HIV Futures Community Report

Health, Relationships, Community, and Employment

1998

Douglas Ezzy, Richard de Visser,
Michael Bartos, Karalyn McDonald,
Darryl O'Donnell and Doreen Rosenthal

NCHSR

National Centre in
HIV Social Research
People Living with HIV/AIDS
and their Carers

Centre for the Study of Sexually Transmissible Diseases
Faculty of Health Sciences, La Trobe University

ISBN Number: 1864464704

CENTRE FOR THE STUDY OF
SEXUALLY TRANSMISSIBLE DISEASES

LA TROBE
UNIVERSITY

Acknowledgments

Nine hundred and twenty five people living with HIV/AIDS completed the survey. We are grateful for their interest in, and contribution to, the study.

We would also like to thank a number of individuals and organisations for their assistance with the distribution of the HIV Futures questionnaire.

The study was endorsed and supported by the Australian AIDS Federation Organisation [AFAO] and the National Association of People Living With HIV/AIDS [NAPWA]. Assistance was also provided by the Haemophilia Foundation of Australia.

Assistance in New South Wales was provided by the AIDS Council of New South Wales [ACON], ACON Hunter, Albion Street Centre, Bobby Goldsmith Foundation, Coastal Lynx, Mid North Coast Health Service, the New South Wales Department of Health, Foley House, the Gender Centre, John Hunter Hospital, Kempsey Community Health Centre, Karumah Day Centre, Luncheon Club, Dr Marilyn McMurchie, North AIDS, NSW Blood Bank, New South Wales Users and AIDS Association [NUAA], People Living With HIV/AIDS in New South Wales [PLWHA NSW], People Living With HIV/AIDS Day Centre, Population Health Unit (Department of Health), Positive Heterosexuals, Royal Prince Alfred Hospital, and the Sydney Men and Sexual Health [SMASH] Project.

In Victoria promotion of the study was assisted by the ALSO Foundation, the Alfred Hospital, Barkly Street Medical Centre, Carlton Clinic, Centre for Social Health, Country AIDS Network, Melbourne Sexual Health Centre, Mountfield Clinic, Positive Women (Victoria), Prostitutes' Collective Victoria, Royal Melbourne Hospital, Straight Arrows, Victorian AIDS Council, and the Victorian Intravenous AIDS Association [VIVAIDS].

In Queensland we were assisted by the AIDS Medical Unit, the Brisbane Sexual Clinic, Brunswick Street 7 Day Medical Centre, Gladstone Road Medical Clinic, Nambour Hospital, Princess Alexandra Hospital, Queensland Positive People [QPP] Brisbane, QPP Bundaberg, QPP Gold Coast, QPP Mackay, QPP Rockhampton, QPP Sunshine Coast, Queensland AIDS Council [QuAC], QuAC Cairns, and QuAC Townsville.

In South Australia assistance was provided by the HIV/AIDS Women's Project, Rosemont - PLWHA (SA), Royal Adelaide Hospital, and the AIDS Council of South Australia. Recruitment in South Australia was also assisted by the work of Shaun McCausland funded in part by a grant from the South Australian Health Commission.

Assistance in Western Australia was provided by Dr Ric Chaney, Positive Living (WA), Royal Perth Hospital, AIDS Pastoral Care, and the Western Australian AIDS Council.

In Tasmania, support was provided by the HIV/AIDS Unit, Royal Hobart Hospital, Rose Cottage, the Tasmanian AIDS Council, and the Tasmanian Health Department.

Assistance in the Australian Capital Territory was provided by the Australian Capital Territory Intravenous League [ACTIV], the AIDS Action Council of the ACT, Gilmore Clinic, Interchange General Practice, Dr Steve Jamieson, and PLWHA (ACT).

In the Northern Territory the Northern Territory AIDS Council provided assistance.

We would also like to thank the many anonymous individuals who helped the study by ensuring the widest possible distribution of the survey in their networks of their friends and colleagues.

The work was supported by a Commonwealth AIDS Research Grant.

