

**A Summary of Data  
From the  
2000 *Positive Living* Readership Survey**

**Michael Hurley  
HIV Treatments Education Project  
Researchers in Residence Program**

**Australian Federation of AIDS Organisations  
Australian Research Centre in Sex, Health and Society**

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ARCSHS  
Level 1  
215 Franklin St  
Melbourne  
Victoria 3000  
Australia

Telephone +61 3 92855382  
Fax +61 3 92855220

[www.latrobe.edu.au/www/arcshs/](http://www.latrobe.edu.au/www/arcshs/)  
e-mail [arcshs@latrobe.edu.au](mailto:arcshs@latrobe.edu.au)

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I would like to thank the respondents to the 2000 *Positive Living* Readership Survey, and those who helped in the development and testing of the questions. A preliminary analysis of this data was fed back to the survey participants in *Positive Living*, June 2000:12. A more detailed analysis of the data subsequently appeared in the *Positive Living* section of AFAO's website: [www.afao.org.au](http://www.afao.org.au)

Jill Sergeant from the AFAO/NAPWA Education Team (ANET) made the *Positive Living* readership survey data base possible. Alan Brotherton, the then Education Manager of ANET, and Kirsty Machon, the then editor of *Positive Living*, were consistently helpful on a variety of matters. So too were the members of the Researchers in Residence Steering Committee for the HIV Treatments Education Project: Alan Brotherton and Robin Gorna (AFAO), Gary Dowsett, Doreen Rosenthal, Marian Pitts and Michael Bartos (ARCSHS).

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## EXECUTIVE SUMMARY

- 1. SAMPLE.** The 184 respondents to the survey were male (80%), gay (70%), HIV positive (61%), female (20%), transgender (1%) and mostly came from east coast cities and regional towns.
- 2. RESPONDENTS OVERWHELMINGLY LIKED *Positive Living*:**
  - as a primary source of information (88%).
  - as highly informative (89%) and stimulating.
  - for its combination of humour and reliability.
- 3. RESPONDENTS CONSTITUTED A READERSHIP THAT WAS FAITHFUL, AGEING AND CRITICALLY ENGAGED.** They have multiple motivations and uses for reading *Positive Living*, but mostly read it “to find out what’s happening”.
- 4. PL HAD A SUBSTANTIAL NON HIV POSITIVE READERSHIP.** 39% of the sample were not HIV positive and read *Positive Living* for reasons of professional, personal and community engagement and solidarity with clients, HIV positive friends and HIV positive communities.
- 5. HIV POSITIVE RESPONDENTS WERE LARGELY UNITED IN WANTING A GENERAL PERSPECTIVE THAT LOCATED TREATMENTS INFORMATION WITHIN LIVING WITH HIV PERSPECTIVES, BUT WERE DIVIDED ON HOW THIS IS BEST DONE AND HOW ‘FAR’ IT SHOULD GO.** Respondents generally asked that clinical information be narrated in non-clinical genres with no loss of quality in the information. The capacity of *Positive Living* to do this was seen as a great strength by the readership. Differences in emphasis emerged over whether living with HIV was best understood inside or outside a modified clinical framework.

- 6. POSITIVE LIVING PERFORMS FIVE KEY ROLES. IT SIMULTANEOUSLY:**
  - enables social bonding amongst the HIV positive and with HIV negative.
  - educates and informs.
  - entertains.
  - brokers techniques of treating and living with HIV.
  - negotiates tensions between clinical and living with HIV perspectives that are mediated variously by gender, sexual identity and differences in clinical best practice.

**These roles are best thought of as interlocking and equally important.** They are ‘enacted’ through a combination of stylistic, informative and attitudinal characteristics that together constitute the content, authority and aura of the magazine.



**Respondents to the survey said:**

~

*'[Positive Living] maintains interest, clarifies issues, covers all emotions-humour in the face of a serious issue is not misplaced.'*

~

~

*'I would like more stories from different PLWHA on coping with treatments, it's not the science, it's the living, stupid'.*

~

~

*'These issues affect our lives. Balanced discussion with citation of what little research is available will help HIV positive [people] make informed decisions. Oral sex/drug holiday/long term affects of treatments etc warrant informed discussion so often not available anywhere else in the media.'*

~

~

*'Regardless of what scientists are prepared to publish, or the CDC to fund, I still have to make decisions about my life, otherwise I become a lab rat.'*

~

~

*'I like the science and culture mix.'*

~

~

*'It's readable not dry, deals better with being HIV+ and having a "lifestyle" not just as a medical issue in isolation.'*

~



## SUMMARY OF DATA

### **POSITIVE LIVING:**

- was overwhelmingly seen to be pitched at the right level (82%).
- was a major primary source of HIV treatments information for all respondents.
- had a critically engaged readership.
- was strongly liked for its combination of humour and reliability.
- was strongly liked as an informative, learning resource.
- was seen to have an engaging mix of writing styles.

### **POSITIVE LIVING:**

- appeared to have a substantial minority readership that was not HIV positive (39%)
- had a readership significantly wider (40%) than the number of those who pick it up.
- was easy to read for most (65%), but 30% found it “moderately demanding”.
- was usually co-read with the *HIV Herald* by HIV positive respondents (74%), except by those aged 30 or under.

### **IRRESPECTIVE OF HIV STATUS, RESPONDENTS TO THE SURVEY:**

- constituted a faithful, ageing readership that was largely male (80%).
- read most issues regularly (78%).
- read each issue intensively (57% read each issue more than once).
- were mostly gay males (70%), heterosexual females (13%) and lesbians (5%).
- were most likely to be aged 31-49.
- were more likely to be aged 50 or over (24%) than 30 or under (11%).
- read *PL* mostly to find out ‘what’s happening’.

### **FEMALE RESPONDENTS (n=37):**

- were almost as likely to read every issue as males.
- were much less likely to be longer term readers than males.
- might be more likely to be longer term readers if they were HIV positive.

### **NON HIV POSITIVE RESPONDENTS (NEGATIVE, DON'T KNOW, NEVER TESTED, NO ANSWER):**

- read *PL* for reasons of professional, personal and community engagement and solidarity with clients, HIV positive friends and HIV positive communities.

**HIV POSITIVE RESPONDENTS TO THE SURVEY:**

- were likely to be taking antivirals (73%) & to have done so for longer than 2 years (79%)
- were as likely to be long term readers, whether or not they were taking antivirals.
- were very unlikely to be aged 30 or under and generally the younger the respondents the less likely they were to identify as treating. Conversely, the older respondents were more likely to say they were treating.
  
- were highly likely to come from the east coast of Australia.
- were much more likely to be rural or regionally based if they come from NSW (25%) or Queensland (46%) than if they come from Victoria (12%).
  
- were far more likely to receive *PL* 'anonymously' as a gay and lesbian press insert (49%) than be on a mailing list (21%) or pick it up from an AIDS Council (20%) or PLWHA organisation (9%).

**HIV POSITIVE RESPONDENTS TO THE SURVEY:**

- were highly informed and stimulated by reading *PL*.
- had multiple motivations and uses for reading *PL*.
- were more likely to identify general uses for reading *PL* than specific uses.
- felt part of a wider group as a result of reading *PL* (86%).

**HIV POSITIVE RESPONDENTS TO THE SURVEY:**

- when asked about how *PL* should think of its audience, and how to write for them, oscillated, often uncomfortably, between identifying as (a) PLWHA on the basis of their HIV status, as (b) gay men, women, heterosexual, bisexual or lesbian, and, to a lesser extent, as (c) citizens or activists.
  
- often confused issues of legal and social equality around a positive HIV status, (social discrimination and access to treatments and treatments information) with the different ways treatments and side effects play out in different HIV populations.
  
- were open minded and formally inclusive of differences amongst themselves.

**HIV POSITIVE RESPONDENTS ALSO:**

- preferred articles to be written in a personal style that was informative and accurate.
  
