EXPLORING THE TREATMENT INFORMATION NEEDS OF HIV-POSITIVE BRITISH COLUMBIANS

by

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EXECUTIVE SUMMARY

This report was commissioned by the Treatment Information Program (TIP) at the British Columbia Persons with AIDS Society (BCPWA) as a research project to investigate the reasons why access to TIP's programs and services is declining. The goal of the research was to assess the treatment information needs of HIV-positive British Columbians so that TIP could effectively and proactively develop strategies to better meet those needs.

The research for this paper focused on two main questions:

1. Why is TIP use decreasing?
2. How can TIP better meet the needs of HIV-positive British Columbians?

Answering these questions entailed designing and conducting an online survey using a participant recruitment strategy that attempted to reach the widest possible range of HIV-positive respondents. Key findings from the survey include:

1. A strong majority of HIV-positive people prefers face-to-face interaction to obtain HIV/AIDS treatment information;
2. Physicians, followed by TIP, are the treatment information sources HIV-positive people are most likely to use;
3. While the Internet appears to be considered reliable, it is not among the top treatment information sources HIV-positive people are likely to use;
4. HIV-positive people continue to seek treatment information when they feel well;
5. HIV-positive people are somewhat overwhelmed by too much treatment information;
6. Although some of TIP's information resources have been rarely accessed, a generally high level of awareness exists for TIP overall;
7. Community outreach forums and TIP's online treatment information blog are considered to be the most specific and relevant;
8. Side effects and nutrition rank highest as treatment information topics of importance. Survey respondents also want to know about the effects of long-term use of antiretroviral medications and the interactions their HIV medications have with other drugs and foods.

Options for TIP to consider in response to the survey's findings include drawing on its current infrastructure to implement programming changes directed toward the core segment of HIV-positive British Columbians that responded to the survey. Largely in good health, this group of treatment-experienced individuals over the age of 40 has told TIP of its preference for face-to-face discussions about HIV/AIDS treatment information and of topics that are important, such as how long-term ARV use affects the body, how to mitigate medication side effects, and how to better adhere to treatment regimens.

In light of growing evidence that a younger generation of HIV-positive people seems to prefer the Internet for community building and for obtaining information about

HIV/AIDS, TIP might engage this particular generation going forward by making enhancements to its electronic treatment information resources. Given that the survey findings revealed a strong preference for physicians as a treatment information resource, an opportunity also exists for TIP to explore potential ways that partnering with physicians could improve the accessibility, quality and reliability of HIV/AIDS treatment information. Some other groups of HIV-positive people, such as women and those newly diagnosed with HIV, were not well represented in the survey sample. Additional research that targets these groups, as well as non-users of TIP, will augment the findings discussed in this paper and will provide TIP with stronger evidence on which to base future programming decisions.

It is hoped that the findings and discussion in this paper will be disseminated throughout BCPWA and to other ASOs to elicit further thought and discussion. Through ongoing dialogue and the exchange of new evidence and ideas, better strategies to meet the treatment information needs of HIV-positive people can be developed.

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INTRODUCTION

It has been more than twenty-five years since AIDS and its precursor, HIV, were first identified as a serious global health threat. For the first decade of the epidemic, the prognosis for HIV-positive people was grim: in the absence of effective treatments, HIV disease progressed quickly to full-blown AIDS and near-certain death. Since then, in many parts of the world, the combination of powerful antiretroviral drugs (ARVs) in HIV treatment regimens[1], together with routine viral load testing and drug efficacy monitoring, has helped to make living with HIV more of a chronic, manageable condition than the debilitating, life-threatening illness it was in the early days of the epidemic.

Information about HIV treatment continues to be one among many topics of interest to HIV-positive people, from the newly diagnosed to those that have been aware of their condition for many years. Treatment information is a vital resource for HIV-positive people to make important decisions, ranging from when to start medications to how to manage side effects and how to improve quality of life through better nutrition or complementary therapies. Given the rapid pace of treatment advancements and the vast amount of HIV/AIDS information for an HIV-positive person to navigate, the need for accurate, up-to-date, and reliable treatment information is essential.

This report was commissioned by the Treatment Information Program (TIP) at the British Columbia Persons with AIDS Society (BCPWA) as a project to investigate the reasons why, against a backdrop of constant change and continued need, access to its programs and services is declining. Because of this decline, concern exists that HIV-positive people may not be as involved, connected or informed as they were in the past. TIP is faced with the important questions of how to reverse the declining trend in access to its services and how to proactively make changes to its programming to better meet the needs of the HIV-positive community in British Columbia. To help answer these questions, key deliverables for this project included conducting a survey to assess the treatment information needs of HIV-positive British Columbians and developing a participant recruitment strategy to reach the widest possible range of survey respondents.

The remainder of this report is organized in the following way. First, the background section provides key global and local statistics about HIV/AIDS and an organizational overview of BCPWA and TIP. The literature review section introduces additional themes that informed the development of survey questions and the participant recruitment strategy, followed by a conceptual framework section that demonstrates how the research questions are connected through the methodology to the remainder of the paper. A detailed description of the methodology follows. The main research findings are presented next, followed by a discussion of the implications of the findings for TIP and options for TIP to consider in its planning for future programming.

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[1] ARV drug treatment regimens are commonly referred to as highly active antiretroviral therapy (HAART). Not every HIV-positive person is on a HAART treatment regimen.

BACKGROUND

Globally, an estimated 33 million people were living with HIV/AIDS in 2007. Two-thirds of these cases (22 million) were in sub-Saharan Africa (UNAIDS, 2007). The British Columbia Centre for Disease Control (BCCDC) reports that from late 1985 to December 31, 2007, there have been 13,003 cumulative cases of HIV infection in British Columbia. The rate of infection per 100,000 people has declined from a high of 30.5 in 1987 to a low of 8.3 in 2006. This rate, however, climbed in 2007 to 9.1 per 100,000 people with the reporting of 395 new positive HIV tests (38 more than in 2006). The BCCDC calls the number of new infections the "best proxy indicator for HIV incidence in BC" (13) and explains that this number[2] "may be the best indicator of new service needs of individuals with HIV, including the need for treatment" (13).

When HIV/AIDS appeared in the early 1980s, the first response of the community in British Columbia, as in others nationally and internationally, was to mobilize in an effort to address the basic needs of people in a sudden and profound crisis of sickness and dying. Mobilization was at first difficult because of the stigma and backlash associated with the social taboos of homosexuality and drug use that had quickly become linked with HIV/AIDS. However, by the late 1980s, a growing sense of urgency around issues like treatment access, funding for research, and protecting the human rights of people with HIV and AIDS contributed to the emergence of a highly politicized activism in the HIV/AIDS community. By that time, community-based AIDS Service Organizations (ASOs) had become established and had begun to play a central, key role in areas such as advocacy and the fight against discrimination for people living with HIV/AIDS.

Over the last decade or so, the focus at ASOs has shifted from being political 'hubs' to being consumer-driven providers of information, education and support services. As HIV continues to enter the wider population, there may be a perception that ASOs continue to primarily target their services to more marginalized communities. These trends exist against a backdrop of growing pressure from funding organizations and governments for ASOs to diversify their services while providing evidence-based programming (Ibanez-Carrasco, 2007).

Overview of the British Columbia Persons with AIDS Society

The British Columbia Persons with AIDS Society (BCPWA), Western Canada's largest ASO, was established in 1987. With a provincial mandate and a current membership of 4,664 HIV-positive people from across British Columbia, BCPWA's mission is to "enable persons living with AIDS and HIV disease to empower themselves through mutual support and collective action" (BCPWA Annual Report 07/08).

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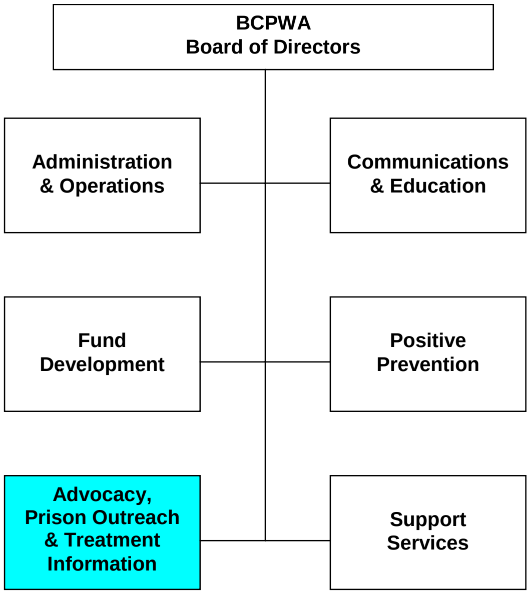
[2] Care must be taken when interpreting HIV and AIDS statistics. Trends in the number of new cases (HIV incidence) may be due to various factors, such as improved testing procedures or higher numbers of people being tested. The actual prevalence of HIV infection is difficult to ascertain because many HIV cases are undiagnosed or unreported.

BCPWA is part of a network of dozens of closely aligned local, provincial and national HIV/AIDS organizations that exist to disseminate information and/or provide services to HIV-positive people. Other municipal examples in Vancouver include AIDS Vancouver and A Loving Spoonful. Other regional services include AIDS Vancouver Island, Living Positive Resource Centre Okanagan, AIDS Society of Kamloops, ANKORS, and Positive Living North (Prince George). While each of these organizations is distinct in its focus on different clientele and service provision, there is some overlap in the types of programs and services they deliver, although most are limited to a specific catchment area. The formation of partnerships among organizations to target certain groups for outreach or to collaborate on joint education or health promotion initiatives is common practice.

As shown in Figure 1, BCPWA's current organizational structure comprises six main departments, responsible to a Board of Directors. Unique among Canadian ASOs, BCPWA's Board of Directors is composed entirely of HIV-positive individuals.

Figure 1: BCPWA organizational structure



Responsibility for treatment information belongs to the department of Advocacy, Prison Outreach and Treatment Information (APT). A description of APT's Treatment Information Program (TIP) follows.

BCPWA's Treatment Information Program

BCPWA's Treatment Information Program (TIP) relies on a rapidly changing informational infrastructure of HIV/AIDS treatment subject files drawn from a vast network of resources to provide treatment information programs and services to BCPWA members and the wider HIV-positive community. Supported by one paid full-time Coordinator and twenty-five HIV-positive volunteers, TIP's mandate is to provide members with accurate, reliable and up-to-date information on treatments and therapies for HIV disease so HIV-positive people can make the best possible decisions for their health.

The greater part of the TIP Coordinator's time is devoted to providing support and training to TIP volunteers. The Coordinator also creates printed and electronic HIV treatment information resources, organizes community forums and outreach educational workshops, and writes articles for BCPWA's bi-monthly member magazine, *living+*. Together with the Coordinator, TIP volunteers are involved in the delivery of TIP's key programs and services:

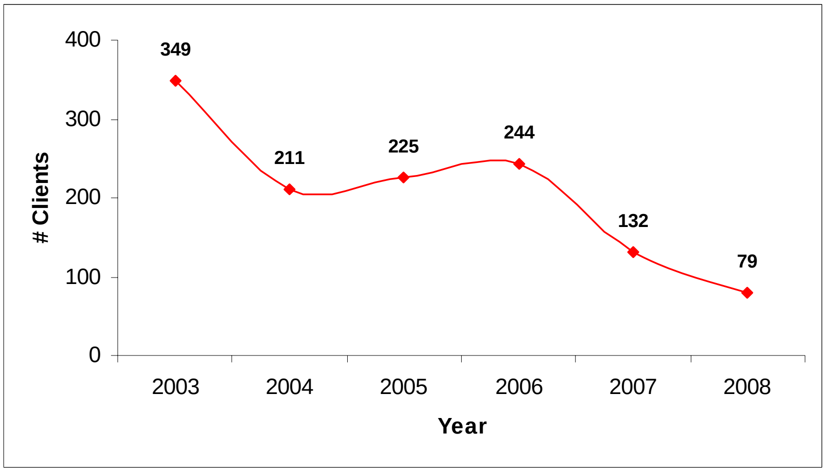
1. Treatment peer counselling – drop-in, telephone, and online counselling for HIV-positive clients provided by HIV-positive peers, drawing on the peer's insights and understandings derived from personal experience living with HIV;
2. Online treatment information blog – an online discussion forum that posts a new treatment information topic every week and notes topics of potential interest from discussion contributors;
3. Treatment publications – easy-to-read pamphlets, brochures and articles on a variety of HIV/AIDS treatment related issues;
4. Treatment information hotline – a toll-free treatment information and peer counselling resource line, staffed weekdays by peer volunteers from 10:00 AM to 5:00 PM;
5. Community outreach forums – HIV treatment-related workshops, presentations and discussions for HIV-positive individuals, healthcare providers, and other interested groups, mostly delivered in British Columbia's Lower Mainland but also throughout the province;
6. Weblinks to other online treatment information resources – direct links to the websites of renowned national and international HIV/AIDS information resources such as the Canadian AIDS Treatment Information Exchange (CATIE), AIDSmeds, Project Inform, Canadian Treatment Action Council, and the Gay Men's Health Crisis, together with brief descriptions of these resources; and
7. Complementary and alternative medicine (CAM) therapies – presently, a reiki practitioner provides free massages to BCPWA members.

