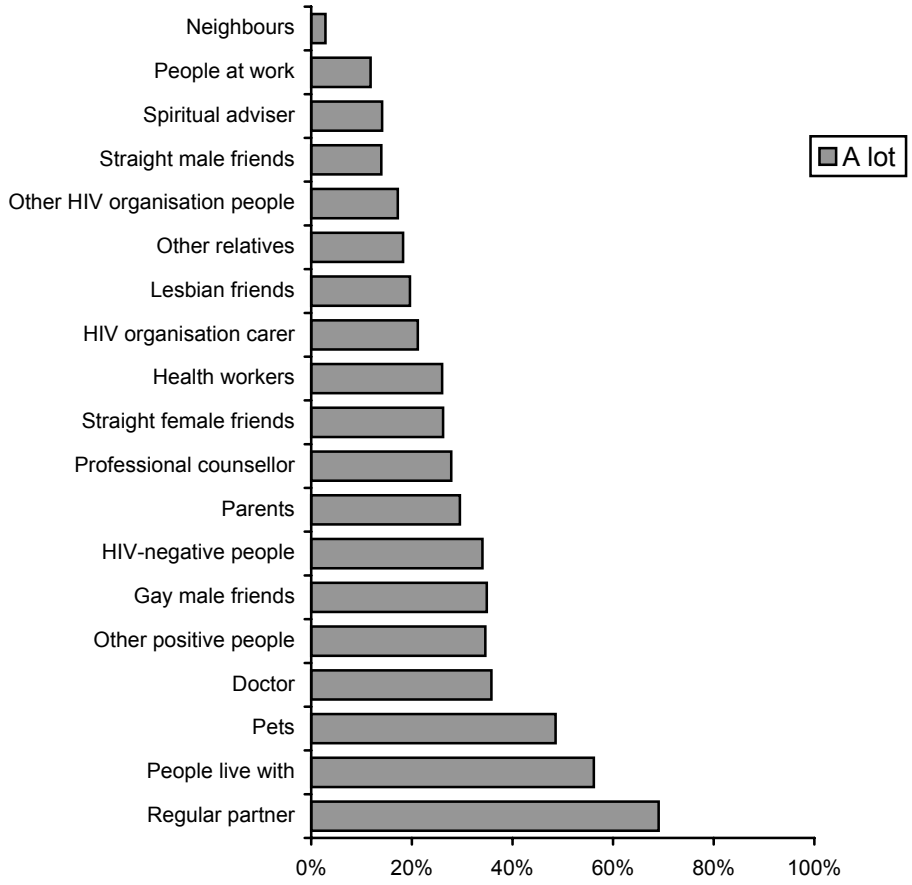

Figure 16 Sources of emotional support

Note: Percentages were calculated by including only those participants for whom the nominated source(s) in each item existed.

When asked about their most important sources of emotional support, participants most commonly referred to a regular partner (28%), various friends (18%); 6% specifically cited gay friends. One in five participants said that they did not receive emotional support from anybody.

Most participants had both HIV negative and HIV positive friends: about a quarter had mostly HIV positive friends and nearly half had mostly HIV negative friends. About 40% reported spending 'a lot' of their free time with HIV positive friends while half said they spent 'a lot' of time with HIV negative friends.

SERVICES AND INFORMATION

Most participants had access to some HIV-related publications. The most widely read of these publications were Talkabout (a NSW publication) and Positive Living (see Figure 17).

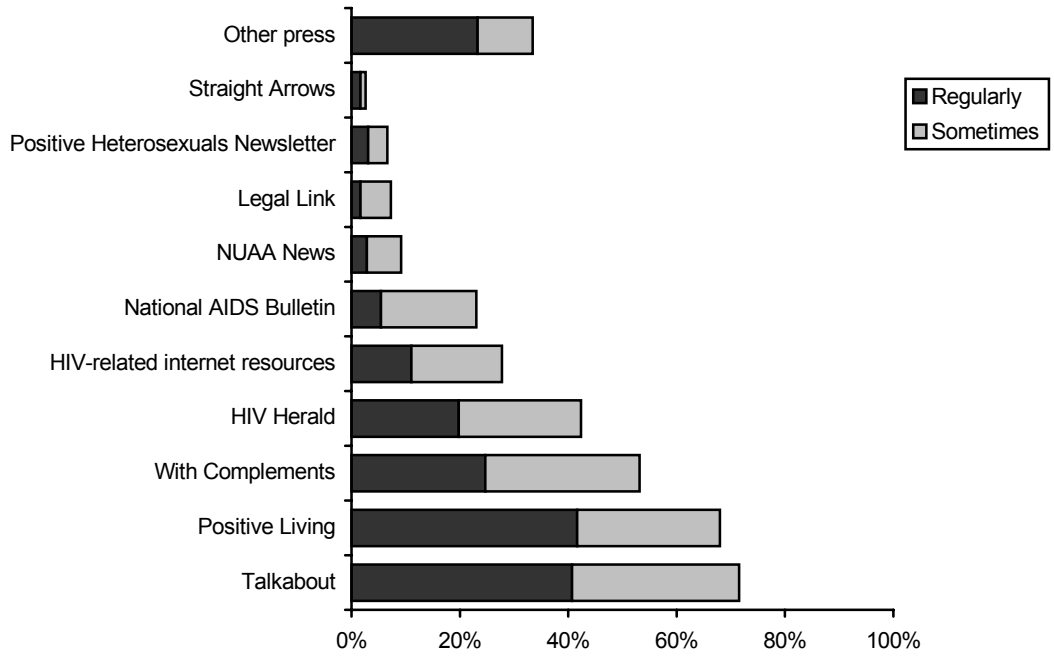

Figure 17 HIV publications read

Many of the participants were actively involved in community organisations. Nearly a third of the participants indicated some involvement with an AIDS Council, with one in eight involved as a volunteer or employee. About a quarter of participants were involved in either the Bobby Goldsmith Foundation or a PLWHA organisation.