Acronyms Used in the Report

AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
IAESR	Institute of Applied Economics and Social Research
NAPWA	National Association of People Living With HIV/AIDS
NCHSR	National Centre in HIV Social Research
NCHECR	National Centre in HIV Epidemiology and Clinical Research
PLWHA	People Living with HIV/AIDS

1 Executive Summary

The HIV Futures Survey draws together the largest sample of people with HIV/AIDS to have been surveyed in Australia. The survey was conducted from 1 July 1997 to 5 September 1997. The 925 respondents represents over eight percent of the current population of PLWHA in Australia. While a substantial number of the participants are gay men living in Sydney, the survey includes significant numbers of PLWHA from smaller sub-populations such as women, and people living outside NSW and Victoria. The survey has good national coverage with respondents from all states and territories, and from both rural and urban locations.

The survey examines five main issues: health, relationships, community life, finances, and employment. The section on health focuses on PLWHA's experiences of, and attitudes toward, the new anti-retroviral treatments, in particular the new class of protease inhibitor drugs which have become increasingly available since the latter part of 1995. The section on relationships explores the changing nature of relationships with family, friends and partners, as well as sexual practice. The section on community examines the role of HIV/AIDS-related organisations and publications. The section on finances examines the experience of poverty and changes in accommodation. The section on employment explores the movement of PLWHA in and out of the work force.

Health Status and Management

The survey reveals that 99% of PLWHA have taken a CD4/T-cell test and 96% have taken a viral load test. This provides a strong indication that PLWHA are actively engaged in monitoring their health status. This includes those who may not be currently using anti-viral treatments.

The majority of PLWHA rate their health positively with nearly three-quarters describing their health as excellent or good. Despite this, nearly one-third of PLWHA - a very significant minority - report having at least one major health condition other than HIV/AIDS. The most common other conditions reported were Hepatitis C (6%) and psychological or psychiatric conditions (6%). The coexistence of major health conditions as described poses considerable challenges for the coordination and delivery of health services.

PLWHA have long had a reputation for being pro-active in the management of their own health and for their high levels of engagement with new medical information about the management of HIV. The results of this survey support this reputation, showing that over 80% of PLWHA like to find out as much as they can about medical aspects of HIV and that over one-third consider themselves to be more knowledgeable about the treatment of HIV than the doctors who treat them. Not surprisingly, most (85%) people with HIV/AIDS work together with their doctors in their decision-making around treatments.

Despite significant educational efforts encouraging early treatment, respondents remain unconvinced about the optimal time to begin treatments. When asked whether people with HIV/AIDS should begin treatments as early as possible, over half either disagreed (26%) or were unsure (27%).

Anti-viral Treatments, Prophylaxis and Complementary Therapies

Given the complexity and novelty of current treatment regimes, the survey reveals extremely high rates of use of anti-viral treatments. Seventy eight per cent of respondents were using anti-viral treatments, and of these, 85% were using three or more in combination. Nonetheless, among those not using anti-virals, there remains a substantial group of PLWHA (38% of those not using anti-virals) who current evidence suggests are at high risk of disease progression.

The high rates of anti-viral use are especially noteworthy given that over two-thirds of respondents experience side-effects from the treatments and that over three-quarters experience difficulties such as remembering to take medications on time and organising medications around meals.

The significance of the relationship PLWHA have with their doctors is revealed in the finding that despite high levels of treatments knowledge among PLWHA themselves, over three-quarters of respondents began treatments on the advice of their doctor.

Among those respondents who were not using anti-viral treatments, over one-quarter had used them at some stage in the past. Problems with side-effects were by far the most common reason for ceasing anti-viral use. Most (84%) PLWHA who were not currently treating were open to the possibility of commencing treatment in the future, and most of these (83%) would be influenced by signs that their health was deteriorating.

The majority of PLWHA (59%) believe that the new treatments have brought hope and better prospects. However, over one-third of PLWHA say that it is too soon to tell whether the new treatments mean better prospects. Individual PLWHA see themselves as more uncertain about the new treatments than the broader HIV community.