The HIV/AIDS treatment information topics most widely covered in TIP's materials include starting and switching medications, ARV side effects, nutrition, alternative treatment therapies, new developments in treatments, and treatment guidelines (both provincial and international).

Decline in TIP Access

As shown in Figure 2, TIP's client tracking system for its peer counselling and treatment information hotline services shows a decline of 77% over the last six years, from 349 client consultations in 2003 to 79 client consultations in 2008. Sharp year-over-year declines occurred from 2003 to 2004 and in the last two years.

Figure 2: Number of TIP clients served: 2003 to 2008



This decline, believed to reflect corresponding declines in access to TIP's other HIV/AIDS treatment information resources, is assumed by TIP to be attributable to a number of interrelated factors, including:

- The use of the Internet as a resource to access health and treatment information is replacing the need for face-to-face interaction at community organizations;
- The general good health of many HIV-positive people today, because HAART has reduced the need for regular information and contact with ASOs;
- A sense of 'community' among HIV-positive people has diminished in recent years, contributing to lower levels of awareness, use and/or satisfaction with the services offered by TIP.

The Need for Research

Given the decline in access to TIP resources, there is some concern that HIV-positive people may not be as involved, connected or informed as they were in the past. By exploring the treatment information needs of HIV-positive British Columbians, TIP hopes to identify programming changes for it to better deliver treatment information to BCPWA's growing membership base and the wider HIV/AIDS community in British Columbia.

The findings from this research will inform BCPWA (and other similar organizations across Canada) in their efforts to effectively and proactively develop treatment information strategies to meet the needs of the HIV/AIDS community. HIV-positive people and AIDS Service Organizations will potentially benefit from the development of better HIV/AIDS treatment information delivery strategies and will also benefit from a better understanding of the various factors that contribute to HIV/AIDS treatment information access and use.

In the following section, themes from the academic literature provide additional insight into HIV/AIDS information-seeking behaviours that may impact TIP.

LITERATURE REVIEW

There are three purposes for the literature review: (a) to augment the background discussion and client assumptions regarding the decline in access to TIP resources with themes gleaned from previous academic research on the topic of HIV/AIDS treatment information; (b) to compare previous findings to those in this paper; and (c) to draw out insights or recommendations for TIP to consider going forward. Main themes are summarized next; the others follow later in the discussion section and the options section of this paper.

Themes

HIV/AIDS literature is limited with respect to the study of treatment information, where discussion focuses primarily on the following themes: (1) advantages and problems associated with the proliferation of treatment information on the Internet; (2) the contribution of the Internet to a shift in the HIV/AIDS 'community' from a physical space to a virtual one; (3) the different treatment information-seeking preferences and practices of HIV-positive people; and (4) barriers experienced by minority groups of HIV-positive people in accessing treatment information.

It is commonly recognized that HIV-positive people have come to rely on the Internet as one of their main sources of HIV/AIDS treatment information (Reeves, 2001; Kalichman et al, 2006; Hogan & Palmer, 2005; Kidd, 2006; Curioso & Kurth, 2007). While significant growth in the quantity of treatment information in the past decade has been advantageous in terms of increasing its accessibility, the sheer amount of information can also be overwhelming (Brashers, 2002; Taylor, 2002; James, 2006; Curioso & Kurth, 2007) and can be of questionable quality (Hogan & Palmer, 2005; Kidd, 2006).

The Internet may also be gradually displacing ASOs as the primary community space for HIV-positive people to 'connect' and share information. While Westacott (2008) has only recently championed the Internet as an underutilized space where community-building can happen, Flicker et al (2004) observe that HIV-positive people, especially youth, are already forming connections with other HIV-positive people through chat rooms, message boards and online personal ads specifically geared to HIV-positive people. In the past decade, there has also been an increasing trend in using the Internet's varied dissemination means (e.g. listservs, patient education bulletins, clinical trials information) to strengthen HIV/AIDS advocacy activities (Reeves, 2001; Brashers, 2002; Kalichman et al, 2006).

Taylor (2002) notes that each HIV-positive person is on a point somewhere along a continuum of information-seeking behaviour. This point changes for each person over time in the context of his or her shifting physical and emotional health and day-to-day priorities. On the one end of the continuum, there are HIV-positive people who avoid seeking information about their condition and its treatment altogether, because it is viewed as too confusing, upsetting or depressing. At the other end, there are HIV-positive people who actively and regularly seek information because they believe that it is empowering and that it contributes to improved health outcomes (Hogan & Palmer, 2005; Harris & Veinot, 2004; DHHS Report; Taylor, 2002). Reeves (2001) also found that newly diagnosed HIV-positive people are more haphazard in their search for treatment information while people that have been living with HIV for longer are more focused with respect to the topics they seek information about and the sources of information they favour.

While research does not show how much treatment information is optimal or ‘enough,’ it does reveal that differences exist in the ways that HIV-positive people prefer to receive their treatment information. Studies are divided between those that conclude HIV-positive people prefer personalized, face-to-face delivery of treatment information from support groups or physicians (Sseruma, 2007; Taylor, 2002; Harris & Veinot, 2004) and those that demonstrate HIV-people prefer to get their information from the Internet as a ‘one-stop shop’ (Reeves, 2001; Kalichman et al, 2006; Flicker et al, 2004). No research has been undertaken to establish that one method is more beneficial than another (i.e. no best practices in the academic literature), but questions have been raised about whether or not these differences might relate to culture, age, or literacy and income level disparities (Flicker et al, 2004).

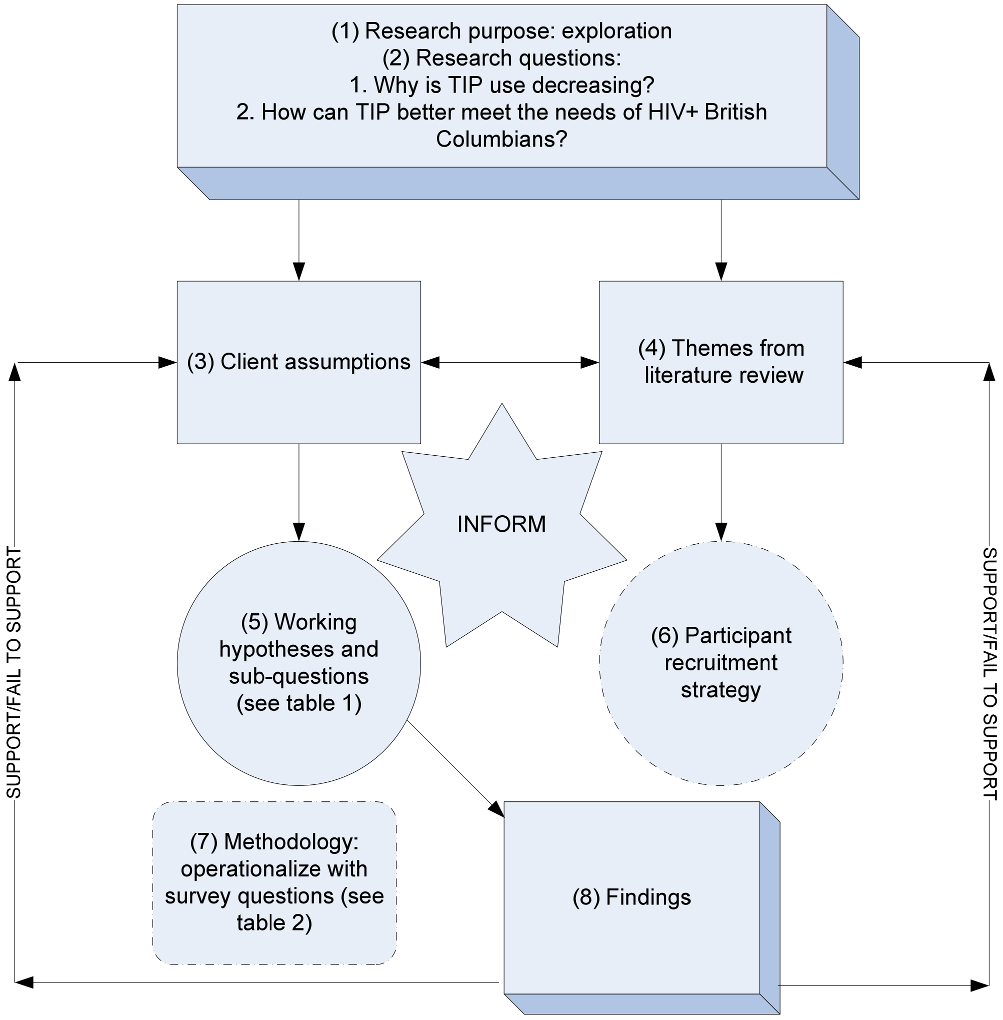
Not all target audiences for HIV/AIDS treatment information are easily reached by any method. Some groups of HIV-positive people find it difficult to obtain treatment information in accessible formats and appropriate literacy levels because the language of treatment information is too scientific, or because it is not culturally appropriate or available in enough minority languages (DHHS working group; Harris & Veinot, 2004; Curioso & Kurth, 2007). Stigma and discrimination associated with being HIV-positive are also barriers for accessing HIV treatment information because some HIV-positive people fear the consequences of being ‘found out’ (Sseruma, 2007, Harris & Veinot, 2004; Ibanez-Carrasco, 2007). Noring et al (2001) suggest that difficult-to-reach and other marginalized populations, such as IV drug users and sex trade workers, are deprived of information about HIV treatment because they are too transient and can also be disadvantaged by multiple barriers such as poverty and mental illness. Findings like the ones reported in the literature support the recommendation made by the DHHS Working Group (2007) and Harris & Veinot (2004) that existing models of information dissemination from community-based organizations be investigated and evaluated for their efficacy in delivering treatment information to the many varied sub-groups of HIV-positive people.

The next section shows how the assumptions from the client and the themes from the literature review form a key part of the conceptual framework (or ‘roadmap’) used to guide the research for this paper.

CONCEPTUAL FRAMEWORK

The creation of a conceptual framework gives coherence to a research paper by connecting the research purpose and questions to the other component pieces of the research. As shown in Figure 3, the conceptual framework for this paper begins with (1) the research purpose and (2) the research questions.

Figure 3: Conceptual framework diagram



The purpose of this research is to explore the HIV/AIDS treatment information needs of HIV-positive British Columbians. The two main research questions are:

1. Why is TIP use decreasing?
2. How can TIP better meet the needs of HIV+ British Columbians?

The client's assumptions (3) about why access to TIP is declining together with themes (4) that emerged from a review of the literature informed the development of both (5) working hypotheses and sub-questions to answer the main research questions, and (6) a strategy to recruit participants for the research. Table 1 lists the working hypotheses and sub-questions that were developed to answer the two main research questions and indicates whether these were derived from the client's assumptions, the literature review, or both.

Table 1: Working hypotheses and sub-questions

Research Question	**Working Hypothesis/Sub-Question**	**Source**	
		Client	**Literature**
1. Why is TIP use decreasing?	**A.** The Internet is replacing the need for HIV+ people to have face-to-face interaction to obtain treatment information.	√	√
	B. HIV+ people don't seek treatment information when they feel well.	√	√
	C. HIV+ people are overwhelmed by too much treatment information.		√
	D. Stigma/isolation may prevent HIV+ people from seeking treatment information.		√
	E. HIV+ people aren't aware of TIP.	√	
	F. HIV+ people aren't likely to use TIP as a source of treatment information.	√	
	G. TIP isn't providing relevant information.	√	
2. How can TIP better meet the needs of HIV+ British Columbians?	**H.** What among TIP's main treatment information topics do HIV+ people consider to be most important?	√	√
	I. What other treatment information topics are important to HIV+ people?	√	
	J. What else might TIP provide to meet the treatment information needs of HIV+ people?	√	

In the next section, the methodology (7) shows the specific survey questions that were asked to test the working hypotheses and answer the research sub-questions. The statistic (e.g. frequency distribution, percentage, mean score, chi-square test) used to support or fail to support each of the working hypotheses in the findings (8) is provided in Appendix D.

METHODOLOGY

Operationalization of Conceptual Framework

To operationalize the conceptual framework, a standard survey (refer Appendix A) was created. The client's initial assumptions and questions, together with the themes that emerged from the literature review, informed the development of the 25 questions in the survey. A small group of volunteers tested the survey and provided feedback that was incorporated into its final version, which included a mix of Likert scale questions, closed-ended questions, and open-ended questions. Table 2 demonstrates how the working hypotheses and sub-questions from the conceptual framework are connected to the research methodology ("operationalized") through specific survey questions.

