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**Evaluation of**  
***PositiveLiving***  
**2003**

**Final version, February 2004**

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## Executive summary

The readership of *Positive Living* is overwhelmingly male and gay. Readers are more likely to be over 40 than under 40, with less than 5% being aged under 30. Readers are most likely to live in the Sydney or Melbourne metropolitan areas, although significant numbers live outside of these zones and *Positive Living* should not be seen as a publication for a Sydney/Melbourne audience.

Most readers of *Positive Living* are HIV-positive although, as indicated by past surveys, the publication has a significant HIV-negative readership. Readers with HIV and HIV-negative readers are generally in agreement about the merits and shortcomings of *Positive Living*.

Most HIV-positive readers received their HIV diagnosis prior to 1995.

Almost half of all *Positive Living* readers are working on a full-time or part-time basis, and almost half again are in receipt of a government benefit (generally a Disability Support Pension or part thereof).

83% of all HIV-positive readers have taken or are taking antiviral therapies, although a significant number of people within this group are currently on a treatments break. Over two-thirds of those respondents who have taken antivirals first did so more than five years ago. Most are taking complementary therapies of some kind.

A large majority of readers either read most editions or read every edition, and most have been reading the publication for more than three years. A sizeable minority keep copies of *Positive Living* for future reference, and a sizeable minority of these people keep editions for over a year.

Most readers obtain their copies of *Positive Living* through the gay/lesbian community press and the overwhelming majority support current distribution strategies as appropriate. In some states/territories, particularly where there is no community paper, AIDS Councils and PLWHA organisations are facilitating highly effective distribution of *Positive Living* to local HIV-positive people through regular mail-outs. This strategy is targeted and reaching over a third of local PLWHA in several jurisdictions. Web-based distribution of *Positive Living* requires some further attention by NAPWA, particularly in relation to promoting its electronic availability and the format in which it is made available online.

HIV-positive readers have many reasons for reading *Positive Living*, but the most common reason is 'to find out what's going on'. A fifth of all readers use *Positive Living* to connect with other HIV-positive people.

Almost half the HIV-positive readership describes the publication as being reasonably important in the context of multiple sources of treatments information, although it is the most important source of treatments information for 10% of this population.

A huge majority of readers find the publication accessible and over half find it an easy read. The overwhelming majority of readers consider that technical or scientific terms are generally adequately explained.

Almost 90% of readers find the publication to be visually appealing. Most readers consider the lead story to be relatively unimportant to their decision to pick up a copy of *Positive Living*.

## Executive summary (cont.)

The most common responses to reading *Positive Living* are that readers are informed and stimulated.

Readers like lots of different aspects of *Positive Living*, but the most popular components are *Positive Living's* information about HIV treatments and side effects, information about living with HIV, personal stories by people living with HIV/AIDS, Briefs, and national news.

While almost all survey respondents indicated what they liked about *Positive Living*, significantly fewer answered the question about what they did not like. For this group, the aspects of *Positive Living* nominated most often as the least preferred are the book and film reviews, the PLWHA Broadsheet, complementary therapies column, personal stories by people living with HIV/AIDS and the mix of information and entertainment.

Readers are strongly in favour of publishing articles on emerging issues or new research (even where there is limited research).

Readers believe *Positive Living* has struck the right balance between stories on treatments and stories on non-treatments issues. They approve also of the balance between scientific data and informal/personalised writing styles, and of the balance between articles for all people with HIV/AIDS on the one hand and for particular groups of positive people on the other. The need for balances in these areas was a key challenge to emerge from the 2000 evaluation and, particularly given the complexity of these issues, these are important and affirming results for *Positive Living*.

While there is division within the readership on the question of how to spend additional funds (should they ever become available), more readers would support larger issues at current intervals rather than more frequent issues or coloured editions. Readers also give a cautious 'yes' to commercial advertising.

Key personnel within the pharmaceutical companies sponsoring *Positive Living* are strongly supportive of the publication, although NAPWA will need to do more to ensure the ongoing security of this funding. The Commonwealth Department of Health and Ageing supports *Positive Living*, but recent attempts by the Commonwealth to increase its role in content review jeopardise the publication's timeliness, its perceived independence and, subsequently, its utility as a treatments education tool.

# 1. History of *Positive Living*

*Positive Living* began originally as a community magazine for people living with HIV/AIDS in Victoria around 1989. The publication's original focus was lifestyle issues relevant to people with HIV/AIDS and in its early days it was distributed through the Victorian AIDS Council and PLWHA (Victoria). By 1994 *Positive Living* had become a publication primarily concerned with HIV/AIDS treatments and was being distributed throughout Victoria via the gay and lesbian community newspaper, the *Melbourne Star Observer*.

In 1996 responsibility for production of *Positive Living* was transferred to the Australian Federation of AIDS Organisations (AFAO) through an arrangement with the Positive Living Centre (Victoria). As a key element of AFAO's Positive Information and Education Project, *Positive Living* was subject to the advice and direction of an editorial committee comprising nominees of AFAO and the National Association of People Living With HIV/AIDS (NAPWA). Since 1996 *Positive Living* has been distributed nationally through gay and lesbian community newspapers where they exist, and otherwise through a mailing list to individuals, to AIDS Councils and PLWHA organisations and to selected health and other services.

From 1998-2002 the publication was managed through the AFAO/NAPWA Education Team and since January 2003 *Positive Living* has been under the control and management of NAPWA.

## 2. Purpose of the evaluation

The evaluation tender document identifies key objectives:

- Establish demographic profile of the readership
- Measure the effectiveness of *Positive Living*
- Measure the effectiveness of the current distribution arrangements

In developing the survey instrument to be used, secondary objectives emerged as follows:

- To be able to compare results with the previous evaluation of *Positive Living* (2000)<sup>1</sup>
- To be able to use results to complement/supplement data from the *HIV Futures 3* study<sup>2</sup>.

While not a specific objective, it has also been possible for results to be compared with data from a 1998 evaluation of *Positive Living*.<sup>3</sup>

## 3. Methodology

A survey instrument was prepared by the evaluator in consultation with an advisory group established by NAPWA to oversee the evaluation of *Positive Living*. The survey instrument is annexed to this evaluation report.

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<sup>1</sup> Hurley, M. A Summary of Data From the 2000 Positive Living Readership Survey. Australian Federation of AIDS Organisations and Australian Research Centre in Sex, Health and Society, 2001.

<sup>2</sup> Grierson, J. et al. HIV Futures 3 Positive Australians on Services, Health and Well-Being. Australian Research Centre in Sex, Health and Society, 2002

<sup>3</sup> Malcolm, A. Evaluation of Positive Living: A Magazine for People Living With HIV/AIDS. Anne Malcolm Consulting, 1998.

The survey was distributed through the following means:

1. Inclusion in the October 2003 edition of *Positive Living*. Distribution of *Positive Living* is through inclusion in gay and lesbian community newspapers around Australia, by direct mail-out to those on the *Positive Living* mailing list, and by distribution to AIDS Councils, PLWHA organisations and selected health services. Readers were encouraged to return the survey by reply paid post with a deadline of 21 November 2003.
2. Distribution to those readers entering a *Positive Living* competition to win free travel to the NAPWA conference in Cairns. This prize was offered in the September edition of *Positive Living* and entry was conditional upon willingness to be sent a survey (although there was no requirement that the survey be returned).
3. Distribution to people attending the 2003 NAPWA conference; conference delegates were able to deposit completed surveys in a box at the conference registration desk.
4. On-line at the NAPWA website.