- were divided over a greater non treatments focus for *PL*, with a majority saying yes (57%) to a greater non treatments focus.
  
- wanted information about antivirals located within a living with HIV framework, rather than in either a purely "factual" medical perspective or in a living with HIV framework that dissipated the authority of medical knowledge and the experience of treating allopathically.
  
- wanted more personal stories of HIV positive treatments experience.
  
- overwhelmingly wanted *PL* to cover stories on new research with limited subjects and/or alarming implications and to include cautions about the limits of the research.

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## References

## Appendix One: *Positive Living* Survey Questions



## 1. INTRODUCTION

This data summary will be followed by an analytic report. Readers are also referred to Hurley, M. (2001) *Strategic and Conceptual Issues for Community-Based, HIV/AIDS Treatments Media*, Monograph Series Number 20, Australian Research Centre in Sex, Health and Society, LaTrobe University, Melbourne.

*Positive Living. A Magazine for People Living with HIV/AIDS* is a national treatments information publication produced every 8 weeks by the AFAO/NAPWA Education Team (ANET). AFAO and NAPWA have recently negotiated a time line for the transfer of the publication from AFAO to the National Association of People Living with HIV and AIDS (NAPWA).

*Positive Living* appears in two formats: tabloid newsprint and, more recently, electronically on the AFAO website: [www.afao.org.au](http://www.afao.org.au). Since *PL* went national under AFAO's auspices, the editor has been a full-time staff member of AFAO, though not a full-time editor of *PL*. Contributions have been written by other AFAO staff and also include regular columns by volunteer writers, Dr Ron McCoy and David Menadue. David Menadue is also the Associate Editor.

*Positive Living* is distributed by several methods: as an insert in the state based gay and lesbian media; through AIDS Councils and PLWHA organisations; as a pick-up in clinic waiting rooms (GPs, sexual health centres) and through a subscribers' mailing list. The Positive Partnerships Project of GlaxoWellcome pays for distribution.

Readers of *Positive Living* were surveyed anonymously using both a print and web site questionnaire. The survey was published in the March-April 2000 edition of *Positive Living*, and appeared on the AFAO web site after the print survey had been circulated in NSW. People considering returning an electronic copy of the survey were asked not to do so if they had already sent in a print copy. Because the distribution of *Positive Living* is staggered in different states, according to the publication cycles of the local gay and lesbian presses, no closing date for the survey was given and returned questionnaires were accepted until the end of April.

184 readers responded to the survey, including 25 from the Internet. The survey is part of a wider analysis of *Positive Living*, designed to:

- (1) assess the ways in which *Positive Living* is positioned as a publication delivering up to date, accessible information and discussion to a variety of HIV positive audiences;
- (2) identify connections between characteristics of the publication and its intended audiences that are amenable to changes to increase the usefulness of the publication.

## 2. SURVEY DESIGN

**2.1** Discussions were held with the then editor of *Positive Living*, Ms Kirsty Machon, and the publishers, represented by Mr Alan Brotherton, then manager of ANET. During this process key issues were identified. They included:

- the degree to which the readership saw its interests as being met by writing which spoke to it as a general audience of people living with HIV and AIDS,

rather than as an audience constituted by gender and/or sexual identity: gay man, woman, lesbian, heterosexual, bisexual;

- who the readers were and how the readers used the publication;
- the manner in which research was incorporated into the publication and how it was reported, with a particular emphasis on 'emerging' research that had major limits and a perceived potential for causing alarm.

These interests were fed into the general design of the survey, including as particular questions (for example, questions 45, 46).

**2.2.** As a result of a literature search that included previous evaluations of *PL* (Malcolm 1998; PLWHA Program 1998) and the *HIV Herald* (Nicholson 1996: 15) and current critical discussions of media generally and of HIV treatments, particular attention was also given in the design of the survey to:

- questions of how *Positive Living* 'spoke' to its readers through its use of a reader friendly, parodic combination of tabloid newspaper conventions, the reporting of technical information and a 'campy' style, and how the readership responded to being spoken to in these ways. The literature search indicated that while 'camp' was a gay friendly sensibility it was also a cultural form that had a wider currency amongst audiences able to identify it as an aspect of popular magazine, film and television culture, whether or not they were at ease with it or liked it (Hamer and Budge 1994; Lumby 1999; Mort 1996; Sinfield, 1998);
- the relations between gender, sexual identity and genres of writing (clinical, personal, tabloid);
- the relations between 'infotainment' and information.

**Note:** The task of developing questions that were suited to a questionnaire but covered some of the complexities of speaking position and of a notional generic reader, without pre-empting responses from particular reading positions more strongly based on gender or sexual identity, was particularly challenging. These issues will be further discussed in the final report.

**2.3.** In order to analyse the results, in relation to data from earlier surveys of *Positive Living* (Malcolm 1998), and to the research on readerships done as part of the *HIV Futures* (Ezzy *et al* 1998) and *HIV Futures II* (Grierson *et al* 2000) surveys, questions were formulated in ways which assisted this. However, because all the samples differ no strict comparison is possible.

**2.4.** Three types of questions were used: closed, requiring yes/no answers; multiple choice; and, open-ended questions where space was left for individual responses.

**2.5.** A draft questionnaire was tested with selected individuals living with HIV and AIDS and selected key players in national treatments information media. Questions were adjusted for sense and clarity.

**2.6.** An agreement was negotiated with ANET for the inclusion of the questionnaire in *Positive Living* and slightly later on the AFAO web site. ANET agreed to pay for the reply paid facility and to place the survey and its results on the web site and in *PL*.

### 3. SURVEY SAMPLE AND READERSHIP OF *POSITIVE LIVING*

- 184 respondents answered the survey.
- 113 respondents (61%) were HIV positive.
- 27 respondents (15%) (16 of whom were HIV positive) answered the survey on the Internet.

It is the largest survey sample of *PL* readers of any survey so far, however we can't assume it perfectly represents the readership:

- The HIV positive respondents match the major exposure categories of the HIV positive population generally, except in one major way. Few people aged 30 and under responded to the survey (n=21), yet this group constitutes about 30% of the HIV positive population. It's not clear whether the low number of respondents aged 30 and under reflects a low readership of *PL* amongst younger people with HIV or whether we are seeing a more common phenomenon-it is harder to get younger people to answer surveys.
- The number of HIV positive females who responded to the *PL* readers survey (n=11), as distinct from the total number of female respondents (n=37), means the numbers of HIV positive females are too small to have any representative force.
- Seventeen respondents spoke a language other than English at home, and of these about half spoke Asian languages. 7 of the 17 were HIV positive and 6 of these 7 spoke a European language at home.
- The one Indigenous response came from the Internet.

## 4. RESULTS AND DISCUSSION

The answers to the survey questions (see Appendix) have been thematically grouped through cross-referencing. The answers to each question are given in each section, followed by a brief discussion where needed.

### 4.1. DEMOGRAPHICS AND HIV STATUS OF RESPONDENTS

#### 4.1.1 Table 1. Gender identity and HIV status of respondents

Responses to questions 1 (Gender identity) and 8 (HIV status).

SEX	HIV STATUS					TOTAL
	Positive	Negative	Don't know	Never tested	No answer	
Male	102	32	4	5	2	145 (79%)
Female	11	23	0	3	0	37 (20%)
Transgender	0	1	0	0	1	2 (1%)
Total	113	56	4	8	3	184 (100%)

- 61% were HIV positive (113).
- 39% were HIV negative (56), or hadn't been tested (8), or didn't know (4).

#### 4.1.2 HIV positive respondents and antiviral treatments

Responses to questions 9 (Are you taking antivirals?) and 10 (How long have you been taking antivirals?). Cross-referenced with question 14 asking how long respondents had been reading *PL*.

73% of HIV positive respondents were taking antivirals, mostly (79%) for longer than two years. Of those who weren't (n=33), half had taken them in the past. A small number (n=8) had been taking antivirals for less than a year.