Table 2: Operationalization of conceptual framework

Working Hypothesis/Sub-Question	**Survey Question(s)**
A. The Internet is replacing the need for HIV+ people to have face-to-face interaction to obtain treatment information.	**Q1.5b** I can usually find the treatment information I am looking for on the Internet. **Q1.5d** I prefer to participate in face-to-face discussions about HIV/AIDS treatment information.
B. HIV+ people don't seek treatment information when they feel well.	**Q1.5e** I look for HIV/AIDS treatment information even when I feel well.
C. HIV+ people are overwhelmed by too much treatment information.	**Q1.5c** I am overwhelmed by "too much information" about HIV/AIDS treatment.
D. Stigma/isolation may prevent HIV+ people from seeking treatment information.	**Q3.11a** I feel "connected" to other people in the HIV/AIDS community. **Q3.11.b** I feel isolated/stigmatized by my HIV/AIDS status.
E. HIV+ people aren't aware of TIP.	**Q2.1** Are you aware of the following BCPWA Treatment Information Programs and Services?
F. HIV+ people aren't likely to use TIP as a source of treatment information.	**Q1.3** Please rank the following six sources of HIV/AIDS treatment information in order from the one you would most likely use to the one you would least likely use. **Q1.4** Do you rely on any sources of HIV/AIDS treatment information other than the ones listed in question 1.3? **Q2.2** How frequently do you access the following BCPWA Treatment Information Programs and Services?

Working Hypothesis/Sub-Question	**Survey Question(s)**
G. TIP isn't providing relevant information.	**Q2.3** Please think of the most recent time you accessed one of BCPWA's Treatment Information Programs or Services. Which one of the following programs or services did you access? **Q2.4** Please think of your experience with the program or service you listed in question 2.3 and indicate to what extent you agree with the following statements.
H. What among TIP's main treatment information topics do HIV+ people consider to be most important?	**Q1.1** Please rank the following five HIV/AIDS treatment information topics in order from the one that is currently most important to you to the one that is least important to you.
I. What other treatment information topics are important to HIV+ people?	**Q1.2** Are there any HIV/AIDS treatment information topics not listed in question 1.1 that are important to you?
J. What else might TIP provide to meet the treatment information needs of HIV+ people?	**Q2.5** What needs do you have for your own well-being and support in addition to BCPWA's current Treatment Information Programs and Services? **Q3.4** When in your experience with HIV/AIDS would you say treatment information has been most helpful?

Conducting Online Surveys

The survey was administered online, hosted by Infopoll, a Canadian online survey software and services provider. Using an online survey tool may help to recruit more participants when the research being conducted is sensitive (Van Selm & Jankowski, 2006) and can be more efficient than paper-based surveys in terms of data collection and analysis and convenience for respondents. Van Selm and Jankowski (2006) suggest that the same principles that guide the conduct of conventional surveys can be applied to online surveys. With respect to this survey, the primary sampling challenges (the survey used a non-probability sample and was susceptible to selection bias) would have been the same regardless of whether the survey was online or paper-based. These challenges are further discussed later in this paper.

Participant Recruitment

Strategy

The online survey was available for completion over an 8-week period beginning March 1, 2009 and ending April 26, 2009. Participation in the survey was voluntary and respondents were not required to provide any information that identified them personally. Participants were recruited by asking 22 ASOs (refer Appendix B) throughout the province to advertise the survey by (a) making one-page recruitment flyers (refer Appendix C) available to their clients; (b) forwarding the survey link, where appropriate, to potential respondents by email; and (c) posting weblinks to the online survey, if possible, on their websites. The recruitment flyer explained the context and benefits of the research and invited only HIV-positive residents of British Columbia to complete the survey. Initial contact with the ASOs was by email invitation. Follow-up email reminders were sent to each of the ASOs twice during the survey period.

As one of the 22 ASOs, BCPWA also promoted the survey by enclosing the recruitment flyer in a general information mail-out to 1,500 members and by providing a weblink to the survey in its weekly e-news bulletin and on its online treatment information blog. Recruitment flyers were also distributed at two HIV/AIDS-related conferences in Vancouver during the survey period: the first, Positive Gathering, was attended by approximately 200 HIV-positive people; and the second, Canadian Association of HIV/AIDS Researchers (CAHR), was attended by approximately 750 people. Finally, advertisements for the survey were placed in the February/March issue of *living+*, BCPWA's treatment information magazine (circulation 3,000) and in the March 11, 2009 issue of *xtra west*, Vancouver's biweekly gay and lesbian newspaper (circulation 30,000). No compensation was provided to respondents. By the end of the survey period, 3,000 flyers had been distributed.

Sampling Limitations

Several limitations exist from the use of the sampling method described above. First, in addition to the lack of available data on the prevalence of HIV infection, privacy concerns and social sensitivities around being HIV-positive render it impossible to randomly sample the population of HIV-positive people in British Columbia. Strict privacy legislation (passed in BC in 2006), together with individual ASO by-laws concerning member/client privacy, prohibit direct access to the population of HIV-positive people. Second, the use of what was largely a convenience sample prevents the survey findings from being generalized to the larger population of HIV-positive people. Third, a response rate could not be calculated since it is impossible to know how many people were ultimately made aware of the survey through the various advertising methods used. Finally, no controls were in place to ensure that only HIV-positive British Columbians actually completed the survey and that there were no repeat submissions. Concern for the latter limitation is, however, mitigated by the lack of any known incentive for repeat submissions or for non-HIV-positive people to participate.

Data Collection Procedures

Survey respondents were required to answer all the survey questions, except open-ended ones that asked for a written response. Data from each completed survey was stored, with several layers of privacy protection, in a database on Infopoll's server. At the end of the survey period, Infopoll's built-in data analysis functions were used to perform frequency and cross tabulation calculations, which were used by the researcher to create charts and tables, calculate mean scores, and perform chi-square tests. These analyses represent the findings reported in the next section.

FINDINGS

A total of 128 surveys were completed over an 8-week period[3]. Table 3 shows the demographic characteristics of the sample.

Table 3: Demographic characteristics of sample

Category	Number of respondents	Proportion of sample
Gender		
Male	114	89%
Female	14	11%
Transgender	0	0%
Sexual orientation		
Gay	100	78%
Straight	23	18%
Lesbian	1	1%
Bisexual	4	3%
Age		
Under 20	0	0%
20 to 29	4	3%
30 to 39	15	12%
40 to 49	57	45%
50 to 59	40	31%
60 or over	12	9%
Number of years HIV-positive		
Under 1 year	4	3%
1 to 5 years	24	19%
6 to 10 years	20	16%
11 to 20 years	37	29%
More than 20 years	43	34%
Treatment Regimen		
HAART	102	80%
Non-HAART	26	20%
Place of Residence		
City of Vancouver	72	56%
Lower Mainland (other than City of Vancouver)	29	23%
Northern BC	2	2%
Interior BC	16	13%
Vancouver Island	7	5%
Outside BC	2	2%

Findings to each of the working hypotheses and questions from the conceptual framework are presented next, in the same order they appear in the operationalization table.

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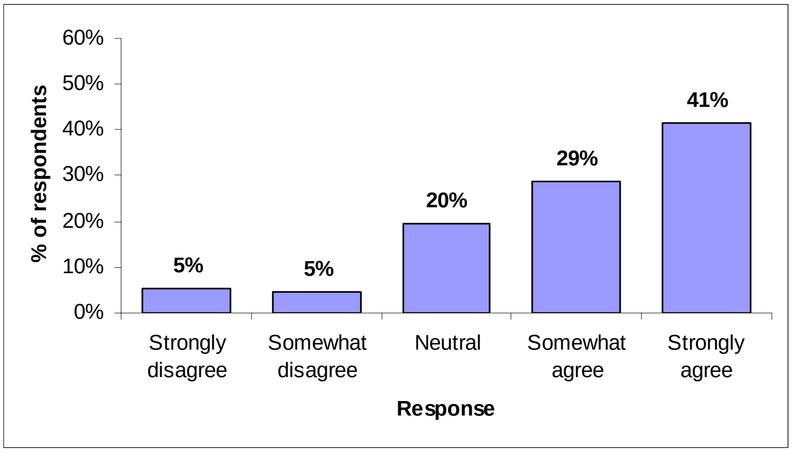
[3] By comparison, the sample size from study that employed a similar online survey method among HIV-positive people was 381 over 8 weeks for a Canada-wide survey (HKDP, 2008) and the sample size from a U.S. study that employed a similar participant recruitment method was 662 respondents from 10,500 distributed survey instruments over a 5-month period (Hogan & Palmer, 2005).

A. The Internet is replacing the need for HIV+ people to have face-to-face interaction to obtain treatment information.

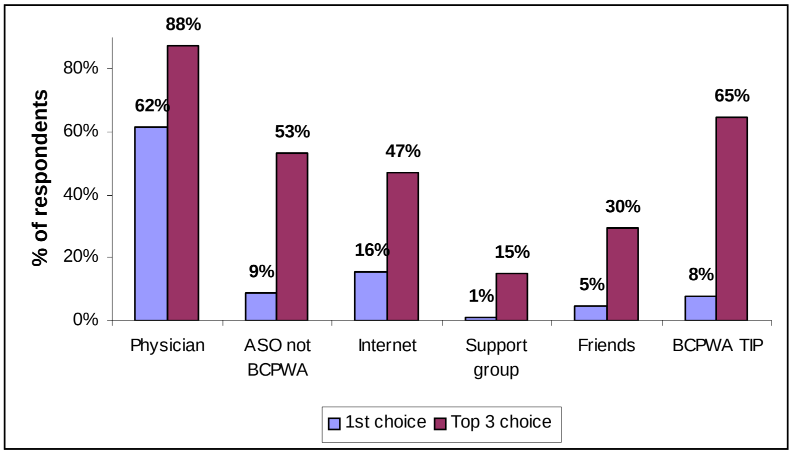
Survey question 1.5d asked respondents to indicate the extent to which they agreed with the statement "I prefer to participate in face-to-face discussions about HIV/AIDS treatment information." Figure 4 shows that overall, 70% of respondents either somewhat or strongly agree with the statement.

Figure 4: Prefer face-to-face discussions



The survey also included questions that assessed the Internet in terms of its popularity and reliability as a treatment information resource. First, survey question 1.3 asked respondents to rank six sources of HIV/AIDS treatment information in order from the one they would most likely use to the one they would least likely use. As shown in Figure 5, the Internet ranks fourth overall as a top-three choice among sources of treatment information HIV-positive people would most likely to use, behind physicians, BCPWA's TIP, and ASOs other than BCPWA.

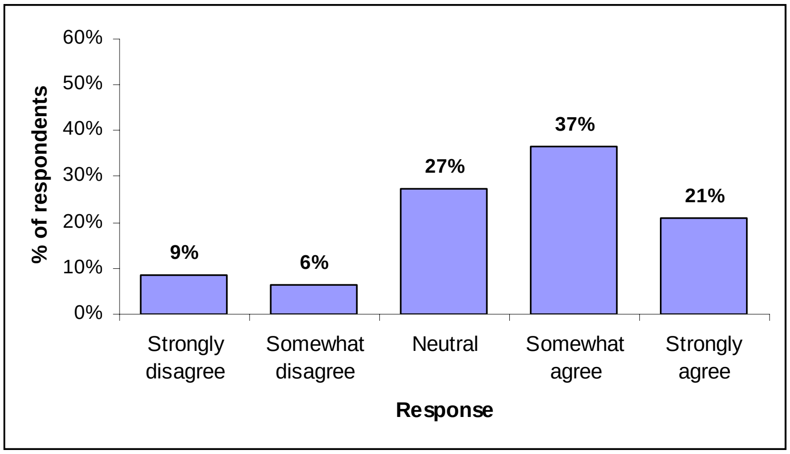
Figure 5: Sources of TI: first choice and top three choice



Second, survey question 1.5b asked respondents to indicate to what extent they agreed with the statement "I can usually find the information I am looking for on the Internet."

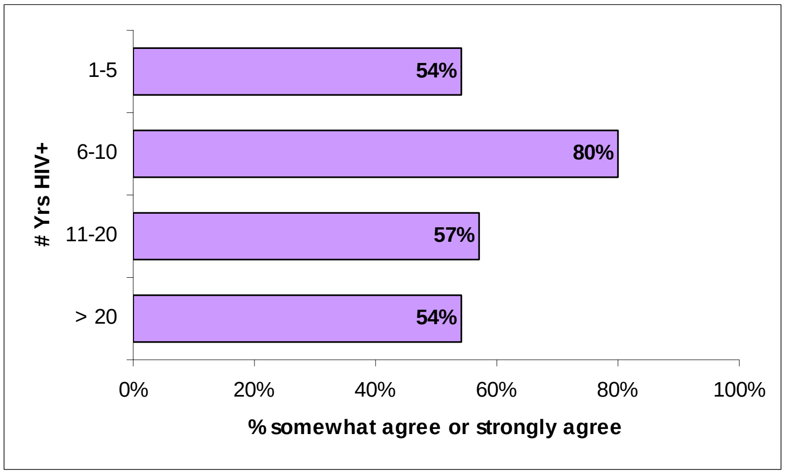
Figure 6 shows that overall, more than half, or 58% of respondents, either somewhat or strongly agree with the statement. Only 15% either somewhat or strongly disagree.