The survey was supplemented with a series of phone conversations between the evaluator and NAPWA-nominated persons from each state and territory. The purpose of these conversations was to identify issues of distribution. The advisory group and evaluator noted the obvious problem in assessing effectiveness of distribution on the basis of feedback from people already receiving the publication – what about those for whom the publication is routinely not available or difficult to obtain? The evaluator contacted NAPWA representatives in each state and territory to discuss the issue of distribution generally, and specifically:

- Whether people with HIV/AIDS in that state/territory were able/likely to access *Positive Living*
- Whether there might be more effective ways of distributing *Positive Living* in that state /territory
- Whether there might be more effective means of distributing treatments information in that state/territory than by distribution of *Positive Living*.

The evaluator also had conversations with representatives of *Positive Living*'s three funding sources: the Commonwealth Department of Health and Ageing and the pharmaceutical companies GlaxoSmithKline Australia Pty Ltd and Gilead Sciences Pty Ltd.

## **4. Response rate**

The 2000 evaluation was based on 184 responses. This evaluation is based on 180 responses with 90 from the publication itself, 12 submitted via the web and 78 from the mail-out and NAPWA conference.

## 5. Who reads Positive Living?

### 5.1 Sex/gender

Respondents were asked if they were male, female, transsexual or transgendered.

180 respondents answered this question with 161 indicating they were male (89%), 16 female (9%) and three transgender (2%)<sup>4</sup>.

The 2000 survey response included 79% male, 20% women and 1% transgender.

### 5.2 Age

Respondents were asked which of the following age brackets was relevant to them: under 30, 30-39, 40-49 or over 50.

169 respondents answered this question.

9 respondents are under 30 (5%), 55 between 30 and 39 (33%), 68 between 40 and 49 (40%) and 37 over 50 (22%).

The 2000 survey had asked respondents to identify their exact age. The average age was 42, 24% were aged over 50 and 11% were aged 30 or under.

### 5.3 Residence/locale

Respondents were asked to identify their current postcode or, if not residing in Australia, their current location outside of Australia. Only one respondent was from outside Australia.

Of the 173 Australian-based readers who provided a postcode, 100 (58%) live in the Sydney or Melbourne metropolitan areas, and 73 (42%) reside in areas of NSW or Victoria outside of the capital cities or other states/territories.

On a state-by-state basis, respondents reside in:

NSW .....	62
Victoria .....	51
Queensland .....	24
ACT .....	13
Western Australia .....	13
South Australia .....	9
Tasmania .....	1
Northern Territory .....	0

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<sup>4</sup> Percentages are rounded up or down to the nearest whole number, so occasionally totals will equal more than 100%.

## **5.4 Sexuality**

Respondents were asked whether they identified as gay/lesbian, bisexual, heterosexual or 'other'.

All respondents indicated a sexuality with 152 being gay or lesbian (this equates to a total of 84% being gay or lesbian, although there were only 4 lesbians (2%) in this sample), 12 heterosexual (7%), 11 being bisexual (6%), and 5 identifying as 'other' (3%).

The 2000 survey included a response rate as follows: 75% gay or lesbian, 16% heterosexual, 5% bisexual and 4% indicating no response.

## **5.5 Heritage/cultural background**

Respondents were asked whether or not they were Aboriginal or Torres Strait Islander and 5 respondents identify as Indigenous (3%).

Respondents were asked whether or not English was their first language. English is a second language for 12 respondents, with Spanish being the most common first language for this group (3 readers), followed by French and Maltese (2 each).

## **5.6 HIV status**

Respondents were asked to identify whether they were HIV-positive, HIV-negative, whether they didn't know/had never been tested or would prefer not to say.

132 respondents were positive (73%) with 41 indicating they were negative (23%) and 6 untested/unsure (3%). One respondent preferred not to say (1%). The proportion of respondents identifying as HIV-positive is higher for the 2003 survey (at 73%) than was the case for the survey in 2000 (61%), but both surveys indicate that *Positive Living* has a significant readership amongst HIV-negative people.

The 2000 evaluation had asked HIV-negative readers why they read *Positive Living*. Responses had indicated a commitment to keeping informed, itself based on personal and professional engagement with people with HIV or with HIV services.

The 2003 survey did not include a specific question for HIV-negative readers, however a number took the opportunity to comment on the experience of being an HIV-negative reader of *Positive Living*:

*Being HIV-negative I realise I am not the main target of Positive Living. However I feel it is important to keep abreast of HIV issues because I feel that HIV is an issue for all of us, and not just positive people's problem; so I can understand what my positive friends are going through; to keep in touch with HIV prevention issues.*

*Thanks to all of your information and education I have not been infected.*

*Positive Living is the only source outlining on a regular basis that HIV medications have significant side effects. It is the best safe sex message for me.*

*It is consistently informative, interesting and relevant to my work as an HIV educator.*

Of those HIV-positive readers, 19 had been diagnosed with HIV prior to 1985 (14%), 44 had received their diagnosis 1985-89 (33%), 24 between 1990-94 (18%), 22 between 1995 and 1999 (17%) and 23 since 2000 (17%).

## 5.7 Income

Respondents were asked whether they were receiving a full-time wage, part-time wage, living on superannuation or otherwise a self-funded retiree, unwaged, receiving a full Disability Support Pension (DSP), receiving a part-DSP or receiving any other Centrelink payment. Readers were not restricted to one category and many ticked multiple boxes.

The results are set out in the table below:

Income source	All respondents	HIV-positive respondents
Full-time wage	66	40 (30%) <sup>5</sup>
Part-time wage	33	24 (18%)
Savings/superannuation	15	12 (9%)
Unwaged	5	2 (2%)
Full Disability Support Pension	51	48 (36%)
Part Disability Support Pension	7	7 (5%)
Other Centrelink payment	14	9 (7%)

Of the 132 positive respondents to the survey, 48 % are in full-time or part-time employment. At least 43% are in receipt of some form of social security payment<sup>6</sup>. This suggests that the *Positive Living* readership will be interested in issues relating to work, issues relating to government-funded income support, and the interrelationship of employment/social security (through periodic employment, return to work experiences etc).

Of the *HIV Futures 3* respondents, 27% were working full-time, 21% working part-time, 49% were receiving some government benefit and 7% were living on superannuation. In terms of employment status, it would appear that the HIV-positive readership of *Positive Living* and the respondent base for *HIV Futures 3* are broadly similar.

## 6. Readership use of HIV treatments

### 6.1 HIV treatments

Of the 131 respondents who answered the question on use of antiviral treatments, 87 are currently taking treatments (66%), 22 are on a break (17%) and 22 have never taken treatments (17%). 83% of respondents have at some stage taken antiviral treatments. Of the 22 who have never taken treatments, half have received their diagnosis since 2000. Only one woman has never taken treatments.

This rate of treatments use is slightly lower than the rate indicated by *HIV Futures 3*. The *Futures* sample showed 71.7% currently using treatments with 86.9% having used treatments at some time.