Of those on antivirals for 2 years or more, 77% have been reading *PL* for 2 years or more.

81% of those **not** on antivirals, had been reading *PL* for 2+ years.

Of those not using antivirals, 36% (n=12) were only using complementary or alternative therapies.

<b>Discussion:</b> Respondents not currently taking antivirals are just as likely to be long term readers of <i>PL</i> as those taking antivirals.
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#### 4.1.3 Table 2 Sexual identity and HIV status of respondents

Responses to questions 4 (Sexual identity) and 8 (HIV status).

SEXUAL IDENTITY	HIV STATUS					TOTAL
	Positive	Negative	Don't know	Never tested	No answer	
Gay male	92	27	4	3	2	128 (70%)
Het male	3	1	0	1	0	5 ( 3%)
Bi male	5	0	0	1	0	6 ( 3%)
Lesbian	1	8	0	1	0	10 ( 5%)
Het female	9	12	0	2	0	23 (13%)
Bi female	0	4	0	0	0	4 ( 2%)
No answer	3	4	0	0	1	8 ( 4%)
<b>Total</b>	113	56	4	8	3	184 (100%)

#### 4.1.4 Age

Responses to question 2 (Age). Cross-referenced with question 8 (HIV status).

- The average age of both respondents overall and of the HIV positive sample was 42.
- Age range of all respondents 21-73.
- Age range of HIV positive respondents 24-66.
- A quarter of all respondents (24%) was aged 50-73.
- 11% of all respondents were aged 30 or under.
- 64% of all respondents were aged 31-49.
- Of 113 HIV positive respondents, 8 were aged 30 or under (8%).

**Discussion:** The survey responses seriously under represent HIV positive people aged 30 years and under. It is not clear from this survey whether this group reads *Positive Living*. Even if they do not, it should not be automatically assumed that *PL* is 'failing' younger HIV positive people. No single piece of print or electronic media may be able to reach all HIV positive people given there now appear to be increasing age and cultural differences emerging between the newly diagnosed, new treaters, longer term diagnosed and long term treaters.

#### 4.1.5 State/territory of respondents

**Table 3 HIV status and state/territory of respondents**

Responses to question 3 (Postcode). Cross-referenced with question 8 (HIV status).

HIV STATUS	NSW/ACT	VIC	QLD	SA	WA	TAS	NT	No Ans	Over Seas	TOTAL
Positive	35	38	21	4	5	3	1	4	2	113
Negative	17	25	4	5	4	0	0	1	0	56
D Know	1	2	0	1	0	0	0	0	0	4
N tested	1	1	2	1	1	0	0	1	1	8
No ans	1	0	1	0	0	0	0	1	0	3
<b>Total</b>	<b>55</b>	<b>66</b>	<b>28</b>	<b>11</b>	<b>10</b>	<b>3</b>	<b>1</b>	<b>7</b>	<b>3</b>	<b>184</b>

#### **HIV positive responses from the East Coast (n=149)**

75% of Qld responses were HIV positive, 64% of NSW respondents and 58% of Victorians.

**Discussion:** One way to read this is to see non-HIV positive Queenslanders as less likely to read *Positive Living* than non-HIV positive people from other states, and to see that in turn as possibly indicating a greater gulf between HIV negative and HIV positive cultures in Queensland.

#### **NSW and ACT all respondents irrespective of HIV status (n=55)**

- 58% (32) came from the inner East and inner West of Sydney. (15/32 came from postcodes 2009-2011 and 12/15 were HIV positive.)
- 9 respondents came from middle western suburbs, North Shore and Northern Beaches.
- 25% (14) came from outside of Sydney (Newcastle & north [6], ACT [4]).

#### **Victorian responses all respondents irrespective of HIV status (n=66)**

41% (27) came from north of the Yarra.

47% (31) came from south of the Yarra.

8 respondents came from outside Melbourne.

#### **Queensland responses all respondents irrespective of HIV status (n=28)**

15 respondents came from Brisbane, mostly from inner city, with 4 from outer fringes.

6 respondents came from mid and far north Queensland.

4 respondents came from Sunshine Coast.

3 respondents came from Gold Coast.

#### **Other states/territories**

The figures from the other states were too small to warrant analysis. I note, however, that 7/11 South Australian responses were from non-HIV positive readers and that the HIV positive and non HIV positive responses from West Australia were equal in number.

## **4.2. WHY AND HOW RESPONDENTS READ *POSITIVE LIVING***

Responses to questions 12 (asking all respondents to identify the single main reason they read *PL* from a list of 4 options) and 47 (asking HIV positive respondents to identify up to 7 ways they use *PL*). Cross-referenced with questions 8 (HIV status) and 13 (do you read every edition?).

### **Why (question 12 open to all respondents)**

- 65% of all respondents primarily read *PL* to find out what's happening, irrespective of their HIV status. Of those reading primarily to find out what's happening, 78% always/mostly read every issue.
- 15% of all respondents read *PL* primarily for work purposes. (Note: Respondents working in the sector also answered "because I want to find out what's happening".)

### **HIV positive respondents to q. 12**

- 67% primarily read *PL* to find out what's happening.
- 27% read to assist in their treatment decisions.

### **How *PL* is used (multiple response question open to HIV positive only)**

- 87% (n=98) "to find out what's going on".
- 75% (n=85) "to identify current treatments options".
- 63% (n=71) "to stay abreast of side effects".
- 60% (n=68) "to balance out other information sources".
- 57% (n=64) "to reinforce current personal treatments choices".
- 36% (n=41) "as background for visit to the doctor".

### 4.3. HOW LONG HAVE RESPONDENTS BEEN READING *PL*, WHO ARE THEY AND HOW OFTEN DO THEY READ *POSITIVE LIVING*?

Responses to questions 13 (How often do you read *PL*?) and 14 (How long have you been reading *PL*?). Cross-referenced with questions 8 (HIV status), 9 (Use of antivirals), 1 (Gender identity), 4 (Sexual identity), and 6 (Do you speak a language other than English at home?).

- 92% of all respondents have been reading *PL* for more than a year.
- 67% of all respondents have been reading *PL* for 2 years or more.
- 76% of HIV positive respondents have been reading *PL* for 2 years or more.
- 77% of HIV positive gay males have been reading *PL* for 2 or more years.
  
- 59% of all respondents who rate *PL* in their top 5 sources of information overall have been reading *PL* for 2 or more years.
- 77% of HIV positive respondents on antivirals for 2 years or more have been reading *PL* for 2 years or more.
- 81% of HIV positive respondents not on antivirals have been reading *PL* for 2 years or more.

#### **Female readers (n=37)**

76% (28) of female respondents always/mostly read every issue compared with 79% of male readers (115/145).

Female respondents (49%, 18/37) were much less likely than male respondents (72%, 104/145) to have been reading *PL* for 2 years or more.

7/11 HIV positive female respondents had read *PL* for 2 years or more.

6/9 HIV positive heterosexual females have been reading *PL* for 2 or more years.

#### **Who reads all or most issues?**

- 78% of all respondents always/mostly read each issue.
- 81% of HIV positive respondents always/mostly read each issue.
- 75% of non-HIV positive respondents always/mostly read each issue.
  
- **Those who speak a language other than English at home** (n=17) read *PL* much less frequently than those who only speak English at home.
  
- **Those who read *PL* sometimes/rarely** were somewhat less likely to be HIV positive (55%) than the entire sample (61%). They were also likely either to have been positive less than a year or longer than two years.

### How many respondents read each issue how many times?

Responses to questions 21 (How many people read each issue you get?) and 22 (How many times would you pick up each single issue and read parts of it?). Cross-referenced with question 8 (HIV status).

#### All respondents

Each issue is read by one person (62%), 2-5 people (34%) and 5+ readers (4%)  
Each single issue is read by the respondent once (34%), two/three times (57%), four or more times (7%).