Figure 6: Can find information on Internet



Further analysis (see Appendix F) of the overall findings above revealed no significant relationships between a respondent's age and their preference for face-to-face discussions about treatment information. In addition, a comparison among groups of respondents that have been HIV-positive for longer than one year[4] showed that while just over half say they can usually find the information they are looking for on the Internet (shown in Figure 7), most agreed they preferred to participate in face-to-face discussions about HIV/AIDS treatment information (shown in Figure 8).

Figure 7: Can find information on Internet by years HIV+



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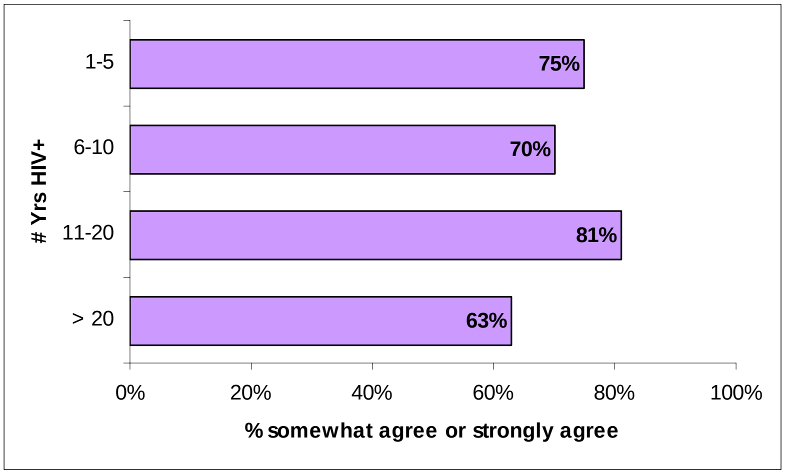
[4] Newly diagnosed (HIV-positive for less than 1 year) respondents are excluded from this analysis due to the low number of respondents in this category (n=4).

Figure 8: Prefer face-to-face discussions by years HIV+



The findings above demonstrate that a strong majority of HIV-positive people prefers face-to-face interaction to obtain HIV/AIDS treatment information. While the Internet appears to be considered reliable, it is not among the top three treatment information sources HIV-positive people are likely to use. Based on these findings, the working hypothesis "The Internet is replacing the need for HIV+ people to have face-to-face interaction to obtain treatment information" is not supported.

B. HIV+ people don't seek treatment information when they feel well.

Survey question 1.5e asked respondents to indicate the extent to which they agreed with the statement "I look for HIV/AIDS treatment information even when I feel well." Table 4 shows that nearly two-thirds, or 64% of respondents somewhat or strongly agree with the statement, while 19% somewhat or strongly disagree and 18% are neutral.

Table 4: Look for treatment information even when well

Response	% of overall respondents
Strongly agree	27%
Somewhat agree	37%
Neutral	18%
Somewhat disagree	10%
Strongly disagree	9%

Based on this finding, the working hypothesis "HIV+ people don't seek treatment information when they feel well" is not supported.

C. HIV+ people are overwhelmed by too much treatment information.

Survey question 1.5c asked respondents to indicate the extent to which they agreed with the statement "I am overwhelmed by 'too much information' about HIV/AIDS treatment." Table 5 shows that 39% somewhat or strongly agree with the statement, while 32% somewhat or strongly disagree and 30% are neutral.

Table 5: Feel overwhelmed by too much information

Response	% of overall respondents
Strongly agree	**15%**
Somewhat agree	**24%**
Neutral	**30%**
Somewhat disagree	**16%**
Strongly disagree	**16%**

Further analysis (see Appendix F) of the overall findings above revealed that people who agree they feel overwhelmed by 'too much information' do not agree they are knowledgeable about HIV/AIDS treatment information (X^2 (1,128)=9.70, p=0.00). Further, those overwhelmed by 'too much information' do not agree they can usually find the treatment information they are looking for on the Internet (X^2 (1,128)=4.69, p=0.03).

Based on these findings, the working hypothesis "HIV+ people are overwhelmed by too much treatment information" is partially supported.

D. Isolation/stigma may prevent HIV+ people from seeking treatment information.

First, *survey question 3.11a* asked respondents to indicate the extent to which they agreed with the statement "I feel 'connected' to other people in the HIV/AIDS community." Second, *survey question 3.11b* asked respondents the extent to which they agreed with the statement "I feel isolated/stigmatized by my HIV/AIDS status."

As shown in Figure 9, 56% of respondents overall agree they felt connected to the HIV/AIDS community, while 44% overall do not agree.

Figure 9: Feel connected to HIV/AIDS community

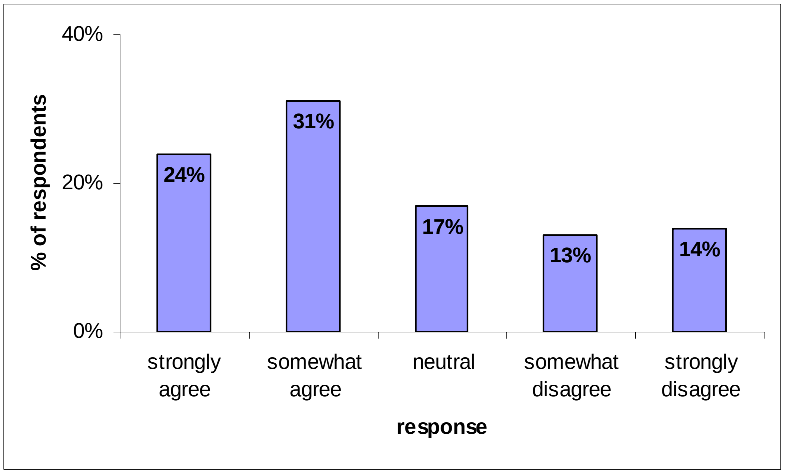
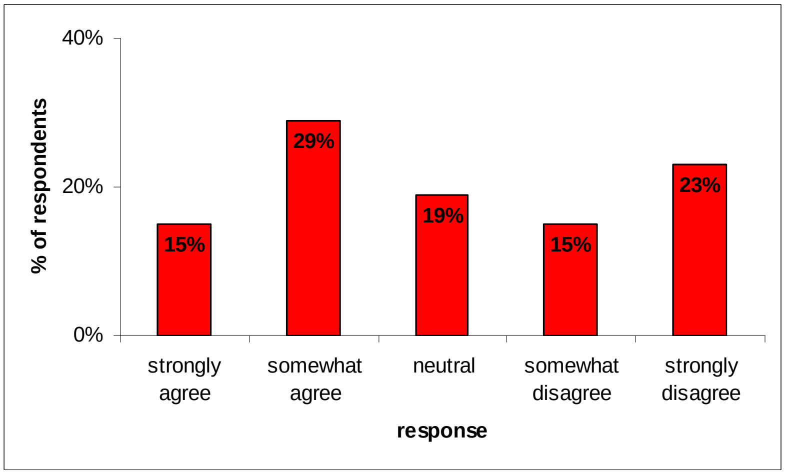


Figure 10 shows that 44% of respondents overall agree they feel isolated/stigmatized by their HIV/AIDS status, while 57% do not agree.

Figure 10: Feel stigmatized by HIV/AIDS status



The overall findings above were further analyzed to determine if differences exist among groups of HIV-positive people relating to feelings of isolation/stigma and if so, how these differences manifest in information-seeking behaviours. Figure 11 shows that straight HIV-positive people (39%) feel less connected to the HIV/AIDS community than non-straight (gay, lesbian and bisexual) HIV-positive people (59%). The difference between the two groups is not quite significant, but it is close (X^2 (1,128)=3.03, p=0.08).

Figure 11: Feel connected to HIV/AIDS community by sexual orientation

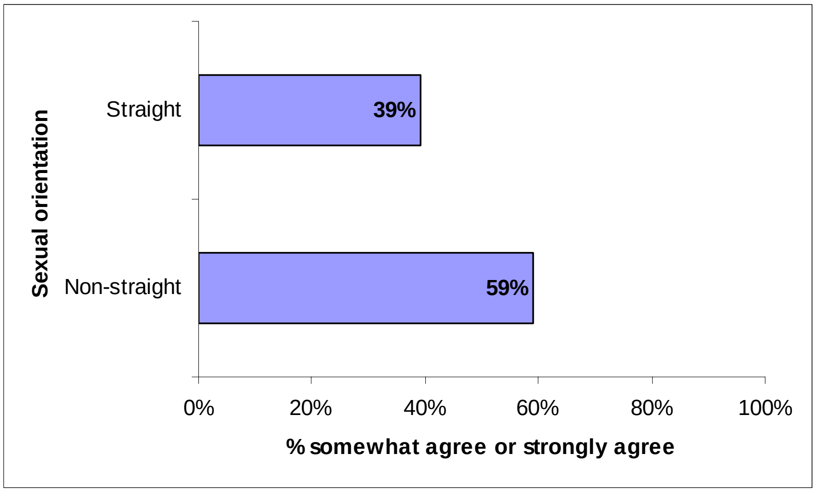
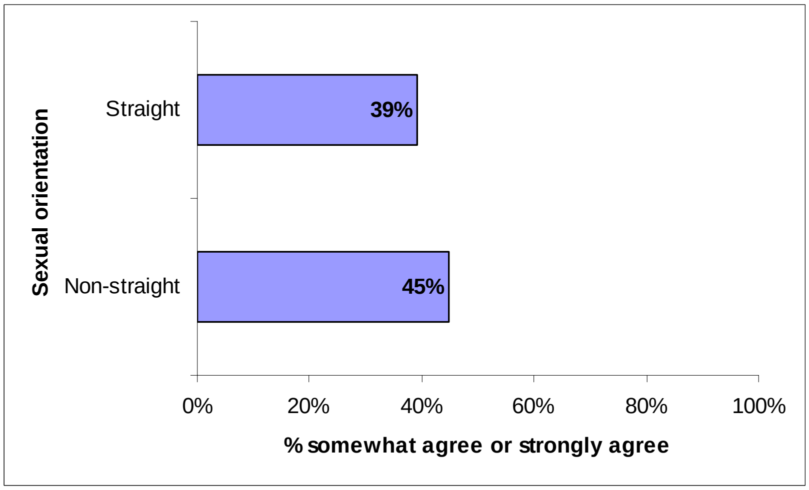


Figure 12 shows that 39% of straight HIV-positive people and 45% of non-straight HIV-positive people feel isolated/stigmatized by their HIV/AIDS status. The difference between the two groups is not significant (X^2 (1,128)=0.24, p=0.62).

Figure 12: Feel isolated/stigmatized by HIV/AIDS status by sexual orientation



With respect to possible influences of isolation/stigma on treatment information-seeking behaviour, further analysis (see Appendix F) reveals that while straight respondents feel less connected to the HIV/AIDS community, there is no significant relationship between a respondent's sexual orientation and the type of TIP program they recently accessed. At the same time, respondents' feelings of connectedness or of isolation/stigmatization do not appear to be related to any of the following:

- Preference for face-to-face discussions about HIV/AIDS treatment information;
- Whether or not they have accessed a TIP program; or
- If a TIP program *was* accessed, the *type* of program that was accessed.

The findings above show that while nearly half of survey respondents agree they feel isolated/stigmatized by their HIV/AIDS status and nearly half do not feel connected to the HIV/AIDS community, those feelings do not necessarily influence treatment information seeking behaviours. Based on these findings, the working hypothesis "Isolation/stigma may prevent HIV+ people from seeking treatment information" is not supported.

E. HIV+ people aren't aware of TIP.

Survey question 2.1 asked respondents to indicate if they were aware of BCPWA's six TIP programs and services. Table 6 compares the level of awareness for each TIP program/service by geographical location[5].

Table 6: Awareness of TIP programs by location

	Island	Interior	Lower Mainland	Van City	Overall
Treatment peer counselling	86%	81%	66%	78%	76%
Online treatment information blog	29%	44%	31%	51%	46%
Treatment publications	86%	88%	80%	92%	88%
Treatment information hotline	57%	44%	45%	46%	46%
Community outreach forums	43%	57%	55%	71%	63%
Weblinks to online resources other than BCPWA	71%	57%	55%	69%	64%

A high level of awareness overall (more than 75%) exists for treatment peer counselling and treatment publications. Lower levels of awareness exist for community outreach forums and weblinks to other treatment information resources outside BCPWA (63% and 64% respectively). Less than half (46% each) of HIV-positive people are aware of TIP's online treatment information blog and treatment information hotline (46% each). Based on these findings, the working hypothesis "HIV-positive people aren't aware of TIP" is partially supported.

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[5] Respondents from Northern BC are excluded from this analysis due to the low number of respondents in this category (n=2).