Of the 109 respondents presumably able to answer the question as to when they had commenced treatments, 106 supplied an answer. 3 respondents (3%) began taking antiviral treatments less

<sup>5</sup> As a percentage of total number of survey respondents with HIV.

<sup>6</sup> It is reasonable to combine the numbers for 'full DSP' with 'other Centrelink payment'. There would be some cross-over between 'part-DSP' and 'other Centrelink payment'

than a year ago, 15 respondents (14%) commenced treatments between one and two years ago, another 15 (14%) between 3 and 5 years ago and 73 respondents (67%) first took antiviral treatments more than five years ago.

## **6.2 Treatments breaks**

Those readers who have taken or are currently taking a break from treatments were asked why. They were asked whether it was on the advice of a doctor, on the advice of another health care professional, because of side-effects, because of drug resistance and treatments failure, because of difficulties associated with sticking to treatments schedules, feeling like they needed a break, for some other reason or whether they would prefer not to say.

Respondents were not restricted to one influence and many ticked multiple boxes. The most common reason was a respondent feeling like he/she needed a break (24 responses), followed by side-effects (23 responses), doctor advice (20 responses), resistance (11 responses), difficulties with treatment regimens (7 responses) and the advice of another health care professional (1 response). No respondent preferred not to state his/her reason. Among the 'other' reasons listed were allergies and sensitivities, respondents' suspicion about the impact of treatments on their bodies, issues of control over their body and the desire to keep some treatments in reserve.

Those participants in the *HIV Futures 3* study who had stopped taking antiviral treatments were also asked to indicate why. 86 of the 145 respondents in this category cited clinical reasons (such as side effects and drug resistance), with 59 giving lifestyle reasons (such as 'cleaning out their system' – which might equate to 'feeling like you needed a break' - and complex drug regimens).

## **6.3 Complementary/alternative therapies**

75 respondents (57%) are taking complementary or alternative therapies while 58 are not (44%). 52.9% of the *HIV Futures 3* sample used complementary therapies<sup>7</sup>.

# **7. Readership patterns**

## **7.1 Length and frequency of readership**

Readers were asked if they read every edition, most editions, some editions or few editions. Of the 178 readers who responded to this question, 68 respondents (38%) read every edition, 62 (35%) read most editions, 30 (17%) read some editions and 18 (10%) read few editions of *Positive Living*.

The 2000 survey showed 78% of readers always/mostly read each issue. Combining the 'all editions' and 'most editions' categories of the 2003 results, the figure is similarly high (at 73%).

Readers were asked whether they had been reading *Positive Living* for less than a year, between one and two years, between three and five years or more than five years. Of the 168 responses to this question 23 readers (14%) replied that they have been reading *Positive Living* for less than a year, 29 (17%) have been reading it for between one and two years, 43 (26%) have been reading the publication for between three and five years and 73 (43%) are long-term readers (more than five years).

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<sup>7</sup> At p.37.

The 2000 survey showed 92% had been reading *Positive Living* for more than a year compared with the 86% of 2003 respondents who have been reading *Positive Living* for a year or more. This is a significant increase in new readers, and a number of respondents commented on its value to them as a new reader:

*When I first became positive, I really found Positive Living a great source of information. I always really like the explanation of how the virus works ... I cut some articles out and used [them] as reference material for 'personal life'.*

## **7.2 Source of publication and ease of obtaining copies**

Readers were asked where they obtained their copies of *Positive Living*. A number of respondents are receiving copies through multiple sources.

114 survey respondents obtain their copies of *Positive Living* as an insert in the gay and lesbian press. 40 obtain the publication through an AIDS organisation, PLWHA organisation or a Positive Living Centre. 36 respondents are on the *Positive Living* mailing list while 10 obtain their copies through a doctor/clinic/hospital/sexual health centre, 4 through the Internet, and a small number of respondents are obtaining it through other sources (mostly AIDS services).

144 respondents believe it is never difficult to obtain a copy of *Positive Living* while 22 sometimes have difficulty obtaining a copy and 9 often have difficulty. Of the 9 readers who often have difficulty obtaining a copy, 4 are from metropolitan Sydney/Melbourne, 4 are from non-metropolitan areas and one did not include a postcode.

144 respondents (80%) believe current distribution methods are appropriate.

Readers suggested the following ways of improving distribution (the number represents the number of times the suggestion was put forward):

<i>Positive Living</i> mailing list for individuals .....	17
Email .....	12
On-line .....	8
Greater distribution through doctors' surgeries.....	4
Health clinics .....	2
Universities .....	1
SX magazine.....	1
Newsstands in metropolitan areas.....	1
AIDS Council mailing lists.....	1
Improved distribution of host gay/lesbian publications .....	1

Distribution of *Positive Living* has been one of its main features, and the mass dissemination of the magazine through the gay and lesbian community press (particularly in Sydney and Melbourne) has been a key characteristic. It has been *Positive Living's* creative distribution strategy that has, as much as anything else, set it apart from other treatment resources.

*Positive Living's* distribution is therefore obviously heavily dependent upon the successful distribution of a community newspaper that people are likely to pick up. There has been significant upheaval in the queer community press around Australia over the last few years. Established papers have collapsed financially and been mostly replaced by newer productions. The community newspapers that continue to be distributed vary significantly in terms of quality, frequency of publication and local appeal. Sydney/Melbourne papers are read in a number of

jurisdictions, and the *Sydney Star Observer* in particular has a widespread readership across a number of states.

Discussions with NAPWA representatives in each state and territory indicate that in states/territories where there is no community newspaper, the distribution of *Positive Living* is largely dependent upon the commitment, interest and capacity of key AIDS Council/PLWHA group personnel. Where distribution is undertaken by an AIDS Council rather than a PLWHA organisation, responsibility usually rests with the Council's positive services program.

Some states include *Positive Living* in a monthly mail out to a list of local people with HIV. This has some benefits: it is regular and targeted, comes with a degree of local endorsement, and is disassociated from the 'gayness' that can cause occasional offence. There are also some negatives: *Positive Living* has a significant HIV-negative readership but people who do not have HIV are unlikely to receive copies under such a scheme. In addition, this strategy inevitably involves delays in the publication reaching readers.

Clearly, many people with HIV will not be on PLWHA organisational mailing lists – and won't want to be. In some jurisdictions, to receive a mail-out a person must be an organisational member. Some stakeholders suggested that such mailing lists are likely to be disproportionately comprised of people who have been positive for a long time, and will include few recent sero-converters. Association with an AIDS organisation requires a degree of acceptance of/identification with HIV greater than that required to pick up a copy of a gay/lesbian community paper. On the up-side, some Councils or PLWHA organisations are able to boast good reach to local positive people – suggested by several states/territories to be around a third of all people with HIV currently residing within that jurisdiction.

In other states, it is only by placement of *Positive Living* at appropriate sites (such as AIDS Councils, PLWHA organisations, infectious diseases hospitals, key GP surgeries and pharmacies, sexual health clinics, sex on premises venues, gay venues such as bars, clubs etc.) that the publication reaches anyone at all. This distribution is varied – it is good in some jurisdictions and poor in others. Again, the key to this being a successful strategy depends upon the skill and engagement of staff on the ground.