The current moment in the HIV/AIDS epidemic has been characterised by many commentators as encompassing both hope and uncertainty. These sentiments were reflected in the responses of PLWHA to a series of attitude statements about anti-viral treatments. For instance, while most (66%) PLWHA agree that new treatments have made life better, a similar number (75%) report being worried that their medication may stop working for them at some stage in the future. These anxieties are tempered by the hope many (72%) PLWHA have that, despite the absence of data on their long-term effectiveness, the treatments may assist them to remain well.

Complementary therapies remain an important part of most PLWHA's treatment regime. Half of all PLWHA use some form of complementary therapy and spend on average $20 per week. About half of all PLWHA use vitamin or mineral supplements and about one-quarter use massage, herbal therapies, or meditation.

Relationships and Sex

One in five PLWHA are not presently having sex, while 50% have sex within a regular relationship - half of whom have casual partners as well, and slightly less than one-third have casual sex only.

Half of the respondents said they are in a regular relationship. Of these slightly more than half are in sero-nonconcordant relationships.

The great majority of PLWHA (97%) who are in regular relationships have disclosed their HIV status to their regular partner. Most partners (67%) were supportive in reaction to this disclosure.

Generally new treatments are having a positive impact on relationships. More than half reported that they are more able to plan their future and two-thirds agreed that they are more optimistic about the future than they were a year ago.

PLWHA generally do not believe that HIV/AIDS is a hindrance to developing long-term relationships but slightly more than half do worry about rejection by potential sexual partners in response to disclosure of their HIV status. More than two-thirds agree that they are afraid of infecting their partner, or potential partner, with HIV.

The availability of the new treatments does not appear to have made PLWHA more confident about having unprotected sex. However, the impact of the new treatments environment in other areas was less certain. PLWHA tended to agree that people with HIV now have a better chance to form relationships, but only one-third agree that relationships with family and friends are improving due to new treatments.

Slightly more than half of the respondents said they would prefer to have a relationship with another PLWHA. These people tended to be bisexual and homosexual men.

Compared to PLWHA in seroconcordant relationships, PLWHA in sero-nonconcordant relationships were significantly more likely to report that they always condoms and less likely to report that they never use condoms. Almost two-thirds of PLWHA who reported unprotected anal and/or vaginal sex with a regular partner in the 6 months prior to the survey sometimes or always withdrew before ejaculation and this practice was not related to the serostatus of the partner.

Of those PLWHA who engaged in anal and/or vaginal sex with a casual partner in the six months prior to completing the survey, more than half had sex with both HIV-positive and HIV-negative casual partners, or did not know their partner’s status. Almost all respondents who had casual sex said they always or sometimes used condoms. Of those PLWHA who sometimes had unprotected sex only a small number said they never withdrew before ejaculation. Again this practice was not related to the serostatus of the partner.

Community Life and Community Organisations

Almost all PLWHA (99%) have disclosed their status to at least one person. Of those with dependant children, half have told their children they are HIV-positive. One in ten respondents said that they have experienced discrimination at some stage.

Half of the respondents said they have changed their plans for the future in the last two years. The majority of these changes were positive but one in five were negative due to declining health.

When seeking advice for both treatment and living with HIV/AIDS respondents most commonly cite their doctor as an important source of information (91%). PLWHA also relied heavily on HIV/AIDS media, the gay press and other HIV-positive friends for information.

Over three-quarters of the respondents had some involvement with HIV/AIDS organisations. Two-thirds of the respondents are in contact with an AIDS Council and over half have contact with a PLWHA organisation (this finding is likely to be influenced by the fact that these organisations were a distribution source for the survey). Contact with organisations tends to be in the form of newsletters and mail-outs, and many PLWHA receive treatments advice and social contact. PLWHA who do not have contact with any HIV/AIDS organisations said this is so because they do not wish to be involved or are not interested. However, a small number (15% of those not involved) said they feel excluded and 7% are unable to have contact because of where they live or the lack of transport available to them.

Most respondents (96%) know at least one other HIV-positive person, mostly friends, acquaintances and past or present sexual partners. Likewise most PLWHA (85%) spend at least some of their free time with other HIV-positive people and just over half have, at some time, been involved in the care of another person with HIV/AIDS. The majority of respondents (81%) said they have lost someone to HIV/AIDS - most commonly a close friend or relative.