F. HIV+ people aren't likely to use TIP as a source of treatment information.

Survey question 1.3 asked respondents to rank six sources of HIV/AIDS treatment information in order from the one they would most likely use to the one they would least likely use. In conjunction with the findings shown in Figure 5 earlier in this paper, Table 7 shows that TIP ranks 2nd overall as the information source HIV-positive respondents would most likely use. TIP was a top three choice by 65% of respondents. Of these, 10 respondents (8%) ranked TIP as their first choice and 44 respondents (34%) ranked TIP as their second choice.

Table 7: Overall ranking of TIP as source of treatment information

RANK	# OF RESPONDENTS	% OF RESPONDENTS
1st	10	8%
2nd	44	34%
3rd	29	23%
4th	18	14%
5th	11	9%
6th	9	7%
Overall rank	**2 of 6**	

Table 8 shows that the length of time a person has been HIV-positive[6] does not appear to influence the ranking of HIV/AIDS treatment information sources he or she would most likely use. Physician ranks first across all categories, followed by BCPWA's TIP from four of five groups.

Table 8: Ranking of sources of treatment information by # yrs HIV+

	1 – 5 yrs	6 – 10 yrs	11 – 20 yrs	> 20 yrs
Physician	1	1	1	1
Other ASO	3	4	4	3
Internet	4	2	3	4
Support group	6	6	6	6
Friends	5	5	5	5
BCPWA TIP	**2**	**3**	**2**	**2**

Survey question 1.4 asked respondents if they relied on any sources of HIV/AIDS treatment information other than the ones listed in question 1.3. Respondents' verbatim answers (n= 22) were analyzed to identify common sources as summarized below.

Of the 22 responses, 13 were related to the question and identified additional sources of HIV/AIDS treatment information. Five (5) responses duplicated one of the choices from question 1.3 and four (4) others were not related to the question. Additional sources of

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[6] Newly diagnosed (HIV-positive for less than 1 year) respondents are excluded from this analysis due to the low number of respondents in this category (n=4).

HIV/AIDS treatment information (with the frequency of times mentioned in brackets) include:

- Pharmacy staff (4)
- Other magazines, newsletters, books (4)
- BCPWA's *living+* magazine (2)
- Library (2)
- Nurses (1)

To augment the preceding findings, survey question 2.2 asked respondents to indicate how frequently they accessed TIP's programs and services. Table 9 shows that overall, treatment publications have been accessed by 67% of respondents at least once. TIP's remaining programs and services have been accessed by less than half of the respondents at least once, with peer counselling and the treatment information hotline showing as the least ever accessed, at 17% and 11% respectively.

Table 9: Accessing TIP programs and services

TIP program or service	% ever accessed
Treatment peer counselling	17%
Online treatment information blog	23%
Treatment publications	67%
Treatment information hotline	11%
Treatment information community outreach forums	33%
Weblinks to online treatment information resources other than BCPWA	48%

Although some of TIP's information resources are rarely accessed, others are fairly well utilized. Combined with TIP's rank as second only to physicians as a preferred source of treatment information, the findings above indicate that the working hypothesis "HIV+ people aren't likely to use TIP as a source of treatment information" is not supported.

G. TIP isn't providing relevant information.

To understand if TIP programs and services are providing relevant treatment information, respondents were asked first, in survey question 2.3 to think of the most recent time they accessed one of BCPWA's Treatment Information Programs or Services and second, in survey question 2.4, to indicate the extent to which they agreed with four statements concerning their experience using the program or service. Table 10 shows that recently, TIP's treatment publications have been most frequently accessed, followed in order by community outreach forums, TIP's online blog, weblinks to other online resources, peer counselling and TIP's treatment information hotline.

Table 10: Ranking of TIP program or service by most to least recently accessed

Rank	TIP Program or Service	# of respondents	% of respondents
1	Treatment publications	37	50%
2	Community outreach forums	14	19%
3	Online blog	10	14%
4	Weblinks to other online resources	6	8%
5	Peer counselling	5	7%
6	Treatment information hotline	2	3%

With respect to the TIP program or service identified as the one most recently accessed, respondents were asked to indicate the extent to which they agreed with four statements concerning their experience with that program or service. Tables 11 and 12 show the average score (out of a maximum of 5.0) for each statement by TIP program or service. The higher the score, the more strongly respondents agreed with the statement.

Table 11: User assessment of TIP: average scores by TIP program or service (1)

Statement	Average score (max 5.0)		
	Treatment publications	Community outreach forums	Online blog
I found the specific treatment information I was looking for.	3.7	4.4	3.8
The information I received was relevant to the length of time I have been living with HIV/AIDS.	3.6	4.5	3.9
The information I received was relevant to my age group.	3.5	3.9	3.9
The information I received was relevant to my overall health situation.	3.9	4.1	3.8
Overall average score	**3.7**	**4.2**	**3.9**

Table 12: User assessment of TIP: average scores by TIP program or service (2)

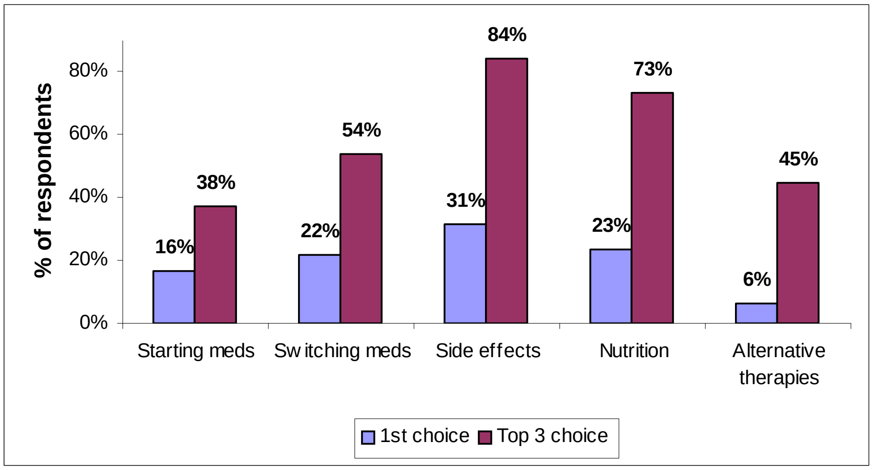
Statement	Average score (max 5.0)		
	Weblinks to other online resources	Peer counselling	Treatment information hotline
I found the specific treatment information I was looking for.	3.3	3.8	3.5
The information I received was relevant to the length of time I have been living with HIV/AIDS.	3.5	3.6	3.5
The information I received was relevant to my age group.	3.3	3.2	3.5
The information I received was relevant to my overall health situation.	3.5	3.8	3.5
Overall average score	**3.4**	**3.6**	**3.5**

The preceding tables show that, as gauged by the overall average score by TIP program or service, community outreach forums (4.2), followed by the online treatment information blog (3.9), are the most specific and relevant. The overall average scores of the remaining TIP programs are similar (in the range of 3.4 to 3.7) and indicate that on the whole, TIP programs and services are specific and relevant. Based on these findings, the working hypothesis “TIP isn’t providing relevant information” is not supported.

H. What among TIP’s main treatment information topics do HIV+ people consider to be most important?

Survey question 1.1 asked respondents to rank five HIV/AIDS treatment information topics in order from the one that is currently most important to them to the one that is least important. As shown in Figure 13, side effects and nutrition rank highest as both the first choice of respondents and as a top three choice. There is no treatment information topic that is of little concern to respondents.

Figure 13: TI Topics: % first choice and top three choice



There does not appear to be a notable difference in responses with respect to the length of time a person has been HIV-positive[7]. As shown in Table 13, side effects and nutrition remain the most important across all categories, while switching medications and alternative treatment therapies rank lower.

Table 13: Importance of TI topics: ranking by # yrs HIV+

	1 – 5 yrs	6 – 10 yrs	11 – 20 yrs	> 20 yrs
Starting meds	3	5	2	5
Switching meds	5	3	5	3
Side effects	**1**	**1**	**1**	**1**
Nutrition	**2**	**2**	**3**	**2**
Alt therapies	4	4	4	4

I. What other treatment information topics are important to HIV+ people?

Survey question 1.2 asked respondents if they considered any HIV/AIDS treatment information topics not listed in question 1.1 important to them. Respondents' verbatim answers (n=46) were analyzed to identify common topics and are summarized below.

Of the 46 responses, 29 were related to the question while eight (8) responses duplicated one of the choices from question 1.1. Nine (9) responses were not related to the question.

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[7] Newly diagnosed (HIV-positive for less than 1 year) respondents are excluded from this analysis due to the low number of respondents in this category (n=4).

The related answers identified the following treatment information topics (with the frequency of times mentioned in brackets):

- Interaction of HIV medications with other drugs, foods, nutritional supplements (7)
- Long-term effects of HAART (3)
- Information about new HIV drugs, vaccines (3)
- Adherence to HIV medications (2)
- HIV treatments and mental health (2)
- Supplements – vitamins, minerals (1)
- Treatments for HIV-related cancers (1)
- Resistance to HIV medications (1)
- Complementary (not alternative) therapies (1)
- HIV treatments and aging (1)
- HIV treatments and STDs (1)
- What to expect after contracting HIV (1)
- HIV treatment costs (1)
- Treatment of conditions associated with HIV, e.g. cholesterol, lipodystrophy (1)
- Information about access to HIV medication for new residents to BC (1)
- Non-traditional modalities w/dr support (1)
- Immune reconstitution syndrome (1)

To augment the data for this section, *survey question 3.4* asked respondents to indicate when in their experience with HIV/AIDS treatment information has been most helpful.

Table 14: Time that treatment information has been most helpful

Answer	# of respondents	% of respondents
Soon after diagnosis	41	32%
After starting ARV therapy	39	31%
As I age	18	14%
When I was in medical crisis	10	8%
When I was in emotional crisis	6	5%
Other (switching medications)[8]	6	5%

As shown in Table 14, treatment information is most helpful to HIV-positive people soon after their diagnosis (32%) and after starting ARV therapy (31%). HIV-positive people also find treatment information to be most helpful as they age (18%).

J. What else might TIP provide to meet the treatment information needs of HIV+ people?

Survey question 2.5 asked respondents if they had any needs for their own well-being and support in addition to BCPWA's current Treatment Information Program and Services.

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[8] Verbatim responses to the answer "other" were analyzed. Of 14 responses, 6 were related to switching medications. The remaining 8 responses were not related to the question.

Respondents’ verbatim answers (n=59) were analyzed to identify common themes and are summarized next.

Of the 59 responses, nine (9) responses were unrelated to the question. Table 15 groups the 50 related responses[9] by four topic types: treatment information support, emotional and physical wellness support; financial and other support; and organizational support tools.

Table 15: Respondent needs in addition to TIP

Treatment information support (21)	Emotional and physical wellness support (11)
Peer support when starting meds Information about drug toxicity levels Alt and CAM at FFL Nutrition Naturopathic Long-term impact of HAART Comprehensive summaries of TI topics Accessing nutritionist Monthly bulletins of facts regarding new issues More peer counselling in my community How to read and understand blood test results Keeping abreast of new developments and taking precautions while in good health but not on meds Access to native traditional healer More information about sweat lodges Vitamin supplementation Neuro-cognitive issues with regard to HAART Adherence issues with regard to HAART Impact of living in city v. country on health HIV meds and heart disease, diabetes Info about treatment challenges and issues for people new to BC Updates on special issues like meds toxicities; world health issues	Dealing with depression Dealing with aging Emotional support Social support from other HIV+ people Social support from other hetero people Relationship and sex counselling Problems with aging Fitness support More retreats Sexuality and sexual dysfunction Spiritual strength
Financial and other support (5)	**Organizational support tools (4)**
Financial assistance Housing support Food Vehicle Dental work	A greater net covering HIV community of all services Memberships in other organizations More activities outside daytime hours Make it easier for those out of the loop

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[9] The number of responses in this table does not add up to 50 because some answers were mentioned more than once.

DISCUSSION

Why is TIP use decreasing?

As summarized in Table 16, one of four working hypotheses related to behaviours and feelings that may influence HIV/AIDS treatment information seeking is partially supported by the survey findings.

Table 16: Working hypotheses related to influences on treatment information seeking

Working hypothesis/sub-question	Finding
A. The Internet is replacing the need for HIV+ people to have face-to-face interaction to obtain treatment information.	Not supported.
B. HIV+ people don't seek treatment information when they feel well.	Not supported.
C. HIV+ people are overwhelmed by too much treatment information.	Partially supported.
D. Stigma/isolation may prevent HIV+ people from seeking treatment information.	Not supported.

Perhaps surprisingly considering its general popularity, the Internet does not rank highly among survey respondents as a preferred source of treatment information. While the Internet is generally considered a reliable source of treatment information, people that feel overwhelmed by too much information do not feel they can find the information they are looking for on the Internet. Too much information also contributes to feeling less knowledgeable about HIV/AIDS treatment information.