The survey results indicate that most respondents receive their copies through the community press, but a significant proportion obtains it through AIDS services (22%) or a mailing list (20%). There may be some overlap between these two categories – respondents who receive it via a mail-out from their local Council or PLWHA organisation might have ticked either box.

Greater distribution on-line is worth exploring. This is an obvious proposition, and while it was the most common suggestion for improving distribution it is not clear that it's the easy answer. A number of people who talked up the on-line option didn't know that it is already available on-line. This suggests that *notification* to potential readers that the publication is available on-line may be the most important issue. NAPWA might like to consider on-line advertising of its electronic availability, through community sites, chat rooms, cruising sites etc.

It is also the case that *Positive Living's* tabloid format does not easily lend itself to on-line availability. The NAPWA website currently promotes *Positive Living* as a series of html pages (although a less obvious downloadable pdf file is also available from the archives section). The preference for the html pages is due in part to the time the pdf takes to download, and also because tabloid-size pdf documents are difficult to read on screen for the majority of potential on-line readers and would be virtually impossible to print out for most of the target audience. Given the fact that many readers keep *Positive Living* editions for ongoing reference, this is a

significant problem. NAPWA would be understandably reluctant to generate an A4 size of the publication as well as a tabloid format, and modifying the paper version to A4 would make distribution through the community press impractical. While *Positive Living* stories are currently easily accessible via the NAPWA website, the on-line and hard copy reading experiences are qualitatively different (compare with the Hepatitis C Council of NSW's on-line availability of the *Hep C Review*).

In summary, *Positive Living* continues to rely on a distribution strategy comprised of several components. The community newspaper distribution is effective and supported by stakeholders. Some states/territories engage in highly effective targeted distribution through mail-outs. Venue distribution is important for some, but is probably the most haphazardly implemented strategy.

NAPWA will continue to rely upon local advice and expertise in the distribution of *Positive Living*, and localised mail-outs to positive people should be supported, particularly in those states/territories where the AIDS Council or PLWHA organization is able to reach over a third of the local positive population.

Electronic distribution deserves continued support and some additional attention, particularly in terms of raising awareness of its availability and consideration of the format of on-line availability.

### **7.3 Retention of Positive Living**

Readers were asked if they discarded *Positive Living* after reading it, whether they kept all editions or just those editions of relevance. They were then asked if they generally kept these editions for less than a year or more than a year and whether they referred to them rarely, occasionally or frequently.

Of the 173 respondents to this question, 105 discard *Positive Living* after reading it (61%). 50 respondents keep editions of relevance (29%) and 18 keep all of them (10%).

21 respondents generally keep their editions for less than a year while 31 keep them for more than a year (46%). 19 look at kept editions rarely, 40 occasionally and 3 frequently. The figure of 21 keeping editions for less than a year is slightly suspect – the survey instrument should have diverted people who discarded their editions away from the following question but instead these people were asked to answer it. It may be that many who ticked the box 'generally less than a year' in fact discard their copies almost immediately.

While it is significant that 39% of respondents keep editions of *Positive Living* for future reference and that 45% of this group keep them for more than a year, this is down on the number recorded in the 2000 survey (which indicated 48% of readers saved copies with 53% of this group keeping them for more than a year).

## **8. Why do readers read Positive Living?**

Readers were asked to indicate how they use *Positive Living*. They were presented with a range of options and asked to tick as many boxes as they liked. The options included: to identify current treatments options, to stay abreast of side effects, as background for visits to the doctor, to reinforce current personal treatments choices, to find out what's going on, to balance out other information sources, to connect with other HIV-positive people and 'in other ways'. Most respondents ticked more than one option.

155 readers indicated they read *Positive Living* to find out what's going on, 85 respondents identify the balancing of information as an important *Positive Living* purpose, 77 respondents use *Positive Living* to identify current treatments options, 66 respondents read *Positive Living* to stay abreast of side effects information, 53 read *Positive Living* to re-enforce current treatments choices, 43 as background for doctors' visits and 30 to connect with positive people.

The 2000 survey reserved this question for HIV-positive readers only. The comparison between the 2000 respondents and the 129 HIV-positive 2003 respondents who answered this question is set out below:

Purpose	2003 results (HIV+ only)	2000 results (HIV+ only)
What's going on	112 (87%)	87%
Balance	60 (47%)	60%
Current treatment options	53 (41%)	75%
Side-effects information	48 (37%)	63%
Re-enforce personal decisions	50 (39%)	57%
Background	40 (31%)	36%
To connect	26 (20%)	Not asked

The addition of an extra option in the 2003 survey question makes direct comparison difficult, but the results demonstrate a continuing reliance upon *Positive Living* for finding out what's going on, suggest a slight decline in reliance upon *Positive Living* for clinical information, and show that *Positive Living* has an important role in connecting HIV-positive readers to other people with HIV/AIDS.

The support for the 'connection' option should come as no surprise. The 2000 evaluation showed *Positive Living* as having a strong role in forging linkages. 86% of 2000 respondents had said that reading *Positive Living* helped them feel part of a wider group of HIV-positive people. 56% had said that reading *Positive Living* gave them a sense that their commonality with other positive people because of treatments needs was greater than their differences in sexuality or gender.

Support for the 'what's going on' option is consistent with a role for *Positive Living* which is about contextualising HIV treatments within life. The 2000 evaluation suggested that this was what readers wanted of the publication.

It is not possible to say whether the addition of an extra choice (to connect) accounts for the drop in support for some of the other options, but it is certainly a possibility.

## **9. How important is Positive Living in the context of multiple information sources?**

*HIV Futures 3* revealed that 51.3% of its sample read *Positive Living*. While 49% of the sample cited HIV magazines and newspapers as sources of treatments information, less than 5% identified these sources as the *most* important means of obtaining HIV/AIDS treatments information. The same sample indicated, however, that for information about living with HIV,

almost 10% find HIV magazines the most important source<sup>8</sup>. In this context, use of *Positive Living* ‘to find out what’s going on’ makes sense.

Readers were asked whether, out of all their sources of HIV treatments information (including doctor, other health care provider, AIDS Council, PLWHA organisation, resource booklets, internet, friends, gay press, medical journals), *Positive Living* was most important, very important, reasonably important or not important.

176 readers replied to this question with 24 nominating *Positive Living* as a most important source, 58 seeing it as very important, 78 saying *Positive Living* is reasonably important and 16 not considering *Positive Living* important. Considering only responses from the 130 HIV-positive readers who answered this question, the figures show 64 respondents finding *Positive Living* reasonably important (49%), 41 very important (32%), 15 most important (12%) and 10 not important (8%).

The 2000 survey showed that 13% of HIV-positive respondents found *Positive Living* to be their most important source of treatments information, while 89% of all HIV-positive readers found it to be in their top five sources. The 1998 survey had indicated that *Positive Living* was an important source of treatments information for 89% of readers.

*Positive Living* has a history as a key source of treatments information for positive readership, and the current survey indicates this tradition continues. The proportion of HIV-positive readers for whom *Positive Living* is the most important source of treatments information remains steady.

## **10. Accessibility of information**

Readers were asked whether *Positive Living* is written in a way that makes it accessible and easy to understand.

Of the 154 readers who replied to this question, 145 said the publication was so written (94%). Nine readers (6%) did not agree. Respondents liked such aspects as the long, thin columns, the good use of simple language, the placement of text within interesting page layouts and the newsy style of presentation. Others were critical of medical articles being too long, the language being too complex and aimed at too high an intellectual level, the ‘same old writers’ and the publication being too full of jargon. There were no particular patterns of criticism.