SUMMARY

The demographic profile of this sample was much as one would expect of a sample of HIV positive people living in New South Wales and Victoria. Participants lived predominantly in private accommodation in urban areas, with many participants living in inner metropolitan Sydney. Although many lived alone, a third lived with their regular partner. Most participants were male, and their mean age was 41. They were largely of Anglo-Celtic cultural background and only about half held a religious belief. About half of all participants were in receipt of social security, and a similar proportion received an income of less than $15,000 a year. Of those who were employed, over half were in professional or managerial occupations. About a third of the participants had received some tertiary education. Half the sample was currently in a relationship with either a male or female partner and about one in six participants had children.

As would be expected from the nature of the epidemic in Australia, most participants were homosexual men, and most of these identified as gay. Gender and sexuality were considered important aspects of participants' self-identity, more important than their HIV status. Participation in gay community subcultures was widespread and, although participation in HIV positive functions was less common, most participants saw themselves as being part of a 'positive community'. Most participants also had extensive contact with the epidemic and had had close relationships with people who had died from AIDS.

Most participants had disclosed their HIV status to a wide range of people close to them. For those in a relationship, their partner was usually a main, and often most important source of emotional support. Other important sources of emotional support included housemates, friends and pets. Most participants had some HIV negative friends and some HIV positive friends, but about one in eight had no positive friends. Most participants had access to some HIV-related publications, the most common of which were Talkabout and Positive Living. Many participants were actively involved in HIV organisations, with nearly a third having some involvement in an AIDS Council.

Half the participants were current tobacco smokers: a much higher proportion than found in the general population. The level of alcohol consumption was not markedly different from that found in the general population. However there were considerably more 'high risk' drinkers, with one in eight drinking heavily at least once a week. Recreational use of other drugs was considerably higher than that found in the general population. Marijuana and amyl nitrate were the most commonly used drugs, and about a third reported using speed and ecstasy in the previous six months. One in six participants had injected recreational drugs (usually speed) in the previous six months. Although most participants cited some benefit from using recreational drugs (most commonly to relieve stress), most also agreed that there were drawbacks (usually that they damage one's health).

BIBLIOGRAPHY

Australian Bureau of Statistics. (1991). *Census of Population and Housing. Basic Community Profile ABS Catalogue No. 2722.1 New South Wales Statistical Division: 05 (Sydney), 1994.* Canberra: Australian Government Publishing Service.

Australian Department of Health Housing and Community Health. (1992). *Statistics on Drug Abuse in Australia, 1992*. Canberra: Australian Government Publishing Service.

Australian Department of Health Housing and Community Health. (1993). *1993 National Drug Household Survey.* Canberra: Australian Government Publishing Service.

Grierson, J., Bartos, M., de Visser, R. and McDonald, K. (2000). *HIV Futures II. The Health and Well-Being of People with HIV/AIDS in Australia.* Melbourne: Australian Research Centre in Sex, Health and Society.

Hood, D., Prestage, G., Crawford, J., Sorrell, T. and O'Reilly, C. (1994). *Bisexual Activity and Non Gay-Attachment. A Report on the BANGAR Project*. Sydney: Western Sydney Area Health Service.

Kippax, S., Crawford, J., Connell, R. W., Dowsett, G. W., Watson, L., Rodden, P., Baxter, D. and Berg, R. (1990). *Social Aspects of the Prevention of AIDS Study. Report No. 7. The Importance of Gay Community in the Prevention of HIV Transmission*. Sydney: Macquarie University School of Behavioural Sciences. A revised version of this report "The importance of gay community in the prevention of HIV transmission: a study of Australian men who have sex with men" has appeared in P. Aggleton, P. Davies and G. Hart (Eds.) *AIDS: Rights, Risks and Reasons.* (1992). London: Falmer Press.

National Heart Foundation of Australia. (1990). *Risk Factor Prevalence Study. Survey No. 3*. Canberra: National Heart Foundation of Australia and Australian Institute of Health.

Prestage, G., Kippax, S., Noble J., Crawford, J. and Cooper, D. (1994). *Methods and Sample. Report A.1. Sydney Men and Sexual Health.* Sydney: National Centre in HIV Epidemiology and Clinical Research, National Priority Program in HIV Social Research (Macquarie University) and AIDS Council of NSW.

Tindall, B., Swanson, C., Donovan, B. and Cooper, D. (1989). "Sexual practices and condom usage in a cohort of homosexual men in relation to human immunodeficiency virus status", *The Medical Journal of Australia, 151,* 318-322.

APPENDIX A

Risk of alcohol consumption classification table
(Number of days per week alcohol is consumed)

Drinks on each occasion	Less than one	1 – 2	3 – 4	5 – 6	Every day
0 – 2				No risk	
3 – 4				Low risk	
5 – 8			Low	Moderate risk	
9 – 12	Low		Mod	High risk	
13 – 20	Mod		High	Very high risk	
More than 20	High				