Contrary to TIP's assumptions, HIV-positive people also continue to seek treatment information even when they feel well, and most HIV-positive people prefer to participate in face-to-face discussions about treatment information. Although nearly half of HIV-positive people feel isolated/stigmatized by their HIV/AIDS status, there is no evidence that this feeling influences treatment-information seeking behaviours.

As summarized in Table 17, one of three working hypotheses related to TIP's delivery of treatment information is partially supported by the survey findings.

Table 17: Working hypotheses related to TIP's delivery of treatment information

Working hypothesis/sub-question	Finding
E. HIV+ people aren't aware of TIP.	Partially supported.
F. HIV+ people aren't likely to use TIP as a source of treatment information.	Not supported.
G. TIP isn't providing relevant information.	Not supported.

Survey data shows that a generally high level of awareness exists among HIV-positive people across British Columbia for four of TIP's six main programs and services: treatment peer counselling, treatment publications, community outreach forums and weblinks to other treatment information resources outside BCPWA. Of these, treatment publications and community outreach forums were specified as the services that respondents most recently accessed at TIP. Awareness was lower for TIP's online blog and treatment information hotline; these two services also showed low levels of historical and recent usage.

Physicians were the first choice among respondents of the main source that HIV-positive people go to for HIV/AIDS treatment information. This is consistent with previous findings in the literature, which show that the main sources people go to for HIV/AIDS treatment information have changed little over the last ten years. In 1999, BCPWA's *you told us* survey showed that an individual's doctor was the top source of treatment information for HIV-positive people across all regions of British Columbia. More recently, Hogan and Palmer (2004) reported that doctors were the first choice of HIV-positive people as a treatment information source, followed by HIV-positive counsellors. Last year in Canada, respondents to HKDP's (2008) survey said they looked to their physician and their local ASO as the two leading sources of information about HIV and its treatments. TIP's rank in this survey, as the second most likely source of treatment information a respondent would use, continues this trend of earlier findings.

The relevance of information provided by a TIP program or service can be considered as a measure of satisfaction with that program or service. Community outreach forums received high scores from respondents along the three dimensions of relevance (age, overall health, and length of time living with HIV) they were asked to assess. Each of the other programs and services received lower, but similarly adequate, scores.

How can TIP better meet the needs of HIV+ British Columbians?

Table 18 summarizes the findings for three sub-questions related to how TIP can better meet the needs of HIV+ British Columbians.

Table 18: Summary of treatment information topics of importance

Working hypothesis/sub-question	Finding
H. What among TIP's main treatment information topics do HIV+ people consider to be most important?	Nutrition and side effects rank highest by survey respondents among the treatment information topics of importance to HIV-positive people. These are followed by switching medications, starting medications, and alternate treatment therapies. The importance of these topics does not vary widely according to the number of years a person has been HIV-positive, except for people that have been

Working hypothesis/sub-question	Finding
	newly diagnosed with HIV. Not surprisingly, this group lists starting medications as the treatment information topic most important to them. When asked to specify the time of life when treatment information has been most important, one-third of respondents answered "soon after diagnosis" and another one-third answered "after starting ARV therapy."
I. What other treatment information topics are important to HIV+ people?	Survey respondents also listed other treatment information topics of importance, including the interaction of HIV medications with other drugs, foods, and nutritional supplements, the long-term effects of using HAART, learning about new HIV drugs and vaccines, and adherence to HIV medications.
J. What else might TIP provide to meet the treatment information needs of HIV+ people?	Refer table 15.

Considerations and implications for TIP

Any discussion of the implications for TIP must recognize that: (a) in addition to the methodological limitations discussed earlier in this paper, the findings from the survey must be considered in light of the fairly homogeneous respondent sample; and (b) since only two of the working hypotheses were partially supported by the survey findings, the specific reasons for declining access to TIP programs and services remain partly unknown.

From the demographic characteristics of the sample, the survey has largely made it into the hands of treatment-experienced gay males over the age of 40. Unfortunately, insufficient data exists to make accurate comparisons between the sample and the population of HIV-positive people in British Columbia. The BCCDC has data on the *incidence*[10] of HIV in British Columbia (i.e. the number and rate of new positive HIV tests over a certain period), but no up-to-date data exists on the *prevalence* of HIV in British Columbia (i.e. the number and rate of people currently living with HIV). A comparison of the sample to BCPWA's membership base (see Appendix E) shows some similarities in age and geographical location, but the sample seems to under-represent straight people and females. Newly diagnosed HIV-positive people were also barely reached (n=4), so the survey findings are not necessarily representative of all HIV-positive people or of sub-groups of HIV-positive people.

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[10] From 2001 to 2007, there were 2,849 cumulative positive HIV tests in British Columbia. Of these, 55% were in the <40 age group and 45% were in the >40 age group. This statistic cannot be directly compared to the number of people in the sample or to the number of BCPWA members.

Nevertheless, the views of the respondent sample are relevant because this demographic, which makes up a large part of BCPWA's membership, provided evidence to refute most of the assumptions for declining usage of TIP's programs and services. In doing so, this core group has provided TIP with a better understanding of how its particular treatment information needs can be met. By meeting these needs, TIP may find that this group will access TIP programs and services more frequently.

The finding that most HIV-positive people from the sample prefer to participate in face-to-face discussions about treatment information has key implications for service delivery at TIP. Since both treatment peer counselling and community outreach forums are predicated on face-to-face interaction, each of these services has the potential to be better utilized going forward. Each also received favourable ratings from recent users with respect to the relevance and specificity of the treatment information provided. The success of these services, like that of all other information resources, will depend on how quickly TIP recognizes treatment information topics relevant to different sub-groups of HIV-positive people, and on how well this information is disseminated and discussed by its workshop facilitators and peer counsellors.

Although the Internet was not highly favoured by survey respondents[11] as a treatment information resource, TIP might benefit future treatment information seekers by building on the Internet mechanisms it currently uses. There is a growing body of evidence in the literature that shows HIV-positive people, particularly youth, have begun to use the Internet as a 'one-stop-shop' for many different community-building reasons, including seeking and sharing treatment information (Flicker et al, 2004; Kalichman et al, 2006; Harris & Veinot, 2004). In support of this evidence, this survey showed that HIV-positive people under the age of 40 access Internet-based treatment information delivery methods such as TIP's online blog and weblinks to other Internet resources (X^2 (1,128)=4.58, p=0.03). Considered together with concerns over information overload and the quality of information found on the Internet, there are also calls in the literature for better tools to assist with HIV/AIDS treatment information dissemination. Kidd (2006) proposes that treatment information seekers limit their Internet searches to sites that are recognized authorities or to those recommended by trusted leading experts. To this end, TIP could act as a key resource by consulting the resources it lists in its online weblinks section and bringing forward key news and information for publication on its online blog or webpage. By directing treatment information seekers to reliable, high-quality, topical Internet resources, the potential exists for TIP to provide a valuable complement to the services it provides in face-to-face settings.

From the demographic profile of the survey respondents, it appears that while people living with HIV for a number of years continue to access TIP, the newly diagnosed do not. Two-thirds of respondents indicated that treatment information was most helpful in their lives either soon after diagnosis or after starting ARV therapy. It can be reasonably assumed that this will remain the case, so TIP may wish to focus on connecting the

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[11] Based on the wording in the recruitment flyer, HIV+ people that don't feel they need better access to HIV/AIDS treatment information may have selected out of participating in the survey. It is possible that this group of people may prefer the Internet to other information resources.

newly-diagnosed to treatment information while still directing some resources toward the group of treatment-experienced HIV-positive people it largely serves at present. Of the group of respondents that was on a HAART regimen, 30% missed doses at least once or twice a month. This suggests that adherence to an individual's ARV regimen is a treatment information topic TIP should give particular attention to. This insight is shared by the DHHS (2001) and by Hogan and Palmer (2005) who state that it "may be possible to promote adherence through explicit information about the experience of treatment" (p. 438).

Since most survey respondents specified that they look for HIV/AIDS treatment information even when they feel well, TIP can be a vital information resource throughout the 'life-cycle' of living with HIV. Given that HIV is now a decades-long journey for most people, the range of important HIV/AIDS treatment information topics has widened beyond traditional topics such as medications, nutrition and side effects. While these remain critical for HIV-positive people to be aware of, particularly when they are newly diagnosed or when they are starting a medication regimen, new topics continue to emerge as HIV-positive people are living healthy lives both on and off HAART. As learned from the survey respondents, HIV-positive people now want comprehensive treatment information on topics such as HIV and aging, long-term implications of ARV use, and how to better integrate complementary and alternative therapies into the routines of daily life.

Further research that targets sub-groups not well represented in this survey sample, as well as non-users of TIP, may prove beneficial in learning ways that TIP can better deliver HIV/AIDS treatment information. There are recommendations in the literature regarding some methods (such as making treatment information publications culture-specific and providing culture-specific peer support) that might be used to deliver treatment information to different sub-groups, but as Harris and Veinot (2004) point out, no research has been undertaken to determine the effectiveness of these methods. Since the homogeneity of the survey sample suggests that TIP may not be reaching some of British Columbia's smaller, culturally distinct or marginalized HIV-positive communities, further research could uncover reasons, more specific than the ones explored in this survey, for declining usage of TIP services. Answers to questions asked of minority or marginalized groups regarding the effectiveness of different information dissemination methods may allow TIP to focus some of its resources in future on the development of community-appropriate treatment information programming.

OPTIONS

Together with insights from the preceding discussion, the survey's results have been used to identify the following options for TIP to consider as it plans its future programming.

1. Complement survey findings with additional research

The survey's findings represent a broad base of data that can be used to pose further questions and collect additional qualitative information for a richer understanding of the treatment information needs of HIV-positive British Columbians. Focus groups, which have often been used to conduct research in the HIV/AIDS community (African HIV Policy Network, 2004; Sseruma, 2007; Taylor et al, 2008), can be used for this purpose. For TIP, the main intent of the focus groups would be to:

a. Clarify and discuss the issues raised from the survey findings to gain additional insights; and
b. Ask questions, similar to the ones from the survey, of HIV-positive people not reached by the survey (for example, non-users of TIP, people newly diagnosed with HIV, and straight males and females).

Preparation for the focus groups would entail consulting with other stakeholders (such as a TIP working group and the BCPWA Board of Directors) after their review of this report to identify specific groups to target, topics to discuss and questions to ask at the focus groups. Much of the planning for the focus groups could take place over the summer months for the groups to be conducted during October and November. A supplementary report to this one could be written by the end of the year. The chief benefit of this additional research will be the contribution it makes in creating a more complete picture to help with future TIP programming and resource allocation decisions. Additionally, supplementary findings to the ones in this paper will help in reaching agreement about other potential courses of action, including the ones described below.

2. Implement programming changes for core membership

The respondents to the survey, despite being a fairly homogeneous sample, have provided rich data to inform viable changes to the way TIP provides service to this core demographic (i.e. treatment experienced HIV-positive people over the age of 40). Largely in good health, this group has indicated that they continue to seek information when they feel well, and that they prefer to participate in face-to-face discussions about treatment information. In addition, they have identified the treatment information topics that are important to them together with some additional topics of interest.

Given this information, in the next six months, TIP can draw upon its existing infrastructure to plan and deliver programming that specifically targets treatment-experienced HIV-positive people, particularly those over the age of 40. A short time frame is recommended because it is important to demonstrate that the survey findings, and the feedback provided by the survey respondents, are being acted upon. Approaches to targeted programming could include planning one or two community outreach forums (which TIP respondents rank highly in terms of relevance) facilitated by outreach volunteers to present information to attendees on specific issues of primary interest to this group. According to the survey results, these issues include the effects of long-term ARV use on the body, the interaction of HIV medication with other drugs and food, and how to better adhere to treatment regimens. The forums could be advertised widely through BCPWA e-news, member mailouts, other ASOs, and by placing posters throughout the community. New approaches, such as combining forums with one-on-one peer counselling sessions that respond to individual participant concerns, might also be tested as a way to strengthen outreach effectiveness.

TIP's blog could also be used to post well-researched information about the aforementioned topics or to post short news bites that point readers to where they can find more comprehensive information. Links to the blog, with short headlines that advertise the blog's recent topics, could be made consistently available on BCPWA's homepage, on TIP's section of the BCPWA website, and on BCPWA e-news.

3. Explore potential for partnering with physicians to disseminate treatment information

There has long been support in the literature for the encouragement of strong collaborative relationships between physicians and ASOs to increase the quality and reliability of the treatment information provided to HIV-positive people (Noring et al, 2001; DHHS Working Group, 2001; Stefanski et al, 2004). Given that this survey's respondents have indicated their preference for both physicians and ASOs as the primary sources of trusted treatment information, TIP may wish to explore ways that it can partner with HIV-care physicians to disseminate treatment information.