#### HIV positive respondents

68% of HIV positive respondents say it is read by one person, 29% say 2-5 people read it.

62% of HIV positive respondents say they read each issue two/three times, 29% read it once and 7% read it 4 or more times.

61% of HIV positive gay males say they read it two/three times

**Discussion: These results indicate the possibility of an overall readership 39% greater than the number of copies actually picked up.**

This is slightly less likely to be the case amongst HIV positive readers. However the readership is complicated to analyse because of mass distribution of *PL* via the gay and lesbian press. The magazine is read intensively by a majority of all respondents. No assumption should be made either that all sections are read or that each or all sections are read more than once.

#### 4.4 DO READERS SAVE *PL* AND REFER TO SAVED COPIES?

Responses to questions 22 (Do you save copies of *PL*?), 22 (How long do you keep them?) and 24 (Do you refer to them?)

- 48% of all respondents saved copies of *PL*.
- Of those who saved *PL*, 46% did so for less than a year and 53% kept them more than a year. That is, **26% of all respondents save *PL* for longer than a year.**
- Of those who kept *PL* less than a year, 37% “rarely” referred to it, 59% “sometimes” referred to it and 5% “frequently” referred to it.
- Of those who kept *PL* longer than a year, 19% “rarely” referred to it, 70% “sometimes” referred to it, and 9% “frequently” referred to it.

**Discussion:** A significant minority of respondents saves and refers to *PL* for over a year. In this sense it has some status as a time limited reference work. Of more interest potentially, is whether ‘saving’ signifies a sense of being linked into wider cultures of care

#### 4.5. HOW IMPORTANT IS *PL* AS A SOURCE OF TREATMENTS INFORMATION?

Responses to question 15 (Importance of *PL* as a source of treatments information).  
Cross-referenced with question 8 (HIV status).

Respondents to question 15 were offered 4 choices. The results are listed firstly for each choice and are then aggregated in **bold print**.

13% of all respondents rated *PL* as their first source of treatment information.  
4% of all HIV positive respondents rated *PL* as their first source.

29% of all rated *PL* in their top two sources of information.  
29% of all HIV positive respondents rated *PL* in their top two sources.

46% of all respondents rated *PL* in their top 5 sources.  
56% of all HIV positive respondents rated *PL* in top five sources.

12% of all respondents said *PL* was in none of these categories, including 11% of all HIV positive respondents.

**88% of all respondents rated *PL* as being in their first five sources of information.**  
**89% of HIV positive respondents rated *PL* overall as being in their top 5 sources.**  
**HIV positive readers were less likely to rate *PL* as being in the top two sources overall**

**Discussion:** The aggregations indicate *PL* is seen as a very important source of treatment information for both HIV positive and non-positive respondents.

#### 4.6. ARE RESPONDENTS AWARE OF *HIV HERALD* AND DO THEY READ IT?

Responses to questions 16 (Are you aware of the *HIV Herald*?) and 19 (Do you read both *HIV Herald* and *Positive Living*?). Cross-referenced with questions 2 (Age), 3 (Postcode), 4 (Sexual identity) and 8 (HIV status).

- **86% of HIV positive respondents are aware of the *HIV Herald***
- **74% of HIV positive respondents read both *PL* and *HH*.**
- 72% of all respondents were aware of the *HIV Herald*.
- 84% of respondents aware of the *HH* read both *PL* and *HH* (61% HIV positive).
- 40% of the non-HIV positive readership read the *HH*.
- Those aged 30 or less were much less likely to be aware of *HIV Herald*.

15/49 of those **not aware** of *HIV Herald* were HIV Positive, and 12/15 came from Victoria and NSW. 11/15 were taking antivirals and 7/15 had been taking antivirals 2 years or longer. 12 were gay males, one a heterosexual male and one a heterosexual woman.

**Discussion: There is a very high level of awareness of *HIV Herald* amongst HIV positive respondents, and a high dual readership.** Non HIV positive respondents were less aware and, not surprisingly, less likely to read it.

#### **4.7. WHERE DO RESPONDENTS GET POSITIVE LIVING?**

Responses to question 20 (Where do you get *PL*?). Cross-referenced with questions 1 (Gender identity), 2 (Postcode), 4 (Sexual identity) and 8 (HIV status).

- 52% of all respondents get *PL* as a gay press insert.
- 63% of gay male respondents get *PL* as a gay press insert.
- 21% of all respondents received *PL* from a mailing list.

#### **Of HIV positive respondents (n=113)**

49% received *PL* as a gay press insert.

21% received it from a mailing list.

20% received it from AIDS Councils

9% received it from PLWHA organisations.

#### **Of those respondents who received *PL* as a gay press insert (n=96)**

57% were HIV positive.

84% were gay males, and 53% were HIV positive gay males.

31% were negative/don't know/never tested gay males.

35% live in NSW/ACT, 30% in Victoria, 12% in Qld, 7% in WA, and 8% in SA.

#### **Of those who use a mailing list (n=40)**

60% (24) were HIV positive.

53% (21) were HIV positive males.

38% were female (15/40, mostly HIV negative, often heterosexual (25%) using *PL* for work purposes in NSW).

#### **Of those who received *PL* from AIDS Councils (n=23)**

69% were HIV positive.

26% were heterosexual (6 pos/3 neg) and were about as likely to be female as male.

96% (22/23) live outside of NSW.

#### **4.8. IMPORTANCE OF HEADLINES AND FRONT PAGE GRAPHICS TO PICK UP?**

Responses to questions 26 (Importance of headline) and 27 (Importance of graphic). Cross-referenced with questions 2 (Age), 8 (HIV status) and 20 (Where do you get *PL*?).

##### **Headline**

68% (126) said that the headline was “not at all” important to whether they picked up a copy.

24% (45) said it was “moderately important” and 6% (11) said “very” important.

Of those saying the headline was moderately or very important (56), 47% were HIV positive.

Of those who obtained *PL* as a gay press insert, only 25% said the headline was very or moderately important.

On average, the younger the respondent the more important they rated the headline. Those saying headlines were “very” important (11) had an average age of 36. Those saying headlines were “moderately” important (45) had an average age of 41. Those saying headlines were “not at all” important had an average age of 43.

##### **Front Page Graphic**

74% (137) said front page graphic was “not at all” important to whether they picked up a copy of *PL*.

18% (34) said it was “moderately” important and 7% (12) said it was “very” important.

41% of those who said the graphic was “moderately” or “very” important (n=46), were HIV Positive.

Of all respondents saying the graphic had a “moderate” importance the average age was 40, and those saying “very” had an average age of 42 and respondents saying “not at all” had an average age of 43.

## 4.9. ATTITUDES TO *POSITIVE LIVING*

### 4.9.1 Is *PL* pitched at the right level for you and do you like the mix of racy headlines, campy graphics and serious articles?

Responses to questions 28 (In general, is *PL* pitched at the right level for you?), 29 (If you answered no to 28 what is the problem?), 30 (Do you like the mix of humorous or racy headlines, campy graphics and serious articles?) and 31 (If you answered no to 30 what do you see as the problem?).

Cross-referenced with questions 1 (Gender identity), 4 (Sexual identity) and 8 (HIV status).

#### Pitch

**83% agreed *PL* was pitched at the right level for them and 14% said that no it wasn't.**

There were no strong, common themes amongst those who disliked the pitch: 6 said versions of "it's too gay" (4 HIV positive, 2 HIV negative). 4 said it's too medical (2 HIV negative) or too complex (2 HIV positive). 2 said the pitch was too simple (2 HIV negative). 3 said needs to go beyond treatments and 2 said more natural therapies.

Amongst the HIV positive who didn't like the pitch (n=15), 4 said *PL* was 'too political/opinionated/smart arsed/fashionable'.

#### Mix

**75% liked "the mix" of humorous, racy headlines/campy graphics/serious articles.** 11% disliked "the mix" and 10% answered "don't know".