Over two-thirds of respondents see themselves as being part of the gay community and, not surprisingly, most of these people are homosexual men. Half of the respondents are also members of gay organisations, and the majority of respondents go to gay venues such as nightclubs, bars and saunas.

Finances

The majority of respondents have difficulty meeting the expenses of day-to-day living. This is not surprising given that over half of respondents reported a government benefit as their main source of income.

One-third (32%) of respondents reported incomes below the poverty line. One-third of respondents share financial resources with a partner, and this protects PLWHA from some of the extremes of economic hardship. Very few people who are earning an income from paid employment reported incomes below the poverty line.

People with incomes below the poverty line have fewer assets and are more likely to rely on HIV/AIDS-related organisations for a variety of services and facilities. A significant minority of respondents (11%) have incomes below the poverty line and assets worth less then $5,000.

Housing and accommodation

Slightly fewer than half of PLWHA live alone, and just over half live in rental accommodation, typically private rental accommodation. Forty per cent of PLWHA live in inner city Sydney where the average weekly rent or mortgage cost is $136.

Nearly half of all PLWHA felt their accommodation was too expensive. Many PLWHA had changed their living arrangements as a result of having HIV/AIDS, typically for reasons related to finances.

Employment

Over half of PLWHA are not in paid employment, although the majority were in paid employment at the time they were diagnosed HIV-positive. Most PLWHA left their career or in someway reduced their career goals after their diagnosis.

Over one-third of PLWHA have not disclosed their HIV status to anyone at their workplace, and most have difficulty maintaining their confidentiality. Thirteen per cent of respondents have experienced workplace discrimination.

Nearly two-thirds of respondents have stopped work at some time in the past for reasons related to having HIV/AIDS. Three-quarters cited stress, depression or anxiety as the reason for stopping work, and half cited poor health. Over half of the respondents changed their accommodation arrangements within a few months of leaving work. Of those who had left work, one-third returned to work, typically for financial reasons.

The effects of the new anti-virals on PLWHA's employment appears to be largely positive, with many PLWHA considering staying at work or returning to work.

One-quarter of those working said that HIV/AIDS has affected their capacity to work. Over one-third of respondents are considering changing the amount of work they do. About half of these want to work less - to reduce stress, or due to poor health. About half want to increase the amount of work they do, mainly for financial reasons.

The majority of PLWHA who are not working are considering returning to the workforce, but most think that this will be difficult to do so. Just under half of PLWHA cited improved health as a reason for wanting to return to work, while the majority cited financial reasons, and psychological, emotional or social reasons for wanting to return to work.

2 Introduction

In many ways Australia leads the world in its response to HIV/AIDS. Australia’s early responses to the HIV/AIDS crisis significantly limited the impact of the epidemic in comparison to similar countries elsewhere in the world. They laid the groundwork for continuing successful efforts in both limiting the spread of HIV and in ameliorating its impact. In the late 1990s, new challenges are appearing. Advances in treatments hold out the hope of longer life expectancies and are provided within a medical system which promises universal access to these medications. In this broader context, the longer-term consequences of living with HIV/AIDS are becoming an increasingly important issue for people living with HIV/AIDS (PLWHA) in Australia. While new treatments remain a central concern for many PLWHA, relationships, community identity, employment, finances and housing are also of major importance. For example, many PLWHA are considering returning to work as a consequence of improved health. The interlocking ‘HIV Futures’ studies, of which the HIV Futures Survey reported here is one part, take as their starting point an investigation of the various ramifications of the changed perception and experience of HIV on the ways that people living with HIV/AIDS live their lives.

The HIV Futures Survey draws together the largest sample of PLWHA to have been surveyed in Australia. The 925 respondents represent over eight per cent of the current population of PLWHA in Australia. While a substantial number of the participants are gay men living in Sydney, the survey includes significant numbers of PLWHA from smaller sub-populations such as women and people living outside New South Wales and Victoria. The survey has good national coverage with respondents from all states and territories, and from both rural and urban locations.