Readers were asked if they found *Positive Living* a difficult read, a moderately demanding read or an easy read. Of 168 readers who replied to this question, 13 (8%) found it a difficult read, 69 (41%) found it moderately demanding and 86 (51%) found it an easy read. When asked whether unfamiliar scientific/medical concepts were usually adequately explained, 134 readers replied in the affirmative (79%) as compared with 36 who did not think such terms were explained (21%).

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<sup>8</sup> At pp. 49-50.

14 respondents were prepared to make no effort to read medical/scientific information (9%), 83 were prepared to make some effort (54%) and 58 were prepared to make lots of effort (37%). The 2000 survey had indicated 7% being prepared to make no effort, 45% prepared to make some effort and 42% prepared to make a major effort.

Effort level	2000 survey	2003 survey
No effort	7%	9%
Some effort	45%	54%
Lots of effort	42%	37%

The 2000 survey had also asked a question about whether *Positive Living* was pitched at the right level, with 83% agreeing that it was appropriately pitched. The 1998 survey had indicated 96% found the publication's language simple and easy to understand.

Some sample reader comments on accessibility of information are set out below:

*Articles are like letters to and from family: supportive and not patronising.*

*NAPWA ought to be congratulated on producing consistently informative and well-researched copy. Make sure Positive Living stays in positive hands. Don't allow it to go back to AFAO or any other non-PLWHA organization.*

*Issues dealt with are generally current, well researched, informative, important for me to be able to understand and background is given where necessary.*

*A very good ability to explain the most difficult scientific issues.*

Overall, the survey results indicate a high degree of success in making treatments information accessible.

## 11. The 'look' of Positive Living

*Positive Living* has always focussed on being a graphically appealing publication. Design and presentation have been important components of the *Positive Living* strategy. 79% of respondents to the 1998 survey found the paper's look "appealing and interesting". The 2000 survey, asking a slightly different question, had identified that 75% liked the mix of humorous, racy headlines/campy graphics and serious articles.

2003 readers were asked whether they think 'the look' of *Positive Living* (including its graphics, layout and design) is appealing.

164 readers responded to this question with 142 believing the paper to be visually appealing (87%). 22 respondents disagreed (13%).

Critics bemoaned the absence of colour, its tired retro look, the dense text, small print, need for more diagrams/charts/photos/images and its lack of imagination. There was no clear pattern of criticism. Some sample criticisms include:

*Pretty primitive.*

*I would prefer a larger print than all the 'graphic space' around articles.*

*I find the retro format and hype-talk a bit distracting.*

*Lacks funk.*

People who like the publication's look applauded its clean and crisp graphics, its humorous pictures, its professional look and the way it offered clear entry points to each story/article. Fans of the design commented:

*Simple and not too cluttered.*

*Contemporary, comprehensive and comprehensible important information about health and treatment. It helps me in making my decisions.*

*Very easy to decide which articles are relevant to me. Good 'entry' points.*

*I like the look because it stands out.*

## **12. Lead story**

Readers were asked how important the front-page story was in terms of their willingness to pick up *Positive Living*. Of the 177 readers who responded to this question, 115 respondents replied that it is not at all important (65%), 46 replied that it is moderately important (26%) and 16 suggested it is very important (9%).

The 2000 survey had asked two questions about the front page – one on the headline and one on the front page graphic. 68% of 2000 respondents said the headline was not at all important (24% said moderately important and 6% said very important) while 74% said the front page graphic was not at all important (18% said moderately and 7% said very important).

## **13. Reading experience**

Readers were asked to nominate their two major responses to reading *Positive Living* from a list of eight. 155 respondents indicated they are informed by *Positive Living*, 78 stimulated, 29 challenged, 23 entertained, 13 made anxious, 13 bored, 10 confused and 5 intimidated.

Considering only HIV+ responses, 113 readers were informed, 58 stimulated, 19 challenged, 11 entertained, 12 anxious, 12 bored, 10 confused and 3 intimidated.

<b>Response</b>	<b>2000 survey</b>	<b>2003 survey</b>
Informed	89%	86%
Stimulated	40%	44%
Challenged	23%	21%
Made anxious	4%	9%
Bored	9%	9%
Entertained	13%	8%
Confused	5%	8%
Intimidated	2%	2%

## 14. Preferred components

Readers were offered a full list of *Positive Living* features and asked to nominate their preferred aspects (up to a maximum of three). These are ranked below in order of descending popularity according to all responses. The column on the right indicates responses from readers with HIV.

Component	All responses	Responses from HIV+ readers
Information about HIV treatments and side effects	103 (57%)	85 (64%)
Information about living with HIV	85 (47%)	78 (59%)
Personal stories by people living with HIV/AIDS	70 (39%)	52 (39%)
Briefs	68 (38%)	52 (39%)
National news	60 (33%)	44 (33%)
International news	58 (32%)	42 (32%)
Mix of information and entertainment	57 (32%)	33 (25%)
What's your problem	53 (29%)	47 (36%)
Complementary therapies	48 (27%)	42 (32%)
Features	46 (26%)	30 (23%)
Regular features	24 (13%)	16 (12%)
Broadsheet	17 (9%)	17 (13%)
Reviews	15 (8%)	9 (7%)
Backgrounder	12 (7%)	11 (8%)
Other	3 (2%)	0 (0%)

These results indicate that readers with HIV, when compared with the general readership, are significantly<sup>9</sup> more likely to favour information about HIV treatments and side effects, information about living with HIV, and the 'What's your problem?' column. Readers with HIV are also more likely to favour articles on complementary therapies and the Broadsheet. Readers with HIV are significantly less likely to list the mix of information and entertainment as their favourite component. The order (most commonly preferred component to least commonly preferred) is generally the same for HIV-negative and HIV-positive readers, except for those shaded cells above.

Readers were offered the same list and asked to identify their least preferred sections. Relatively few respondents filled out this part of the questionnaire. The results are listed below in order of the descending popularity of sections.

<sup>9</sup> For the purposes of this evaluation, a significant difference is greater than 5%.

Component	All responses	Responses from HIV+ readers
Reviews	48 (27%)	36 (27%)
Broadsheet	22 (12%)	19 (14%)
Complementary therapies	15 (8%)	9 (7%)
Personal stories by people living with HIV/AIDS	12 (7%)	9 (7%)
Mix of information and entertainment	10 (6%)	10 (8%)
International news	10 (6%)	9 (7%)
Information about HIV treatments and side effects	8 (4%)	7 (5%)
Backgrounder	6 (3%)	2 (2%)
Other	6 <sup>10</sup> (3%)	6 <sup>11</sup> (5%)
What's your problem?	5 (3%)	1 (1%)
Regular features	5 (3%)	3 (2%)
National news	3 (2%)	3 (2%)
Information about living with HIV	2 (1%)	0
Briefs	1 (1%)	1 (1%)
Features	0	0

These results indicate that book and film reviews remain far and away the least popular component. The Broadsheet is also unpopular with a portion of the readership, but nothing else rates above 10%. There are no significant variations between all responses on the one hand and responses from readers with HIV on the other, although there are some variations in order of ranking (as marked by shaded cells above).