**Of those who liked the mix**, there was overwhelming support for the humour, lightness of touch and reliability of information. There was recognition that it's "Tricky to get the balance right, and that it's very worth trying for because it enables accessibility, engagement and identification without morbidity and self-pity: "reflects a non-victim approach".

**Amongst those who disliked the mix**, (n=21), there was some convergence between those who disliked camp and/or tabloid newspaper conventions, those who only wanted information and those who saw 'the look' as passé.

Only 6 HIV positive respondents disliked both the pitch and mix of *PL*. All six were male (5 gay, 1 bisexual male).

#### 4.9.2 I like *Positive Living* mostly because ...

Responses to question 33. Respondents were asked to tick up to 3 of 7 possible responses. Some ticked three, some two, some ticked one and some ticked all. Cross-referenced with question 8 (HIV status).

- **64% (118) of all respondents chose “what I learn from it”.**
- **46% (85) of all chose “the mix of information and entertainment”.**

The remaining four choices very roughly came in at 36% each (66 the different ways people write about treatments, 67 major features, 64 letters and doctors, 54 David Menadue’s column).

#### **Of HIV positive respondents (n=113)**

- 62% (70) liked PL for “what I learn from it”.
- 43% (49) said “the mix of information and entertainment”.
- 42% (47) said “the different ways people write about treatments information”.

The remaining four choices came in at about 40% each (36 said “the major feature articles”, 44 said “the letters and doctor’s advice”, 39 said “David Menadue’s column”).

#### 4.9.3 My two major responses to reading *Positive Living* usually are

Responses to question 34, cross-referenced with question 8 (HIV status).

- |   |
|---|
| <ul style="list-style-type: none"><li>• <b>89% of all respondents answered “informed”.</b></li><li>• <b>63% of all said a combination of stimulated &amp; challenged.</b></li></ul> |
|---|

- 40% (73) said they were stimulated.
- 23% (43) said challenged.
- 13% (24) said entertained and 9% (16) said bored.
- 3 respondents said they were “intimidated”, 7 said “confused” and 5 said they were “made anxious”.

- |   |
|---|
| <ul style="list-style-type: none"><li>• <b>Of HIV Positive respondents, 87% (98/113) answered “informed”.</b></li><li>• <b>60% said a combination of stimulated and challenged.</b></li></ul> |
|---|

- 44% (50) were “stimulated”.
- 16% (18) were “challenged”.
- 15% (17) were “entertained”.
- 10% (11) were “bored”, 5 confused, 5 made anxious, 2 intimidated.

#### 4.9.4 What demands does *Positive Living* make on me as a reader and how much effort will I make?

Responses to questions 35 (Ease of reading?) and 36 (Level of effort prepared to make in reading). Cross-referenced with questions 1 (Gender identity), 2 (Age), 4 (Sexual identity) and 8 (HIV status).

##### **Ease of reading:**

**65% (119) of all respondents said they found *PL* an “easy” read.**

30% (55) found it “a moderately demanding read”.

Two respondents said it was “a difficult read” and 7 didn’t answer the question.

Of all respondents aged 30 and under (n=21), 12 found it ‘easy’, 8 found it “moderately difficult” and one gave no answer.

Of those aged 50 and above, 59% found it “easy” & 36% found it ‘moderately demanding’.

**59% of females** found it an easy read compared to 66% of males.

74% (17/23) of heterosexual females found it an easy read compared to 67% of gay males (86/128).

**Of the HIV positive respondents (n=113)**, 72% found it an easy read.

25% (28) found it “a moderately demanding read” and 2 found it “a difficult read”.

##### **Willingness to make an effort in reading:**

7% of all respondents were prepared to make “no effort to read difficult material”.

**45% (82/184) were prepared to make “some effort”.**

**42% were prepared to make “a major effort”.**

11 didn’t answer.

12 of the respondents aged 30 and under (n=21) were prepared to make “some effort”, 5 “a major effort” and 2 “no effort”.

**Of the HIV positive respondents**, 6% were prepared to make no effort.

50% were prepared to make some effort.

42% were prepared to make a major effort.

#### **4.10. WHY DO NON HIV POSITIVE READERS READ *POSITIVE LIVING*?**

Responses to question 37, (invited comments).

63 written responses.

48% were from gay males.

35% were from females.

32% were from heterosexual and bisexual males and females.

16% were aged 30 or less (9/10 were gay-7, lesbian-2, bisexual).

#### **Responses mostly clustered around four themes:**

- work (15),
- community (8),
- information/interest (23)
- service provision/research (10).

**However this is too stark a description of the responses.** For example:

- 8 of the 15 work responses also related their interest directly to the needs of friends or understanding the needs of PLWHA;
- The information/interest responses were also often explicitly linked to friends and to wanting to understand what was happening amongst PLWHA, as were the service provision/research responses.

The tone of the responses was frequently one of keeping informed as an act of both professional and personal community engagement and solidarity:

- “these valuable discussion pieces which impact on the gay community as a whole are important and often cannot be found elsewhere in the gay media”.
- “HIV is everybody’s problem especially in the GLBT community. I am terrified of getting it and losing friends to it so I must keep informed and educated”.
- “To be informed about a health issue which affects all of us”.
- “Keeping up with developments in treatments, the HIV+ community and general interest”.
- “better understanding of day to day challenges of positive people”.
- “work purposes and interests in community”.
- “I work in the sector, I have many positive friends”.
- “work reasons; to keep up with information for positive friends; to keep a watch on the politics of the HIV ‘gurus’ “.

#### 4.11. SHOULD *POSITIVE LIVING* FOCUS LARGELY ON TREATMENTS ISSUES?

##### Questions 38-47 were for HIV positive readers only

Responses to questions 38 (Should *PL* focus largely on treatments issues?), 39 (Would you rather see a greater emphasis on non-treatments related stories of relevance to HIV positive people?) and 40 (If you answered yes to 39 please indicate your three main areas of interest). Cross-referenced with questions 2 (Age) and 4 (Sexual identity).

##### **Q. 38. Focus largely on treatment issues?**

43% (48/113) said *PL* should focus largely on treatment issues (88% gay males).  
57% (65/113) said *PL* should NOT focus “largely” on treatment issues (77% gay males).

46% (42/92) of HIV positive gay males said *PL* should focus largely on treatments issues,  
53% (49/92) of HIV positive gay males said no.

3/11 of HIV positive females said *PL* should focus largely on treatments issues and 8/11 said no.

##### **Note: There is some ambiguity to the answers given to questions 38 and 39.**

The answer “yes” to question 38 seems straightforward. Almost half (43%) want *PL* to focus largely, or even completely, on treatments issues. But given that 73% like articles to be written in a personal style (question 41 below), an unknown number of those who want to focus on treatments are also saying they want this done in non-clinical language that connects with “real life”.

##### **Q. 39. Greater emphasis on non-treatments related stories**

39% (44/113) of HIV positive respondents said they would like to see a greater emphasis on non-treatments related stories and 54% (61/113) said no. 8 didn’t answer.

37% (34/92) of HIV positive gay males wanted greater emphasis on non-treatments related stories and 6/11 of HIV positive females.

The average age of those saying yes to focussing largely on treatments was 43 and of those saying no was 41.

The average age of those saying yes to a greater emphasis on non treatments related stories was 40 and of those saying no was 44.

**The answer “no” to question 38** can be understood as saying *PL* should focus partly or even mostly, but not overwhelmingly, on treatments issues. That this understanding of the question is embodied in the answers seems likely because if the answer “no” is understood in any stronger sense then one might expect a majority of the “no” answers to 38 to be saying “yes” to 39. That is, that they wanted a greater emphasis on non-treatments related stories. This is not what happened. It was possible to say both that you thought *PL* “should not focus largely on treatments issues” and that there shouldn’t be (any) “greater emphasis on non-treatments related stories” (implicit here is the rider ‘than there is now’). The majority of HIV positive respondents took this option. **I have understood this response to mean that respondents want to see discussion of antiviral treatments located within a framework of living with HIV AND that many respondents also see this wider perspective as already characteristic of the writing in *PL*.** However, there appears to be disagreement within the readership on the extent to which this is already occurring and the extent to which it could be taken further.