There are many ways a partnership could work, and these could be explored over the next year by using TIP volunteers to investigate the types of ASO/physician/public health nurse partnership models already in existence (in Canada or internationally) and determining their applicability to TIP. In the absence of existing models to draw from, a working group could devise an original model and pilot it in the local community. The focus groups in (1) above could also be used to gauge the level of interest in ASO/physician partnerships and to solicit ideas on how these partnerships could be most effective. One example of a potentially useful collaboration between TIP and HIV-care physicians or public health nurses might be for a select group of HIV care providers to track treatment information-related questions asked by patients and to provide these questions to TIP at regular intervals. TIP could then research answers to patient questions and subsequently disseminate the questions and answers for a larger audience.

4. Enhance online treatment information blog and website

Despite evidence from the survey's respondents pointing to current lower levels of reliance on the Internet for HIV/AIDS treatment information, there is also evidence in the literature to suggest that this will change. As mentioned in the discussion section of this paper, the Internet is gaining favour among HIV-positive people, particularly youth, as both a community space and a source of HIV/AIDS treatment information. Recognizing this, TIP may wish to enhance its existing web-based treatment information resources to enable their effective utilization going forward.

Drawing on the recommendations of James (2006) and Kalichman et al (2004), TIP's treatment information blog and the weblinks section on TIP's part of the BCPWA website could be complementary resources that provide readers with distinct, but connected, material on treatment information. For example, the TIP section on BCPWA's website could be organized and regularly updated around specific treatment information topics (such as HIV and aging or HAART adherence) or around sub-groups of HIV-positive people (such as women, gay men, newly-diagnosed, or treatment-experienced). If the website cannot be continually updated, the blog could have a weekly research update related to each of these themes or groups. In addition, TIP's weblinks to other online resources could be revamped using a working group's assessment of the 'best' ones to provide links to, and helpful hints could be provided regarding how to navigate those resources, together with background information about the primary purpose behind them.

CONCLUSION

The primary goal of the research undertaken for this paper was to represent a first step in providing TIP with documented evidence to support future programming changes that will better deliver HIV/AIDS treatment information to HIV-positive British Columbians. TIP was concerned about the continuing decline in access to its programs and services, and although reasonable guesses could be made about the reasons for this decline, TIP was not prepared to make program decisions based on unsupported assumptions.

The key deliverable for this project was to gather data for TIP by conducting a survey among HIV-positive British Columbians to test whether or not TIP's assumptions, together with new themes that emerged from a literature review, could be substantiated by the survey findings. While there were recognized limitations in sampling the population of HIV-positive people in British Columbia and in relying fully on the sample's responses, these challenges do not undermine the value of the survey's multitude of findings to inform improvements to TIP programs and services.

Options for TIP to consider for these improvements include drawing on its current infrastructure to implement programming changes directed toward a core segment of HIV-positive British Columbians that responded to the survey. This group of treatment-experienced individuals has provided TIP with valuable information about its information preferences and topics of major importance. Further, in light of growing evidence that a younger generation of HIV-positive people seems to prefer the Internet for community building and for obtaining information about HIV/AIDS, TIP might engage this particular generation going forward by making enhancements to its electronic treatment information resources. Given that the survey findings revealed a strong preference for physicians as a treatment information resource, an opportunity also exists for TIP to explore potential ways that partnering with physicians and public health nurses could improve the accessibility, quality and reliability of HIV/AIDS treatment information.

Some groups of HIV-positive people were not well represented in the survey sample. Additional research that targets these groups will augment the findings discussed in this paper and will provide TIP with stronger evidence on which to base future programming decisions. This research could be carried out in the next several months after additional groups of stakeholders, such as TIP volunteers and other staff at BCPWA, identify findings they wish to be fleshed out and formulate new questions they wish to have asked.

It is hoped that the findings and discussion in this paper will be disseminated throughout BCPWA and to other ASOs to elicit further thought and discussion. Through ongoing dialogue and the exchange of new evidence and ideas, better strategies to meet the treatment information needs of HIV-positive people can be developed.

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APPENDIX A: BCPWA Treatment Information Survey

INTRODUCTION AND CONSENT - PLEASE READ

You are invited to participate in a study entitled "Treatment Information Alternatives for a Changing Culture of HIV-positive people in British Columbia: A Needs Assessment" that is being conducted by Stephen Dunne on behalf of the Treatment Information Program at the British Columbia Persons with AIDS Society (BCPWA). As a graduate student in the School of Public Administration at the University of Victoria, Stephen is required to conduct research as part of the requirements for a Master's degree in Public Administration. This research is being conducted under the supervision of Dr. James MacGregor (tel. 250-721-6435).

Purpose, Objectives and Benefits: The purpose of this research project is to assess the changing HIV/AIDS treatment information needs of the HIV-positive community in British Columbia. The objective is to recommend alternatives for the Treatment Information Program at BCPWA to consider as it plans its future programming. Research of this type is important because the need for reliable HIV/AIDS treatment information remains as critical today as it did 25 years ago. The findings from this research will inform BCPWA (and other similar organizations across Canada) in their efforts to effectively and proactively develop treatment information strategies to meet the needs of the HIV/AIDS community. HIV-positive people and AIDS Service Organizations will potentially benefit from the development of better HIV/AIDS treatment information delivery strategies and will also benefit from a better understanding of the various factors that contribute to HIV/AIDS treatment information access and use.

Participant Selection and Risks: You are being asked to participate because this research relates directly to your opinions and treatment information needs as an HIV-positive person. Your participation in this research must be completely voluntary and involves completing this online survey. Aside from the approximately 15 minutes it will take for you to complete the survey, there are no known inconveniences associated with your participation. If, after beginning this survey, you decide that you do not wish to continue, you may withdraw at any time without any consequences or any explanation.

Privacy and Confidentiality: In terms of protecting your anonymity, you will not be required to provide any personal information when completing the survey, but in case you have been referred by a third party (e.g. an employee or other member of an AIDS Service Organization to which you belong), your confidentiality cannot be fully protected. However, all AIDS Service Organizations have strict confidentiality policies in place and your participation in this research will not be known to anyone outside of any organization that has referred you. The company hosting this online survey ensures the security of the data collected through several levels of password protection and compliance with privacy legislation. Only the researcher has access to the data and survey results, which will be erased from the researcher's computer within six months of the conclusion of this research project.

Research Results: It is anticipated that the results of this study will be shared with others in the following ways:
- Report to BCPWA; and
- Report to the School of Public Administration at the University of Victoria.

Contacts: If you have any questions about this survey, you may contact Zoran Stjepanovic (604-893-2239 or tiproject@bcpwa.org). You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

By completing and submitting the survey, YOUR FREE AND INFORMED CONSENT IS IMPLIED and indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered.

1. HIV/AIDS TREATMENT INFORMATION

1.1 Please rank the following five HIV/AIDS treatment information topics in order from the one that is currently MOST important to you (1) to the one that is LEAST important to you (5).

____ Starting medications
____ Switching medications
____ Side effects
____ Nutrition
____ Alternative treatment therapies

1.2 Are there any HIV/AIDS treatment information topics not listed in question 1.1 above that are important to you? If yes, please specify in the space below (use reverse of page if necessary).

1.3 Please rank the following six sources of HIV/AIDS treatment information in order from the one you would MOST LIKELY use (1) to the one you would LEAST LIKELY use (6).

____ Physician
____ HIV/AIDS service organization other than BCPWA
____ Internet
____ Support group
____ Friends
____ BCPWA Treatment Information Program

1.4 Do you rely on any sources of HIV/AIDS treatment information other than the ones listed in question 1.3 above? If yes, please specify in the space below (use reverse of page if necessary).

1.5 Please indicate to what extent you agree with the following statements:

		Strongly disagree	Somewhat disagree	Neutral	Somewhat agree	Strongly agree
a.	I am knowledgeable about HIV/AIDS treatment information**.**	1	2	3	4	5
b.	I can usually find the treatment information I am looking for on the Internet.	1	2	3	4	5
c.	I am overwhelmed by "too much information" about HIV/AIDS treatment**.**	1	2	3	4	5
d.	I prefer to participate in face-to-face discussions about HIV/AIDS treatment information.	1	2	3	4	5
e.	I look for HIV/AIDS treatment information even when I feel well.	1	2	3	4	5

2. HIV/AIDS TREATMENT INFORMATION RESOURCES AT BCPWA

2.1 Are you aware of the following BCPWA Treatment Information Programs and Services?

	Program/Service	Yes, I am aware of this	No, I am not aware of this
a.	Treatment Peer counselling	☐	☐
b.	Online Treatment Information Blog	☐	☐
c.	Treatment Publications (brochures, easy to read sheets)	☐	☐
d.	Treatment Information Hotline	☐	☐
e.	Treatment Information Community Outreach Forums	☐	☐
f.	Web links to online Treatment Information resources other than BCPWA	☐	☐

2.2 How frequently do you access the following BCPWA Treatment Information Programs and Services?

	Program/Service	Weekly	Monthly	Less than once a month	Never
a.	Treatment Peer counselling	1	2	3	4
b.	Online Treatment Information Blog	1	2	3	4
c.	Treatment Publications (brochures, easy to read sheets)	1	2	3	4
d.	Treatment Information Hotline	1	2	3	4
e.	Treatment Information Community Outreach Forums	1	2	3	4
f.	Web links to online Treatment Information resources other than BCPWA	1	2	3	4

2.3 Please think of the MOST RECENT time you accessed one of BCPWA's Treatment Information Programs or Services. Which ONE of the following programs or services did you access?

☐ Treatment Peer Counselling
☐ Online Treatment Information Blog
☐ Treatment Publications (brochures, easy-to-read sheets)
☐ Treatment Information Hotline
☐ Treatment Information Community Outreach Forums
☐ Web links to online Treatment Information resources other than BCPWA
☐ I have not accessed BCPWA's Treatment Information Programs and Services *(skip to question 2.5)*

2.4 Please think of your experience with the program or service you listed in question 2.3 and indicate to what extent you agree with the following statements:

		Strongly disagree	**Somewhat disagree**	**Neutral**	**Somewhat agree**	**Strongly agree**
a.	I found the specific treatment information I was looking for.	1	2	3	4	5
b.	The information I received was relevant to the length of time I have been living with HIV/AIDS.	1	2	3	4	5
c.	The information I received was relevant to my age group.	1	2	3	4	5
d.	The information I received was relevant to my overall health situation.	1	2	3	4	5

2.5 What needs do you have for your own well-being and support in addition to BCPWA's current Treatment Information Programs and Services? (use reverse of page if necessary)

2.6 Do you have any other comments about BCPWA's Treatment Information Program and Services? (use reverse of page if necessary)

3. YOU AND YOUR HEALTH

3.1 Are you:

☐ Male
☐ Female
☐ Transgender

3.2 Are you:

☐ Gay
☐ Straight
☐ Lesbian
☐ Bi

3.3 How long have you been HIV-positive?

☐ Under 1 year
☐ 1 to 5 years
☐ 6 to 10 years
☐ 11 to 20 years
☐More than 20 years
☐ Don't know

3.4 When in your experience with HIV/AIDS would you say treatment information has been most helpful?

☐ Soon after diagnosis
☐ After starting antiretroviral drug therapy
☐ When I was in medical crisis
☐ When I was in emotional crisis
☐ As I age
☐ Other (please specify) ____

3.5 What is your age?
☐ Under 20
☐ 20 - 29
☐ 30 - 39
☐ 40 - 49
☐ 50 - 59
☐ 60 or over

3.6 Where do you live?
☐ City of Vancouver
☐ Lower Mainland community other than City of Vancouver
☐ Northern BC
☐ Interior BC
☐ Vancouver Island
☐ Outside BC

3.7 Are you a member of BCPWA?
☐ Yes
☐ No

3.8 How would you describe your overall health?
☐ Excellent
☐ Good
☐ Fair
☐ Poor

3.9 Are you presently receiving HAART (highly active antiretroviral therapy: 3 or 4 HIV-treatment drugs taken in combination)?
☐ Yes
☐ No *(skip to question 3.11)*

3.10 If you answered "Yes" to question 3.9, how often do you adhere to your HAART treatment regimen?
☐ I never miss a dose
☐ I miss a dose once or twice a month
☐ I miss more than one or two doses a month

3.11 Please indicate to what extent you agree with the following statements:

		Strongly disagree	**Somewhat disagree**	**Neutral**	**Somewhat agree**	**Strongly agree**
a.	I feel "connected" to other people in the HIV/AIDS community**.**	1	2	3	4	5
b.	I feel isolated/stigmatized by my HIV/AIDS status.	1	2	3	4	5