This report aims to further our understanding of how the longer-term impacts of HIV/AIDS and the new treatments affect the choices made by PLWHA about relationships and sexual behaviour, moving in and out of work, and community participation. We hope that this report will provide PLWHA and government and community bodies with a better understanding of the issues facing PLWHA. We also hope that this increased understanding can be used to inform decisions and develop strategies and policy.

The survey examines five main issues: health, relationships, community life, finances, and employment. The section on health focuses on PLWHA's experiences of, and attitudes toward, the new anti-viral treatments, in particular the new class of protease inhibitor drugs which have become increasingly available since the latter part of 1995. The section on relationships explores the changing nature of relationships with family, friends and partners, as well as sexual practice. The section on community examines the role of HIV/AIDS-related organisations and publications. The section on finances examines the experience of poverty and changes in accommodation. The section on employment explores the movement of PLWHA in and out of the work force.

This report is the first of a number of planned reports as part of the HIV Futures Study. It provides the basic descriptive data from the survey, together with analysis of some of the most important associations which the data reveal. Future reports will examine in more detail the interactions between treatments, health, relationships, community, finances and work as they shape the lives of Australian PLWHA. Among the important issues identified in this report, but requiring more detailed analysis, is the number of PLWHA who also have another major health condition, such as Hepatitis C. Similarly, reports will be prepared in relation to specific sub-populations of PLWHA, such as those living in particular regions, women, heterosexual men and gay/bisexual men. Information from the HIV Futures Survey will also be added to other HIV Futures studies. Two sets of qualitative interviews have been conducted along with the survey. One provides additional close-focus data on relationships and sexual practice and another focuses on movements in and out of work.

3 About the Sample

3.1 Recruitment

A stratified purposive sampling strategy was utilised to sample people living with HIV/AIDS in Australia. Recruitment involved distribution of self-administered mail back questionnaires through HIV/AIDS organisations, a number of mailing lists, and through a targeted advertising campaign. The mailing lists included those of four free publications that provide information about living with HIV/AIDS. These publications were *Talkabout* (New South Wales), *PL* (Western Australia), *QPP Alive* (Queensland), and *Positive Living* (Victorian recipients of the national newspaper insert). It is not possible to know what proportion of the recipients of these magazines are HIV-positive, and as a consequence response rates cannot be calculated.

The recruitment period was from 1 July 1997 through 5 September 1997. Additional targeted distribution occurred in order to ensure the sample included sufficient numbers to enable statistical comparisons from groups which have distinctive issues and experiences and who may not have been contacted through the main distribution channels. These groups included women, people living with Haemophilia, and people living outside of New South Wales and Victoria.

3.2 Sample demographics

The survey was completed by 925 respondents: 834 men and 84 women (seven respondents did not indicate their sex). The sample represents 8.3% of the current population of people living with HIV/AIDS in Australia as estimated by the *Australian HIV Surveillance Report* (National Centre in HIV Epidemiology and Clinical Research [NCHECR], 1997).

Respondents' ages ranged from 18 to 77 years (median = 38.0 years, mean = 39.3 years). Respondents' ages at the time of diagnosis with HIV ranged from 4 to 70 years (median = 31.0 years, mean = 31.8 years). The average length of time since respondents first tested HIV-positive was 7.4 years. Half of the respondents have been HIV-positive for 8 or more years, and half have been HIV-positive for less than 8 years. One-third have been HIV-positive for 10 years or more.

Of the 925 PLWHA who completed the survey, 74% said they are homosexual, 16% are heterosexual and 8% are bisexual. Men and women were distributed through these categories. Three respondents (< 1%) said they are asexual, and 1 respondent (<1%) said they are celibate. Fourteen respondents (2%) did not indicate their sexual orientation.

Respondents were asked to indicate how they believe they were infected with HIV. Table 1 presents these results, grouped into the categories used by the National Centre in HIV Epidemiology and Clinical Research in the Australian HIV Surveillance Report.