If we look at the answers to 39, 40 and 41 we see that:

(a) where those who want an (even) greater emphasis on non-treatments stories indicate their areas of interest (42/45 responded) what emerges is a large list of issues. ALL of these issues can easily be described as involving living with HIV.

(b) of the 73% who said yes to articles being written in a more personal style, there was general agreement on the need for both accurate information and personal experience, with a preference for people relating information through descriptions of personal experience. This was especially the case when it came to describing what it's like taking "the drugs", their side affects and techniques for managing them, as it was with living with the virus more generally.

#### **4.12. I LIKE ARTICLES TO BE WRITTEN IN A MORE PERSONAL STYLE RATHER THAN JUST BEING SCIENTIFIC OR CLINICAL REPORTS.**

Responses to question 41.

**73% (83/113) said yes to articles being written in a more personal style.  
21% (25) said no.**

**Those who answered yes** did so from different perspectives:

- some spoke on the basis that this was already occurring ("the mix in *PL* is just right"),
- whereas a number of others were concerned that there be more HIV positive voices heard:
  - "great to hear first hand accounts of the people taking the treatments";
  - "I would like more stories from different PLWHA on coping with treatments, it's not the science it's the living, stupid."

Specific references were made to Indigenous voices and, also to "male and female responses across the board, of [the length of] times people have been positive".

**Respondents spoke of the greater ease of both relating and understanding when anecdote was combined with information. They expressed desires for both factual accuracy and inspiration. Personal style was seen as giving greater access,** but there was a sub stream of warnings: "not patronising, sentimental", "not too personal, the data are the point"; "but factual information is what I'm after, not anecdotal reports".

One respondent said: “Although I’m intelligent I’m not at all interested in the science—that’s what Drs and TO’s are for. It pisses me off as a LTS I’m expected to know all that shit. I have a hard enough time dealing with it in my life. If I want a specific answer I’ll ask the question. Otherwise I’ll be the one to decide what’s important info for me.”

This insistence on ‘living with’, in terms of people with HIV setting their own priorities, can be seen as characteristic of most of the responses, whether or not this perspective is understood as being restricted to ‘living with’ treatments, or more expansively as ‘living with’ HIV or just ‘living’.

**Discussion.** I read the responses to questions 39, 40 and 41 as a rejection of two common assumptions:

- that what’s needed is more and more treatments information (as distinct from ‘updates’).
- that medical frameworks by themselves are the most useful way of going around the territory of living with HIV.

I draw from this an insistence on angles of vision and lived perspectives.

**Those who answered no to more personal writing styles** again varied. Basically there were two kinds of responses.

**Firstly, there were those who like the present balance,**

- “I think the mix currently offered by *PL* is trustworthy and reliable” - **but who argue against further personalisation** – “many other forums for more personal approaches, stick with the current level of scientific and clinical input on the treatment issues.

**Secondly, there were those who quietly asserted a preference for,**

- “the facts ...in a readable format”, or more strongly argued against, or feared, ‘contamination’-“I want the facts in clinical terms, I don’t want someone’s personal interpretation of clinical data which affects my treatment decisions”.

**So while there was some agreement between the yes and no respondents about the current style, there were fairly equal pushes to both rein it in and expand it.**

#### 4.13. HOW READING *POSITIVE LIVING* CONTRIBUTES TO A SENSE OF SOCIAL CONNECTION.

##### 4.13.1 When I read *Positive Living* I feel part of a wider group of HIV positive people.

Responses to question 42. Cross-referenced with questions 1 (Gender identity), 2 (Age), 3 (Postcode) and 4 (Sexual identity).

- **14%** (16) said **they didn't at all feel part of a wider group** of HIV positive people when reading *PL*. Of the 16 who said no to feeling part of a wider group, 13 came from outside NSW. Of the 3 who came from NSW all came from postcode 2010.
- **59%** (67) said **they did feel part of a wider group** "to some extent"
- **27%** (30) said they **very strongly felt part of a wider group**. 26 of those 30 were gay males. Positive females were somewhat less likely to answer "very strongly" (2/11).

The average age of those saying they didn't feel part of a wider group was 41 as was the average age of those who said they did to some extent. The average age of those who said they "very strongly" felt part of a wider group was 45.

##### 4.13.2 When I read *PL* I have more in common with other PLWHA because of my treatment information needs than any differences with them around gender or sexual preference.

- 56% (63) said they had more in common with other HIV positive people because of their treatment information needs than any differences with them around gender or sexual preference. Average age 43.
- 19% said no (22). Average age 41.
- **23% (26/113) said "don't know"**. (21/26 were gay males.) Average age 35.
- 2 didn't answer.

**Discussion:** These answers could be seen as providing a (quite) limited justification for pitching articles at a general PLWHA audience, however (a) it's clearly an area of disagreement ("no") and confusion ("don't know"). More likely it's a partial justification for arguing that a proportion of articles can be pitched this way. This is itself as much a discussion about modes of address that can veer between no assumptions about, for example, gender and sexual identity, to addressing multiple identities in the one article, to developing some notion of a "mix" that applies to any of single issues of *PL*, to time periods, to runs of issues.

#### 4.13.3 I would mostly prefer articles be written for all PLWHA rather than for specific HIV positive populations.

Responses to question 44, a combination of closed and open options. Cross-referenced with questions 1 (Gender identity), 4 (Sexual identity).

**Question 44 was preceded by a statement asking respondents to assume “that *Positive Living* prints mostly articles written for all HIV positive people, but also regularly includes articles specific to particular groups, for example positive women, positive heterosexuals.**

**Question 44 produced a markedly divergent set of responses.**

- **42% (48) preferred articles to be written for all *PLWHA* (88% gay males).**
- **33% (37) did not (73% gay males; 3 females said no).**
- **8 respondents said don’t know. (5 gay males, 2 heterosexual females.)**
- **18 respondents said don’t care. (17/18 were gay males.)**

**THOSE WHO ANSWERED YES (42%)** interpreted the ‘all’ in the question in two different ways. Both ways were insistently inclusive:

- (a) The first took it to mean simultaneously an aggregation of all the exposure categories (gay males, females, heterosexual males etc), as well as each in its separateness.
- (b) The second had a notion of the *PLWHA* that was constituted initially by HIV positivity rather than gender, sexual identity, race etc.

Sometimes all of these elements in (a) and (b) appeared in the one answer.

**What emerged amongst those answering yes were strong strategic positions made up of different strands:**

**(1) anti-discrimination thinking and education amongst and beyond people living with HIV and AIDS:**

- “the broader the appeal the greater the knowledge and tolerance”;
- “it is not a gay disease and we should know by now that being on the fringe or a lesser statistic with a problem is only harder when you are treated by the contempt of invisibility by those who provide services and information”;
- “the disease doesn’t discriminate, HIV that is, so why should the magazine leave out certain population groups. I think everyone has a right to know as it can educate those who aren’t positive and those who are”;

**(11) *PLWHA* unity:**

- “we are all in the same boat”;
- “everyone needs to know”;
- “to feel part of one community and to see how different groups cope with and see/understand their HIV related problems”;

**(111) medical inclusiveness of two kinds:**

**(a) co-infection and a sense of treatments as being partially population specific:**

- “it puts HIV into a wider context ... allows for the magazine to include articles that may pertain to other issues such as HIV/Hep C co-infection”;
- “even so it should be ok to write for just one constituency occasionally where relevant, it shouldn’t be an either or situation”;
- “selfish interest but more specific articles not a turn off”;

**(b) a particular understanding of HIV treatments as (I) being largely or totally sexed body neutral, and (II) tending to pitch PLWHA identity against sexed bodies:**

- “because we all need up to date knowledge to assist us in understanding our virus – this knowledge is not gender or sexuality specific”;
- “the virus is the same”;
- “basic treatments are the same, treatments do not differentiate, people do”;
- “HIV affects all people in a variety of ways and doesn’t necessarily relate to a particular group”;
- “how a person got HIV is history. Treatments is our future. Being straight or gay or needle users refers only really to how we got it”.