4. ADDITIONAL COMMENTS

4.1 Please provide any additional comments you have in the space below (use reverse of page if necessary).

5. ARE YOU INTERESTED IN PARTICIPATING IN FUTURE RESEARCH?

5.1 Are you interested in participating in a focus group to discuss the findings of this survey?

☐ Yes
☐ No

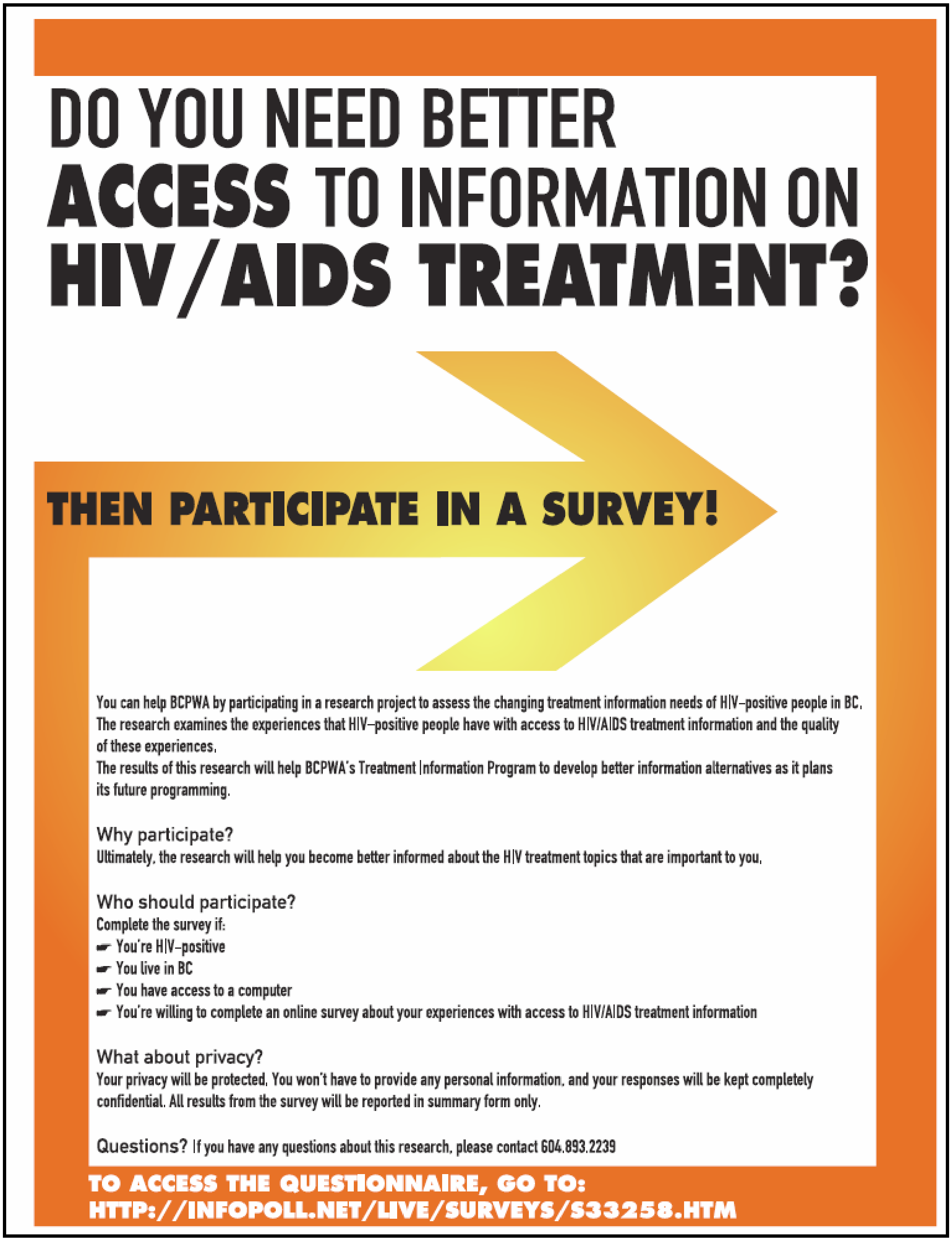
If your answer above was "Yes," please provide your name and telephone number or email address in the space below. You will be contacted in the summer to invite you to a focus group. Your contact information will only be used for the purpose of contacting you regarding the focus group and will not be shared with anyone.

THANK YOU FOR COMPLETING THIS SURVEY

APPENDIX B: ASO List

ASO Name	Contact Information	# Flyers
	Name	
BCPWA	Adriaan de Vries	250
OPTions for Sexual Health	Greg Smith	20
Oak Tree Clinic	Dr. David Burdge	50
BC Centre for Excellence in HIV/AIDS (Dr. Montaner's office)	Dr. Julio Montaner	100
Vancouver Friends for Life Society	Sarah Evans	50
AIDS Vancouver	David Swan	200
Heart of Richmond AIDS Society	Lori Montgomery	40
Victoria AIDS Resource and Community Services	Karen Dennis	40
Carnegie Centre AIDS Support Group	Rika Uto	50
Asian Society for the Intervention of AIDS (ASIA)	Suji Moon	20
ANKORS	Gary Dalton	70
AIDS Vancouver Island - Victoria	Katrina Jensen	40
AIDS Vancouver Island - Nanaimo	Anita Rosewall	20
AIDS Vancouver Island - Port Hardy	Tom Fenton	20
AIDS Vancouver Island - Courtenay	Sarah Sullivan	20
AIDS Vancouver Island - Campbell River	Leanne Cunningham	20
Vancouver Island PWA Society	Michael Yoder	10
Living Positive Resource Centre Okanagan	Daryle Roberts	50
Positive Women's Network	Marcie Summers	20
AIDS Society of Kamloops	Paul Lagace	40
Positive Living Northwest	Lucy Glaim	25
Positive Living North	Vanessa West	25

APPENDIX C: Participant Recruitment Flyer



DO YOU NEED BETTER **ACCESS** TO INFORMATION ON **HIV/AIDS TREATMENT?**

THEN PARTICIPATE IN A SURVEY!

You can help BCPWA by participating in a research project to assess the changing treatment information needs of HIV–positive people in BC. The research examines the experiences that HIV–positive people have with access to HIV/AIDS treatment information and the quality of these experiences.

The results of this research will help BCPWA's Treatment Information Program to develop better information alternatives as it plans its future programming.

Why participate?

Ultimately, the research will help you become better informed about the HIV treatment topics that are important to you.

Who should participate?

Complete the survey if:

- You're HIV–positive
- You live in BC
- You have access to a computer
- You're willing to complete an online survey about your experiences with access to HIV/AIDS treatment information

What about privacy?

Your privacy will be protected. You won't have to provide any personal information, and your responses will be kept completely confidential. All results from the survey will be reported in summary form only.

Questions? If you have any questions about this research, please contact 604.893.2239

TO ACCESS THE QUESTIONNAIRE, GO TO:
HTTP://INFOPOLL.NET/LIVE/SURVEYS/S33258.HTM

APPENDIX D: Statistics Used for Findings

Working Hypothesis	**Survey Question**	**Statistic**
A. The Internet is replacing the need for HIV+ people to have face-to-face interaction to obtain treatment information.	**Q.1.3** Please rank the following six sources of HIV/AIDS information in order from the one you would most likely use to the one you would least likely use.	% first choice and top 3 choice responses
	Q.1.5b I can usually find the treatment information I am looking for on the Internet.	% somewhat agree/ strongly agree by: ▪ overall ▪ # yrs HIV+ ▪ chi-square test for independence of variables
	Q.1.5d I prefer to participate in face-to-face discussions about HIV/AIDS treatment information.	% somewhat agree/ strongly agree by: ▪ overall ▪ # yrs HIV+
B. HIV+ people don't seek treatment information when they feel well.	**Q.1.5e** I look for HIV/AIDS treatment information even when I feel well.	Overall % ▪ strongly/somewhat agree ▪ strongly/somewhat disagree
C. HIV+ people are overwhelmed by too much treatment information.	**Q.1.5c** I am overwhelmed by "too much information" about HIV/AIDS treatment.	Overall % ▪ strongly/somewhat agree ▪ strongly/somewhat disagree ▪ chi-square test for independence of variables
D. Stigma/isolation may prevent HIV+ people from seeking treatment information.	**Q.3.11a** I feel "connected" to other people in the HIV/AIDS community.	% somewhat agree/ strongly agree by: ▪ overall ▪ sexual orientation ▪ chi-square test for independence of variables

Working Hypothesis	**Survey Question**	**Statistic**
	Q.3.11.b I feel isolated/stigmatized by my HIV/AIDS status.	% somewhat agree/ strongly agree by: ▪ overall ▪ sexual orientation ▪ chi-square test for independence of variables
E. HIV+ people aren't aware of TIP.	**Q.2.1** Are you aware of the following BCPWA Treatment Information Programs and Services?	% "Yes" responses by: ▪ geographical location
F. HIV+ people aren't likely to use TIP as a source of treatment information.	**Q.1.3** Please rank the following six sources of HIV/AIDS treatment information in order from the one you would most likely use to the one you would least likely use.	Ranking of BCPWA TIP as an information source by: ▪ overall ▪ # yrs HIV+
	Q.1.4 Do you rely on any sources of HIV/AIDS treatment information other than the ones listed in question 1.3?	Coded and themed responses
	Q2.2 How frequently do you access the following BCPWA Treatment Information Programs and Services?	% ever accessed by: ▪ program or service ▪ chi-square test for independence of variables
G. TIP isn't providing relevant information.	**Q.2.3** Please think of the most recent time you accessed one of BCPWA's Treatment Information Programs or Services. Which one of the following programs or services did you access?	Overall ranking of each BCPWA program or Service from most to least recently accessed
	Q.2.4 Please think of your experience with the program or service you listed in question 2.3 and indicate to what extent you agree with the following statements.	Weighted average score by: ▪ TIP program or service

Working Hypothesis	**Survey Question**	**Statistic**
H. What among TIP's main treatment information topics do HIV+ people consider to be most important?	**Q.1.1** Please rank the following five HIV/AIDS treatment information topics in order from the one that is currently most important to you to the one that is least important to you.	% first choice and top 3 choice responses Individual ranking by: ▪ # yrs HIV+
I. What other treatment information topics are important to HIV+ people?	**Q.1.2** Are there any HIV/AIDS treatment information topics not listed in question 1.1 that are important to you?	Coded and themed responses
	Q.3.4 When in your experience with HIV/AIDS would you say treatment information has been most helpful?	Frequency and percent overall for each response
J. What else might TIP provide to meet the treatment information needs of HIV+ people?	**Q.2.5** What needs do you have for your own well-being and support in addition to BCPWA's current Treatment Information Programs and Services?	Coded and themed responses

APPENDIX E: Sample characteristics comparison

Table 19: Comparison of select sample characteristics to BCPWA membership

Characteristic	Sample		BCPWA membership	
Gender	n=128	% of n	n=4664	% of n
Male	114	89%	3850	83%
Female	14	11%	763	16%
Transgender	--	--	24	<1%
Unknown/not provided	--	--	27	--
Age	n=128	% of n	n=3289	% of n
Under 20	--	--	8	--
20 to 29	4	3%	98	3%
30 to 39	15	12%	570	17%
40 to 49	57	46%	1317	40%
50 and over	52	40%	1296	39%
Unknown/not provided	--	--	1375	
Sexual Orientation	n=128	% of n	n=2089	% of n
Gay	101	79%	992	47%
Straight	23	18%	946	45%
Bisexual	4	3%	151	7%
Unknown/not provided	--	--	2575	*
Place of Residence	n=128	% of n	n=4660	% of n
City of Vancouver	72	56%	3090	66%
Lower Mainland (O/T Van)	29	23%	903	19%
Northern BC	2	2%	57	1%
Interior BC	16	13%	196	4%
Vancouver Island	7	5%	414	9%
Outside BC	2	2%	0	0%
Unknown/not provided	--	--	4	<1%

APPENDIX F: Chi-square tests for independence

Table 20: Summary of chi-square tests for independence

Test #	Hypothesis	Variable1	Variable 2	p	X2	CV	alpha	df
1	A	Age	Prefer FTF discussions	0.15	2.06	3.84	0.05	1
2	A	Age	Ability to find TI on the Internet	0.28	1.18	3.84	0.05	1
3	C	Feel overwhelmed	Feel knowledgeable about TI	0.00	9.70	3.84	0.05	1
4	C	Feel overwhelmed	Ablility to find TI on the Internet	0.03	4.69	3.84	0.05	1
5	D	Sexual orientation	Feel connected	0.08	3.03	3.84	0.05	1
6	D	Sexual orientation	Feel stigmatized by HIV/AIDS status	0.62	0.24	3.84	0.05	1
7	D	Location	Feel connected	0.48	2.48	7.81	0.05	3
8	D	Location	Feel stigmatized by HIV/AIDS status	0.87	0.70	7.81	0.05	3
9	D	Feel connected	Prefer FTF discussions	0.98	0.00	3.84	0.05	1
10	D	Feel stigmatized	Prefer FTF discussions	0.88	0.02	3.84	0.05	1
11	D	Feel connected	Type of TIP program accessed	0.97	0.00	3.84	0.05	1
12	D	Feel connected	TIP recently accessed (Y/N)	0.73	0.12	3.84	0.05	1
13	D	Feel stigmatized	TIP recently accessed (Y/N)	0.39	0.73	3.84	0.05	1
14	D	Sexual orientation	Type of TIP program accessed	0.22	1.50	3.84	0.05	1
15	F	Age	Type of TIP program accessed	0.03	4.58	3.84	0.05	1