## 15. Publishing research findings

Readers were asked whether they thought that *Positive Living*, when faced with articles on emerging or controversial issues (including where there is limited available research), should always alert readers to these new developments (even with such limited research), wait until more conclusive research has been done, or whether they did not know.

168 readers responded to this question. 139 respondents (83%) believe *Positive Living* should always alert readers. Many respondents supported their preference with commentary noting the value of hope. Others complained that while research takes a long time, the lives of people with HIV/AIDS move at a faster pace. A number of respondents suggested that it was not the job of *Positive Living* to play gatekeeper with information, that knowledge was empowering and that *Positive Living* needed to respect the right and capacity of individual readers to make sense of such information. A number of readers warned that their support for this response was conditional upon *Positive Living* incorporating appropriate disclaimers and generally being clear about the limited nature of research. Others noted that with the decision to publish comes a responsibility to follow-up on trials and to report additional data when it becomes available. A number of

<sup>10</sup> No answer emerged more than once within this category.

<sup>11</sup> As above.

readers noted that *Positive Living* is used as a ‘prompt’ for further research and that flagging new developments would encourage individual readers to further investigate these developments themselves.

21 respondents (13%) believe *Positive Living* should wait until more conclusive data becomes available. Comments in support of this position included warnings around the dangers of false hope, and the fact that while other publications routinely publish ‘new cures’, *Positive Living* is respected for its more cautious approach.

8 respondents (5%) did not know the answer to this question.

*Positive Living*’s readership has consistently taken an approach in support of publishing new and controversial data. 88% of respondents to the 2000 survey had argued in support of discussion of issues where there is not much authoritative research and 84% had wanted publication of the early stages of limited research.

Some sample comments provided by 2003 readers in response to this question include:

*No one else is going to tell us, are they?*

*Wait to avoid false hopes, panic, hysteria, whatever.*

*Wait as there is already too many ‘new cures’ regularly published elsewhere.*

*Research takes too long. What we experience is real and does not need to be validated by research.*

*Knowledge of options is important.*

## **16. Balance between treatments information and information about living with HIV**

The 2000 survey had identified the readership was split on the issue of whether or not *Positive Living* should focus largely on treatments issues (43% said yes and 57% said no). Readers were also split on the issue of whether or not they would like to see a greater emphasis on non-treatments related stories (39% said yes and 54% said no). These results seemed at odds with each other – why, if most people were opposed to *Positive Living* focussing largely on treatments, did most say no to more non-treatments articles? Confronted with these potentially contradictory results, the evaluation concluded that *Positive Living* should focus on treatments issues within the framework of living with HIV, and that for many 2000 readers, this was already occurring.

This balance is not an easy ask, and 2003 readers were asked specifically about this balance between treatments and non-treatments information.

173 readers responded to this question with 103 saying the current balance is about right (60%), 27 suggesting there needs to be a greater focus on treatments information (16%), 22 arguing for more non-treatments information (13%) and 21 indicating they don’t care about this issue (12%). Of the 22 arguing for more non-treatments information, 19 are people with HIV/AIDS.

Response	All readers	Readers with HIV
Balance is right	103 (60%)	77 (58%)
Should be more treatments	27 (16%)	23 (17%)
Should be more non-treatments	22 (13%)	19 (14%)
Don't care	21 (12%)	16 (12%)

This would seem a good result as only 28% of readers seek some change to this balance, and readers seeking change are evenly divided between more treatments and less treatments. This suggests *Positive Living* currently occupies the middle ground on this continuum, and on this basis the publication would be tempted to continue its current approach.

## 17. Balance of writing styles

The 2000 survey had asked whether readers liked articles to be written in a more personal style rather than just being scientific or clinical reports. 73% had agreed.

The challenge for *Positive Living* has subsequently been to find the balance between science and personal style. *Positive Living* acknowledges that scientific data need not be impenetrable to readers with limited medical understanding but, at the same time, scientific and technical detail must sometimes be sacrificed in the interests of making an article accessible.

Readers were asked whether the balance between scientific data and informal/personalised writing style was correct, whether there needed to be greater emphasis on informal and personal style, or whether the emphasis needed to be shifted in favour of more technical data. Of the 143 readers who responded to the question, 79 (55%) approve of the current balance, 36 (25%) argue for a greater emphasis on informal, personalised reporting and 28 (20%) suggest they would accept greater reporting of scientific data even where this made some articles more difficult to read.

Some sample comments:

*We as HIV+ people are bombarded with so much technical shit and medical claptrap its hard to spend all that time to learn what someone at a beat told you months ago.*

*Positive Living should report more of its information in a more personalised way because scientific/technical info is readily available and easy to obtain elsewhere.*

*I like the balance of the clinical scientific stories and the personal touch of articles written about people's experiences.*

Again, *Positive Living* appears to occupy the middle ground on this continuum and the outcome seems a good result for *Positive Living*.

## 18. General or specific articles

The 2000 survey had asked whether people preferred articles written for all PLWHA rather than for specific groups. 42% had responded in favour of articles for all PLWHA while 33% did not support this proposition. The survey form commentary indicated that 'balance' and visibility were often factors in choosing both 'yes' and 'no' answers. Respondents in favour of articles for

*all* PLWHA noted the universality of the virus (everyone has the same virus) and the need to ensure all groups felt connected to HIV information. Those in favour of specific articles noted the differing impact of treatments on different groups, the need to ensure visibility for all people affected by HIV and for visibility of smaller groups to not negate the impact of the virus on gay men.

160 readers responded to the 2003 question on balance between articles for all positive people and articles for particular groups. 99 readers approve of the current balance (62%), 20 believe there should be more written for all positive people (14%), while 26 (16%) believe there should be greater attention to specific groups and 15 don't care (9%).

Those suggesting there needs to be more articles written for specific groups identify the groups in need as women (8 responses), heterosexuals (2 responses), Indigenous Australian (2 responses), gay men (2 responses), transgendered people, men who have sex with men, people from non-English speaking backgrounds, HIV-positive people co-infected with HCV, people who have HIV and are employed, people who inject drugs, people using methadone and positive people living in rural areas (one response each).

A number of readers offered comments on this issue:

*I would like to see Positive Living focus on HIV+ issues and people, not on the categorisation of groups.*

*Not important. Still able to relate and we are all sharing a common friend!*

*I think it is very important for non-members of specific groups eg. non-Indigenous to get an insight into Indigenous issues or rural versus non-rural and sometimes trial participants versus non-trial participants.*

This issue of balance is one of the most complex confronting an HIV/AIDS publication, so given that 71% of readers seek no change and that those in favour of change are evenly split between the two change options, *Positive Living* would presumably be pleased with this result.

## **19. Extra funding**

Respondents were asked if, assuming additional funds were available, they would prefer more frequent editions of *Positive Living*, colour editions of the publication or more pages in each edition. They were also offered the option of suggesting an alternative expenditure.

150 readers responded to this question with 61 suggesting more pages in each edition (41%), 56 respondents (37%) suggesting more editions and 33 suggesting colour editions (22%).