**THOSE WHO ANSWERED “NO”** (33%) were no less insistently inclusive than those who answered “yes”, but their sense of the issues at stake was arguably sharper with a greater focus on specific needs. They were also more likely to say the current balance in *PL* was good. (Remember that 83% of all respondents said the current pitch was right and 75% said the mix was right).

**Firstly, there was a similar strand speaking PLWHA commonality, but it was spoken from a position of unity in difference:**

- “I reckon we all learn from reading about each other – the more styles/writers and information content the better” (bisexual male);
- “Coalitions do not blend all ingredients so that the individual ingredients are unrecognisable, rather they celebrate and acknowledge difference. Whilst there are some similarities it is still important to address the specific needs of the different groups. I still read the articles aimed at women or indigenous people, I don’t dismiss them as being irrelevant just because I am gay”;
- “treatments info should be gender/sexuality unbiased where possible. But there should be articles specific to each HIV group as well”;
- “Because gender and sexuality matter in this epidemic, as does practice. I don’t have the same experience of HIV as a straight woman-her needs should not be subsumed under mine” (gay man).

**Secondly, there was an emerging theme on the need for 'balance' not in the sense of equal space for each affected group but for recognition of each group:**

- "sub groups of HIV+ people have special needs that deserve to be addressed in this publication therefore a mix of general and specific is necessary. Balance must reflect proportion of HIV+ population and groups at risk of infection";
- "Because if an article is written specifically for gays I could learn something that I would otherwise never know" (gay man).

**The respondents who said no to the notion of a generic PLWHA tended to see treatments as playing out differently amongst sexed bodies and simultaneously to acknowledge the experience of living with HIV in a wider context than that of discrimination.**

**Thirdly, a strand of the respondents saying no were quite gay specific in focus:**

- "Majority of HIV+ positive people are gay men. This group should be targeted";
- "Should be a specifically gay version";
- "The publication should be directed to gay males firstly" (bisexual woman).

**Again, those who answered don't know tended to deal more directly with questions of how 'representation' might be practically or theoretically dealt with:**

- "It might be appropriate to re-purpose *PL* for different groups ie a straighter version and a gayish version";
- "Don't know=both. It depends on the context. Some treatments issues are generic, some specific (eg interactions between opiates & HIV drugs), side effects for women. IDUs can be vociferous in their demands for specific material there is in fact little specifically gay despite Australia's epidemic."

**11 of the 18 who answered don't care** wrote comments. While a warning against "reaching for lowest common denominator" was one remark, most veered between "everybody needs to know what is happening in a global society ... irrespective of socio-economic subculture", "Everyone has specific needs and you as media must be able to accommodate this", "HIV affects us all the same way" and "It's good to know what other + people are doing".

**Discussion:** My sense from reading the descriptive comments and looking at the proportions of respondents who answered in each of four different ways, yet often spoke similarly about the same matters, is that it's useful to step back and think about how strongly an earlier politicised 'PLWHA' culture based around identity, inclusion and anti-discrimination is evident. Then I ask whether cultures of 'embattlement' are shifting.

For example, gay male respondents: (1) were as likely to say 'be inclusive and respectful of difference' as they were to say 'give us our due'. And 'give us our due' was never said dismissively, though sometimes it had an exclusivist edge, and (11) were as likely as not to acknowledge sexed body differences in how treatments and epidemic effects played out. This combination of generosity and specific interest was also symptomatic of women and heterosexuals.

**One area that indicates confusion about how to deal with changes in PLWHA experience was seen in the assumption that because the virus is common to all groups therefore treatment effects were common.** So an initial position of solidarity based on a common virus and social hostility is transposed into an assumption that therefore the experience of treatments is or ought to be scientifically and experientially the same, and that treatment information can be related and relayed in the same ways to everyone. This is further complicated by assumptions about how social experiences of HIV, particularly when formulated as discrimination, create an identity of experience.

The practical problem is one of how to acknowledge commonality and difference. The price of a PLWHA identity politics often appears to be the effacement of difference, experiential, medical and social. The way out seems to be unity in difference. It's a position that works to the extent that each population is given material specific to it within a more general framework. But there appear to be three major stresses flowing here: (a) effectively an implicit demand by some non gay PLWHA for equal space for sexed body differences; (b) the effacement of gay specific writing which is denied because (1) abstractly it looks as though the fall back position is gay, and currently dominant, and (11) verbal discussion of treatments effects is often gay specific in ways that don't appear in the writing; (c) a limited social capacity to accept, and political tolerance for, methods of mediating these tensions that don't consistently foreground gender and sexual identity.

**I would argue that PL has in fact negotiated these currents very well**, and that a major way of improving this negotiation would be: (1) the inclusion of more positive voices with a consistent practice of making sure these voices come from each of the populations involved, and (11) re-working the speaking position/house style of *PL* in ways that are less gay sensibility defined, but maintain the premium on humour and style. 'Camp' and 50s retro were not gay defined, whatever their origins, and worked extraordinarily well for several years, but their moment has probably passed. We cannot assume it's a matter of gay versus the rest but rather of what might work across varieties of desire relating to hope and differential relations to treatment effects.

#### **4.14 Reporting limited research, controversy and alarm**

Responses to questions 45 and 46. Both questions offered three closed options (yes/no/don't know) and invited open-ended comment.

#### **There was near unanimity in wanting reporting of new research irrespective of its limits.**

- 88% (99) said they wanted discussions on issues where there is not much authoritative research, 9 respondents said no and 5 said don't know.
- 84% (95) said they wanted early stages of limited research reported. 11 respondents said they didn't, 5 said don't know and 2 didn't answer.

#### **In situations where there is little authoritative research should *PL* publish?**

- “Yes, because it's relevant but there shouldn't be reliance on this kind of coverage otherwise you have a publication reporting on issues where there are no answers. Psychologically people want to know what works treatments-wise. Too many speculative articles and you might lose readers or/or credibility.”
- “Science does not have a truth monopoly. New emerging issues constitute 'news' and provided they are clear about speculative nature readers should be able to interpret.”
- “As we all know HIV drugs are pretty experimental and the tiniest bit of knowledge can help.”
- “Print that it is a small study-not authoritative.”
- “Because regardless of what scientists are prepared to publish, or the CDC to fund, I still have to make decisions about my life, otherwise I become a lab rat.”
- “As it draws attention to the anecdotal nature of some reports. This should be used to drive the research agenda from a *PLWHA* perspective rather than just commercial and scientific need.”

#### **During the early stages of limited research should *PL* publish?**

- “Absolutely. *PL* has a history of considered and comprehensive reporting of side-effect profiles. Lypodystrophy was reported in *PL* long before serious consideration was given to the issues by pharmaceutical companies or certain treating physicians in this country and overseas.”
- “With the accompanying riders that put the issues in context. We expect the same of good news with the appropriate caution to any optimism engendered.”
- “any info helps.”
- “I consider withholding info a form of censorship. Info should be published as soon as it becomes available. Readers can draw their own conclusions.”
- “It is better to be aware-you need to monitor your own health.”

- “There are ways to combat alarm through proper reporting techniques rather than patronising the audience through imposing ignorance.”
- “Why not? We as *PLWHA* are restricted by doctors and the media.”

“1. I’ve had pancreatitis from DDI (I didn’t know beforehand). 2 I’ve developed diabetes. (Unknown again). 3 I’ve had to have a spleen removed (complication of 1). 4 I’ve had lipodystrophy, and now have lipoatrophy! All knowledge is helpful.”