Table 1 Mode of transmission of HIV

Perceived mode of transmission	**n**	**%**
Male homosexual/bisexual contact	707	(76%)
Heterosexual contact	73	(8%)
Male homosexual/bisexual contact and injecting drug use	36	(4%)
Injecting drug use (female and heterosexual male)	33	(4%)
Haemophilia/coagulation disorder	24	(3%)
Receipt of blood components/tissue	21	(2%)
Health care setting	13	(1%)
Not specified	18	(2%)

n = 925

Of the 925 PLWHA who completed the survey 404 (44%) reside in New South Wales, 213 (23%) in Victoria, 135 (15%) in Queensland, 78 (8%) in South Australia, 50 (5%) in Western Australia, 9 (1%) in the Northern Territory, 12 (1%) in the Australian Capital Territory, and 8 (1%) in Tasmania. Sixteen respondents (2%) did not indicate in which state they live.

Most respondents (62%) live in the inner suburbs of capital cities, while 18% live in outer suburban areas, 12% live in a regional centre, 8% live in a rural area.

Approximately three-quarters (76%) of respondents identify their ethnic/racial background as Anglo-Australian. The most frequently cited other ethnic/racial background was European (19%), with 3% citing an Aboriginal/Torres Strait Islander background, and 1% citing an Asian background.

Generally, respondents reported high levels of education. Half of the respondents have completed some form of tertiary education. One-quarter (26%) have completed a university degree and 22% have completed a tertiary diploma or TAFE education. A further 24% have completed secondary education, 27% have completed some secondary education, and 1% have completed primary school.

Nearly one-third (30%) of the PLWHA who completed the survey said they have no religious beliefs or that they are atheists. A further 8% said that they are agnostic. Approximately one-third profess Christian beliefs. Of those respondents, 13% are Catholic, 12% are Anglican/Church of England, and 13% have *other Christian* beliefs. Ten per cent of respondents have *new age* religious beliefs, and 5% are Buddhist. While more than half of the sample profess some religious belief, fewer than half attend religious meetings. Most (56%) respondents do not attend religious meetings, while 16% attend less than once a year, 13% attend at least once a year, 8% attend at least once a month, and 7% attend religious meetings at least once a week.

3.3 Representativeness of the sample

To assess the degree to which the sample recruited for this study is representative of all PLWHA in Australia, comparisons were made with the *Australian HIV Surveillance Report* (NCHECR, 1997). As a consequence of the deliberate sampling strategy to include larger numbers of marginalised groups, the Futures survey under-represents PLWHA from New South Wales The survey over-represents women, people who have had an AIDS-defining illness, and people infected through: receipt of blood products; haemophilia/coagulation disorder and in health care settings.

The results reported in the remainder of the Report below are weighted to take account of the under-representation of PLWHA from NSW, and the over-representation of women, people with medically acquired HIV and people with AIDS. The data were weighted to take into account the differences in demographic data reported in the *Australian HIV Surveillance Report* (NCHECR, 1997).

A range of statistical comparisons are made in this report. For clarity, the results of these analyses (χ^2-tests, t-tests, ANOVA, and logistic regression) are not reported in this report. All significant differences reported are significant at $p < .01$.

3.4 Further analysis

The analyses reported here include some detailed comparisons of the experiences of different subgroups of PLWHA. However, future publications will examine some issues in more detail than is possible in this first report. For example, the distinctive experience of women, and of PLWHA also infected with Hepatitis C are occasionally commented on, but the experiences of both of these groups will be analysed in greater detail in future reports.

4 Health Status and Health Management

Key Findings

The survey reveals very high rates of CD4/T-cell and viral load testing among PLWHA. This provides a strong indication that PLWHA are actively engaged in monitoring their health status. This includes those who may not be currently using anti-viral treatments.

The majority of PLWHA rate their health positively with nearly three-quarters describing their health as excellent or good. Despite this fact, nearly one-third of PLWHA - a substantial minority - report having at least one major health condition other than HIV/AIDS. The most common other conditions reported were Hepatitis C and psychological or psychiatric conditions. The coexistence of major health conditions as described poses considerable challenges for the coordination and delivery of health services.

PLWHA have long had a reputation for being pro-active in the management of their own health and for their high levels of engagement with new medical information about the management of HIV. The survey supports this reputation, showing that over 80 per cent of PLWHA like to find out as much as they can about medical aspects of HIV and that over one-third consider themselves to be more knowledgeable about the treatment of HIV than the doctors who treat them. Not surprisingly, the vast majority of people with HIV/AIDS work together with their doctors in their decision-making around treatments.