There were not many alternative suggestions put forward by readers for additional funds, and no patterns of suggestion, however among the suggestions were increasing spending on better design, better paper, more images and photos, better distribution to rural areas, producing *Positive Living* in a more durable booklet form and offering training opportunities for new contributors. Several readers suggested that *Positive Living* is good enough as it is and that NAPWA could use additional funds for other purposes.

## 20. Advertising in Positive Living

Readers were asked whether they would support increasing the funds available to *Positive Living* by incorporating commercial advertising.

158 readers replied to this question. 99 readers (63%) believe *Positive Living* should accept advertising, 35 (22%) oppose the idea and 24 (15%) do not care.

A number of the 'yes' votes were qualified by suggesting that opening up the publication to commercial advertising should be done cautiously and with clear commitment to ensuring advertisers did not purchase editorial influence along with their page space. Readers suggested a number of ways in which advertising might be moderated, such as limiting the amount of the publication that could be used for advertising (readers were keen for *Positive Living* not to become an advertorial publication), requiring that advertised products be relevant to positive people, or that advertising not be permitted from pharmaceutical companies. This latter proposal suggests that perhaps not all readers understand that pharmaceutical sponsorship is already a part of *Positive Living* (albeit in a very 'hands off' way).

Readers opposed to commercial sponsorship indicated they were wary of drug company sponsorship for its potential or perceived capacity to influence editorial policy, wary of advertising more generally because they were weary of being targeted for marketing purposes, or because they were keen for the publication not to become like the gay/lesbian papers that carry them.

Several readers offered comments in support of their position:

*It would create an ethical conflict.*

*I visualise pages of adverts like in most other magazines, but in a small way it would be acceptable if it was the only means to produce it.*

*Yes, but remember the target market...is there a relevance factor or is it just plain dollar-chasing?*

*Drug company [advertisements] are welcome – it's about time some of them gave some money 'back', but not interested in social/lifestyle type ads – gay press has that covered.*

*Don't think it is the right publication for commercial advertising which could lead to HIV population being taken advantage of.*

*Probably not, but if there was advertising I would still read Positive Living.*

*Sell yourself to drug companies and you can forget me.*

## 21. Readers' final comments

A number of readers took the opportunity to make a final comment, and many were positive re-enforcements of *Positive Living's* value and current direction. Other readers offered quite specific advice about how the publication could be improved. Comments were broad ranging and there were no real patterns of advice or criticism. Some sample comments are listed below:

*Well it ain't peaches and cream but it helps keep it real.*

*There are too many articles by the same people time and again. Although good, I think other people should be given the opportunity to write of their experience or state their opinions – maybe a readers' forum would be good.*

*Should be more critical of AIDS Inc., including NAPWA.*

*Focus on health needs of PLWHA and medical treatments stuff. We get all the social and political stuff from state-based AIDS orgs.*

*I find it a vital source of information – and an inspiration to see the stories of positive people.*

*I live in a small community and its great to get Positive Living. It keeps me in contact.*

*Keep up the good work – no doubt another thankless political commitment. You go girls!*

## **22. Funding issues**

The providers of funds for *Positive Living*, the Commonwealth Department of Health and Ageing, GlaxoSmithKline Australia Pty Ltd and Gilead Sciences Pty Ltd are obviously critical to the ongoing viability of *Positive Living*.

Industry sponsorship is provided in a hands-off way that means the sponsoring companies see *Positive Living* at the same time readers do. These companies are not permitted any editorial input and do not seek any. This funding approach is a model often held out by community-based AIDS organisations as the gold standard in pharmaceutical industry sponsorship of treatments resources. Key personnel within sponsoring companies remain highly supportive of the publication, however NAPWA will need to work closely with these supporters to ensure ongoing security of funding.

Sponsorship budgets are constantly under threat, and other AIDS organisations will continue to compete for these limited funds. Notwithstanding the ongoing popularity of *Positive Living*, there is always an incentive for funders to find something new and exciting – and this is particularly so in an environment in which it arguably harder to keep people focussed on treatments information. NAPWA will need to support those people within industry who champion *Positive Living*, as the publication's support within large pharmaceutical corporations will often be limited to these few individuals. This is not to say that other industry employees do not consider the publication worthy, more that they simply don't consider it at all. Apart from maintaining close relations with these key people, NAPWA will need to be willing and able to explain actual or perceived shifts in the publication's focus over time, particularly where this may involve a perception that the focus on treatments has been reduced in favour of 'HIV living'.

In contrast to industry's 'hands off' approach, the Commonwealth has recently adopted a significantly greater role in reviewing the content of *Positive Living*. It appears this role is not restricted to ensuring the scientific reliability of data presented but may also extend (from time to time) to discouraging the publication from including information deemed inappropriate by or at odds with the Commonwealth. In and of itself, this is not a particularly unusual approach for government to take in relation to funded materials. However, leaving aside the appropriateness of government purchasing editorial control through its community organisation funding programs, the results for *Positive Living* are highly problematic.

Readers place a high value on *Positive Living*. This is demonstrated by the responses to the 2003 survey, but such high regard can be tracked over many years by reference to the 1998 and 2000 evaluations. *Positive Living's* independence and timelines have been and undoubtedly remain key factors in *Positive Living's* enduring appeal. Recent Commonwealth changes to the publication of *Positive Living* threaten both these characteristics.

Survey comments indicate a suspicion of industry intervention in the publication of treatments information. This is not new and has been one of the ongoing challenges for *Positive Living*. The need to avoid this intervention, or the perception of interference, has been a factor in establishing the publicly touted hands-off agreement between *Positive Living* and the industry sponsors. Readers will no doubt also be worried by government intervention. *Positive Living's* scope is appropriately 'HIV living', with a strong focus on HIV treatments but in acknowledgement that treatments are taken in the context of each positive person's life. 'HIV living' involves such factors as access to medical services, drug availability, access to income support and other matters directly controlled by federal government policy. Readers will be as dubious about government interference in reporting on these factors as they will be of industry intervention in reporting on treatments. It is not lost on industry that the rules for it and for the government are very different when it comes to influencing the content of *Positive Living*.

This is not to suggest that the Commonwealth does not value *Positive Living*. Its support is reflected in financial sponsorship and is no doubt a factor in the good relations between NAPWA and the Department. Key departmental staff are highly supportive of the publication and of NAPWA's work. However, after ten years of producing independent, timely and trusted health information for people with HIV/AIDS, *Positive Living's* capacity to continue this will be jeopardised by overly intrusive Commonwealth mechanisms of review.



## 2003 Readership Survey

The National Association of People Living With HIV/AIDS (NAPWA) is committed to making *Positive Living* as useful as possible for HIV-positive people. NAPWA has arranged for *Positive Living* to be independently evaluated to help determine the usefulness and accessibility of *Positive Living*. This anonymous readership survey is part of this evaluation.

Your responses will help NAPWA improve *Positive Living*.

Please answer the questions below and return the completed survey in the reply-paid envelope provided. (If you didn't receive a reply-paid envelope, you can return the survey in a plain envelope to the address below – no stamp is required):

Readership Survey  
Reply Paid 51  
Newtown NSW 2042

Surveys received later than last mail **21 November 2003** cannot be considered in the evaluation.

Thank you for your time.