“Editing out discussion about emerging issues is dangerous and controlling and *PL* would lose its edge in discussing contemporary issues. It’s a high quality of *PL* that it stimulates thinking about issues. Sub therapeutic dosing of sequinovir a few years ago is a good point that showed leadership of publication.”

“With cautions, why not? If you don’t do it somebody else will, and you will lose a fan.”

**Discussion: The responses to questions 46 and 47 were consistently forceful and put together articulate very strong support for (a) the notion of *PLWHA* as actively monitoring their own treatments, and (b) the conclusion that respondents are highly active readers of *PL*, rather than passive consumers of treatments information.**

## References

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## APPENDIX ONE: *Positive Living* Readership Survey

The layout of the questionnaire was arranged differently for publication in *Positive Living*.

### HIV TREATMENTS EDUCATION RESEARCH PROJECT Researchers in Residence Program Australian Federation of AIDS Organisations/Australian Research Centre in Sex, Health and Society, La Trobe University

#### Questionnaire for readers of *Positive Living* magazine

**Information for participants** The HIV Treatments Education Project is exploring the relationships between educators, programs, resources and HIV positive people. What are the educational principles and practices at work here?

You are being asked to participate in this project as a reader of *Positive Living* and/or of *HIV Herald*. You are asked to complete the questionnaire below and mail it to the address provided. The questionnaire is **anonymous**.

The findings from this research will be compiled into a report for community organisations and educators and may also become part of conference papers or academic journal articles. Copies of that report will be available from the Australian Research Centre in Sex, Health and Society (03 92855382). Any further questions that you might have on this project can be directed to Michael Hurley who is based in Sydney at the Australian Federation of AIDS Organisations (PO Box 876 Darlinghurst NSW1300 OR e-mail to mhurley@afao.org.au OR telephone 02 92811999).

If you have any complaints about the conduct of the project you may contact the Ethics Liaison Officer, Human Ethics Committee, La Trobe University, Bundoora, Victoria 3083 or telephone 03 94791443.

**Note:** Though the publishers of *Positive Living* actively support this research and will take a keen interest in the results, the researcher has no editorial input into *Positive Living*.

#### Questionnaire

1. Are you female    male    transgender?
2. Age
3. Postcode
4. I am a Gay man      Bisexual man      Bisexual woman      Heterosexual woman  
I am a Lesbian woman      Heterosexual man      Other (specify)\_\_\_\_\_
5. Are you an Aboriginal or Torres Strait Islander? YES      NO
6. Do you speak a language other than English at home? YES      NO
7. If you answered yes to question 6, what is the language? \_\_\_\_\_
8. What is your HIV status? HIV Positive      Negative      Don't Know      Never tested

#### Questions 9-11 are for HIV positive readers only

9. If you are HIV positive are you taking antiviral treatments? YES      NO
10. If you answered yes to 9, have you been taking antivirals:  
less than one year?    1-2 years?    2+ years?
11. If you answered no to 9, (tick as many boxes as needed)  
have you ever taken antivirals? YES      NO  
are you using other prescribed medicines such as Bactrim YES      NO  
do you only use complementary or alternative therapies? YES      NO

**Questions 12-36 are for all readers**

12. I read *Positive Living* (tick one or more) mainly: to assist in my treatments decisions for work purposes because I want to know what's happening because I like it
13. I read every edition of *Positive Living* always mostly sometimes rarely
14. I have been reading *Positive Living* for less than a year 1-2 years 2+ years
15. Out of the following sources of HIV treatments information (Doctor, Other health care provider, AIDS Council, PLWHA organisation, Resource booklets, Internet, Friends, Gay press, Medical journals), *Positive Living* is:  
my first source of information in the top two sources in the top five sources
16. Are you aware of the publication *HIV Herald*? YES NO

**If you answered YES to question 16, answer questions 17-19, otherwise go to question 20.**

Of *HIV Herald* and *Positive Living*,

17. Do you read *Positive Living* ONLY? YES
18. Do you read *HIV Herald* ONLY? YES
19. Do you read BOTH *Positive Living* and *HIV Herald*? YES
20. Where do you get *Positive Living*? Gay press insert AIDS Council Dr's/hospital PLWHA organisation Sexual Health Centre Mailing list Other (please specify)
21. How many people read each issue you get? One 2-5 5+
22. How many times would you pick up each single issue and read parts of it?  
Once Two/Three times Four or more times
23. Do you save copies of *Positive Living*? YES NO
24. If you save copies, do you keep them less than one year? YES  
more than one year? YES
25. Do you refer to the saved copies ? rarely sometimes frequently
26. How important is the front page headline to whether you pick up a copy of *Positive Living*? not at all moderately very
27. How important is the front page graphic to whether you pick up a copy of *Positive Living*? not at all moderately very
28. In general do you think *Positive Living* is pitched at the right level for you? YES NO
29. If you answered no to 28, what is the problem as you see it? [Space left]
30. Do you like the mix of humorous or racy headlines, campy graphics and serious articles? YES NO DON'T KNOW
31. If you answered no to 30, what is it that you see as the problem? [Space left]
32. If you answered yes to 30, what is it that you like about the mix? [Space left]

33. I like *Positive Living* mostly because of (tick up to 3 boxes),  
the mix of information and entertainment  
the different ways people write about treatments information  
what I learn from it  
the major feature articles  
the letters and doctor's advice  
David Menadue's column  
Other (specify)

34. When I read *Positive Living* my two major responses usually are that I am,  
Informed  
Intimidated  
Challenged  
Confused  
Stimulated  
Made anxious  
Entertained  
Bored

35. For me *Positive Living* is usually,  
A difficult read  
A moderately demanding read  
An easy read

36. When it comes to reading complex scientific and medical information on treatments, I  
am prepared to make,  
no effort to read difficult material  
some effort to read difficult material  
a major effort to read difficult material

**Question 37 is for HIV negative or HIV status unknown readers only.**

37. We are interested in hearing about why you read *Positive Living*. What are the main reasons that you read the magazine? [Space left]

**Questions 38-47 are for HIV positive readers only**

38. Do you think *Positive Living* should focus largely on treatments issues? YES NO

39. Would you rather see a greater emphasis on non treatments related stories of relevance to HIV positive people? YES NO .

40. If you answered yes to question 39, please indicate your 3 main areas of interest,  
1  
2  
3

41. I like treatments information articles to be written in a more personal style rather than just being scientific or clinical reports. YES NO

Any further comment in response to question 41? [Space left]

42. When I read *Positive Living* I feel part of a wider group of HIV positive people (tick one only),

not at all  
to some extent  
very strongly

43. When I read *Positive Living*, I feel that I have more in common with other positive people because of my treatment information needs than any differences with them around gender or sexual preference. YES NO DON'T KNOW

**Answer question 44 on the assumption that *Positive Living* prints mostly articles written for all HIV positive people, but also regularly includes articles specific to particular groups, for example, positive women, positive heterosexuals.**

44. I would mostly prefer articles be written for all PLWHA rather than for specific HIV positive populations such as gay men, women, bisexuals, heterosexuals, needle users or sex workers.

YES NO DON'T KNOW DON'T CARE

Why? [Space left]

***Positive Living* has to decide sometimes whether to publish articles on controversial, emerging issues, often in the context of limited research based on a very small number of people, for example, research on effects of 'drug holidays'.**

45. Do you generally agree *Positive Living* should publish discussions on issues where there is not much authoritative research? YES NO DON'T KNOW

Why? [Space left]

46. Reporting the early stages of some limited research sometimes gives rise to serious alarm (e.g. on possible side effects of new drugs). Do you think *Positive Living* should report on these issues automatically?

YES NO DON'T KNOW

Why? [Space left]

47. How do you use *Positive Living*? (tick as many boxes as needed)

to identify current treatments options  
to stay abreast of side effects  
as background for visit to Doctor  
to re-inforce current personal treatment choices  
to find out what's going on  
to balance out other information sources  
in other ways (please specify)