Despite significant educational efforts encouraging early treatment, PLWHA remain unconvinced about the optimal time to begin treatments. When asked whether people with HIV/AIDS should begin treatments as early as possible, over half either disagree or are unsure.

4.1 Health status of respondents

4.1.1 What do PLWHA know about their CD4 and viral load counts?

Nearly all of the PLWHA who completed the survey (99%) have taken a CD4/T-Cell test. The results of respondents' most recent CD4/T-Cell tests ranged from 0 to 1400 cells/mL (median = 390 cells/mL, mean = 418 cells/mL).

Among the PLWHA who have taken a CD4/T-Cell test, 82% reported that at some time in the past they have had a CD4 /T-Cell count below 400 cells/mL, and 54% reported that at some time in the past they have had a CD4 /T-Cell count below 200 cells/mL.

The number of PLWHA who have taken a viral load test was also high (96%). The results of respondents' most recent viral load tests ranged from an undetectable level to 6,000,000 copies/mL (median = 1,000 copies/mL, mean = 58,585 copies/mL).

Table 2 Serological testing

Test	**copies/mL blood**	**n**	**%**
CD4/T cells			
little/no immune system damage	more than 500	264	(31%)
moderate immune system damage	250 - 500	340	(40%)
severe immune system damage	less than 250	249	(29%)
Viral load			
below detectable level	less than 500	367	(46%)
low	500 - 10,000	212	(26%)
moderate	10,000 - 50,000	112	(14%)
high	more than 50,000	114	(14%)

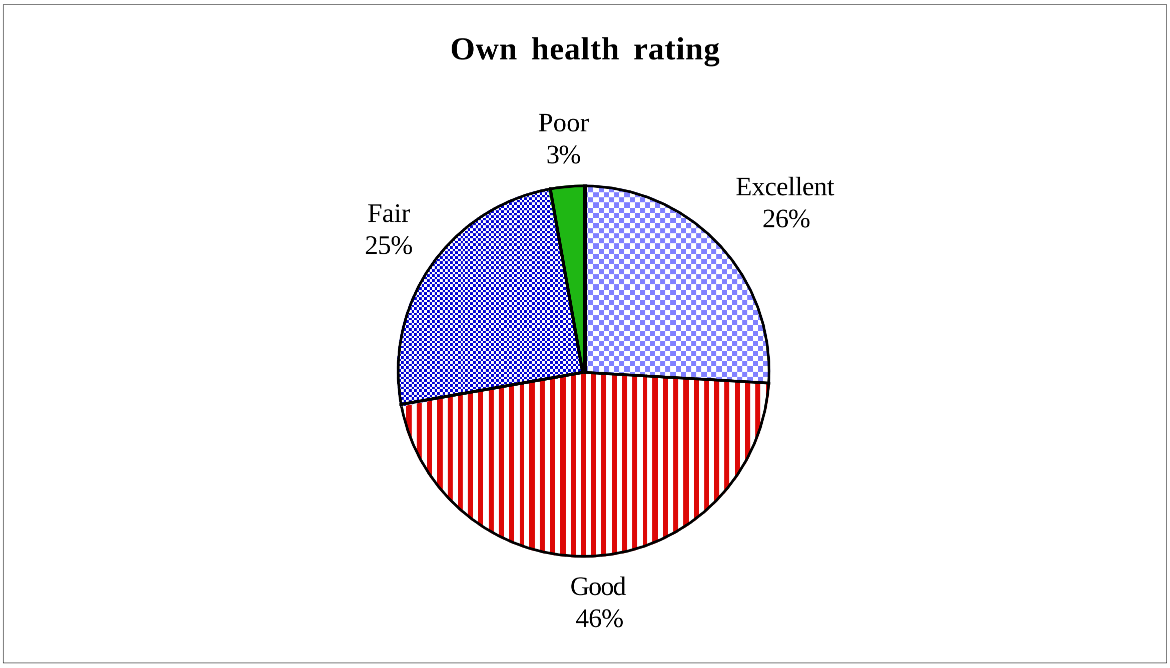
1 - n = 903 for CD4/T-cell test; n = 872 for viral load test

The 4% of participants in the study who have not taken a viral load test gave the following reasons for not having done so: *I don't believe that I need one* (47%); *I don't know enough about viral load tests* (18%); *I'm scared of the results* (18%); *I haven't been offered one* (9*%); I haven't gotten around to it* (6%); *and I don't know how to obtain one* (6%).