- 
1. Are you
    - Male?
    - Female?
    - Transsexual?
    - Transgendered?
  2. Are you aged
    - Under 30?
    - 30–39?
    - 40–49?
    - 50+?
  3. What is your current postcode? .....  
(If you don't live in Australia, in what country are you currently living?  
.....)
  4. Are you
    - Gay or lesbian?
    - Bisexual?
    - Heterosexual?
    - Other?
  5. Are you Aboriginal or Torres Strait Islander?
    - Yes
    - No
  6. Is your first language
    - English?
    - Other?  
(please specify: .....
  7. Are you (please tick as many as are appropriate)
    - Receiving a full-time wage?
    - Receiving a part-time wage?
    - Living on savings or superannuation/a self-funded retiree?
    - Unwaged?
    - Receiving a full Disability Support Pension?
    - Receiving a part Disability Support Pension?
    - Receiving any other Centrelink Payment?
  8. What is your HIV status?
    - HIV-positive? (go to the next question)
    - HIV-negative? (go to question 14)
    - Don't know/Never tested? (go to question 14)
    - Prefer not to say? (go to question 14)
  9. When were you diagnosed with HIV?
    - Before 1985?
    - 1985–1989?
    - 1990–1994?
    - 1995–1999?
    - Since 2000?
  10. Are you currently taking antiviral treatments?
    - Yes (go to the next question)
    - No – I am on a break from antiviral treatments (go to the next question)
    - No – I have never taken antiviral treatments (go to question 13)
  11. When did you first start taking antiviral treatments?
    - Less than 1 year ago?
    - 1–2 years ago?
    - 3–5 years ago?
    - More than 5 years ago?

## Appendix: Questionnaire

- 12.** If you are currently on a break from treatments or have taken a break from treatments before, was your decision to take a break from treatments a result of (please tick as many as are appropriate)
- Advice from your doctor?
  - Advice from another health care professional?
  - Side effects and drug toxicities?
  - Drug resistance/treatments failure?
  - Difficulties sticking with treatments schedules?
  - Feeling like you needed a break?
  - Another reason?  
(please specify: ..... )
  - Prefer not to say?
- 13.** Do you use any complementary or alternative therapies?
- Yes
  - No
- 14.** Do you read
- Every edition of *Positive Living*?
  - Most editions of *Positive Living*?
  - Some editions of *Positive Living*?
  - Few editions of *Positive Living*?
- 15.** Have you been reading *Positive Living* for
- Less than a year?
  - 1–2 years?
  - 3–5 years?
  - More than 5 years?
- 16.** Where do you usually get *Positive Living*?
- Insert in the gay and lesbian press
  - AIDS Council/PLWHA organisation/Positive Living Centre
  - Doctor/hospital/clinic/sexual health centre
  - Mailing list
  - Read it on the internet
  - Other  
(please specify: ..... )
- 17.** How easy is it for you to obtain copies of *Positive Living*?
- Never difficult
  - Sometimes difficult
  - Often difficult
- 18.** How would you **prefer** to receive *Positive Living*?
- The way I get it now is fine
  - Other  
(please specify: ..... )
- 19.** How might distribution of *Positive Living* be improved to make it easier for you to get copies of the publication?
- .....
- .....
- .....
- .....
- 20.** Do you save copies of *Positive Living*?
- No – I read it and discard it (go to question 21)
  - Yes – all of them (go to the next question)
  - Yes – but only those with particular relevance (go to the next question)
- 21.** In relation to your kept copies of *Positive Living*, do you (please tick as many as are appropriate)
- Generally keep them for less than a year?
  - Generally keep them for a year or longer?
  - Refer to them rarely?
  - Refer to them occasionally?
  - Refer to them frequently?
- 22.** How do you use *Positive Living*? (please tick as many as are appropriate)
- To identify current treatments options
  - To stay abreast of side effects
  - As background for visit to doctor
  - To re-enforce current personal treatments choices
  - To find out what's going on
  - To balance out other information sources
  - To connect with other HIV-positive people
  - In other ways  
(please specify: ..... )
- 23.** Out of all your sources of HIV treatments information (including doctor, other health care provider, AIDS Council, PLWHA organisation, resource booklets, internet, friends, gay press, medical journals) how important is *Positive Living* to you?
- Most important
  - Very important
  - Reasonably important
  - Not important
- 24.** How important is the front-page story to whether you pick up a copy of *Positive Living*?
- Not at all
  - Moderately
  - Very
- 25.** In general, do you think that *Positive Living* is written in a way that makes it accessible and easy to understand?
- Yes
  - No
- Why/why not?
- .....
- .....
- .....
- 26.** Do you think the look of *Positive Living* (including its graphics, layout and design) is appealing?
- Yes
  - No
- Why/why not?
- .....
- .....
- .....
- .....

## Appendix: Questionnaire

27. What do you like **most** about *Positive Living*?

(please tick up to three options)

- The mix of information and entertainment
- Information about HIV treatments and side effects
- Information about living with HIV
- Personal stories by people living with HIV/AIDS (*Positive Voices*)
- National news articles
- International news articles
- Briefs (short news and treatment summaries)
- Feature articles
- Book and film reviews
- Regular contributors
- What's your problem?* (advice column)
- Complementary therapies column
- Backgrounder* (inside back cover)
- PLWHA broadsheet* (back cover)?
- Other

(please specify: ..... )

28. What do you like **least** about *Positive Living*?

(please tick up to three options)

- The mix of information and entertainment
- Information about HIV treatments and side effects
- Information about living with HIV
- Personal stories by people living with HIV/AIDS (*Positive Voices*)
- National news articles
- International news articles
- Briefs (short news and treatment summaries)
- Feature articles
- Book and film reviews
- Regular contributors
- What's your problem?* (advice column)
- Complementary therapies column
- Backgrounder* (inside back cover)
- PLWHA broadsheet* (back cover)?
- Other

(please specify: ..... )

29. When you read *Positive Living* what are your two major responses? (please tick two options)

- Informed
- Intimidated
- Challenged
- Confused
- Stimulated
- Made anxious
- Entertained
- Bored

30. You find that *Positive Living* is usually

- A difficult read?
- A moderately demanding read?
- An easy read?

31. When unfamiliar terms or scientific/medical concepts come up in *Positive Living*, are they usually adequately explained?

- Yes
- No

32. When it comes to reading complex scientific and medical information about HIV and treatments are you prepared to make

- No effort to read difficult material?
- Some effort to read difficult material?
- A major effort to read difficult material?

33. *Positive Living* tries to strike a balance between articles on treatments issues on the one hand, and, on the other hand, articles on non-treatments issues relevant to HIV-positive people.

Do you think

- The balance is about right?
- There should be more treatments articles?
- There should be more non-treatments articles?
- Don't care?

34. Which of the following statements is true for you?

- Positive Living* has the right balance between scientific data and informal/personalised style of writing
- Positive Living* should report more of its information in a more informal/personalised way
- Positive Living* should report more scientific data, even if this occasionally makes some articles harder to read

Comments?

.....  
 .....  
 .....  
 .....

35. *Positive Living* tries to strike a balance between articles written for **all** HIV-positive people on the one hand, and articles written for **specific groups** of HIV-positive people (such as gay men, women, heterosexuals, needle users or sex workers) on the other.

Do you think

- The balance is about right?
- There should be more focus on articles written for **all** HIV-positive people?
- There should be more articles written for **specific groups**?  
(Which groups? .....)
- Don't care?