4.1.2 How do PLWHA rate their own health?

Many respondents reported that their current state of physical health is *good* or *excellent*. Compared to respondents who have not been diagnosed with an AIDS-defining illness, respondents who have been diagnosed with an AIDS-defining illness were significantly more likely to report that their health is *poor* or *fair*, and significantly less likely to report that their health is *excellent* . In contrast to a recent American study (Richter et al., 1998), no relationship was found between current health and use of anti-virals.

Graph 1 PLWHA's ratings of their current physical health



n = 914

4.1.3 What major health conditions other than HIV/AIDS do PLWHA report?

Slightly fewer than one-third (29%) of the PLWHA who completed the survey reported that they have at least one major health condition other than HIV/AIDS. The most commonly cited major health conditions were Hepatitis C and psychological/psychiatric conditions (both 6% of total sample). Other commonly cited health conditions included Asthma, Arthritis, Cardiovascular disease, Diabetes, Haemophilia, Hepatitis B, Hypertension (2%); alcoholism/drug dependence, back injury/back pain, Cancer (non-Kaposi sarcoma), Epilepsy, liver disease and lung disease (eg. Emphysema) (1%). There was no association between diagnosis with an AIDS-defining illness and reporting any major health conditions other than HIV/AIDS.

Of the PLWHA who completed the survey, 29% reported that they have been diagnosed with Hepatitis A, and 36% reported that they have been diagnosed with Hepatitis B. The majority of respondents (53%) have been tested for Hepatitis C. Among those who have been tested, 67% tested negative for Hepatitis C, 27% tested positive for Hepatitis C, and 6% do not know the result of their test. Given the high levels of Hepatitis C among respondents who have tested for it, it may be that there is a small but substantial level of undiagnosed Hepatitis C among PLWHA.

4.2 Attitudes towards health management

Respondents were asked a series of questions which assessed their attitudes toward treatments for HIV/AIDS other than anti-viral drugs, and health management in general. Their responses are displayed in Table 3. The vast majority of respondents agree that looking after their physical fitness and keeping an optimistic frame of mind are an important part of living with HIV/AIDS. Nearly two-thirds (62%) of respondents strongly agree that *Keeping an optimistic frame of mind is an important part of managing my HIV infection*, and over one-third (36%) strongly agree that *Looking after my physical fitness is an important part of managing my HIV infection*. It is interesting to note that although the majority (68%) of respondents think that their doctor knows a lot more than them about treatments for HIV/AIDS, over three -quarters (85%) of the PLWHA who completed the survey reported that they work together with their doctor to determine the best treatment regime for them. A significant relationship was found between responses to these two attitude items such that respondents who believe that their doctor knows more than them about treatments tended to report that they work together with their doctor to find the best treatment for them (94% vs 83%). Respondents seemed to be divided on the issue of when PLWHA should begin using anti-viral drugs. While nearly half (47%) agree that PLWHA should begin anti-viral therapy as soon as possible, one-quarter (26%) disagree, with the remainder (27%) unsure as to whether early intervention is desirable.

A significant relationship was found between certain attitudes toward health management and whether or not PLWHA are using anti-viral drugs. Compared to PLWHA who are not using anti-virals, PLWHA who were using anti-virals are significantly more likely to agree that:

- their doctor knows a lot more about the treatment of HIV than they do;

- they work together with their doctor to find the best treatment; and
- people with HIV should start using anti-viral drugs as soon as possible .

The last result echoes the results of a study of American PLWHA (Richter et al. 1998) which revealed that PLWHA with more favourable attitudes toward anti-virals were significantly more likely to be using these drugs than PLWHA with less favourable attitudes.