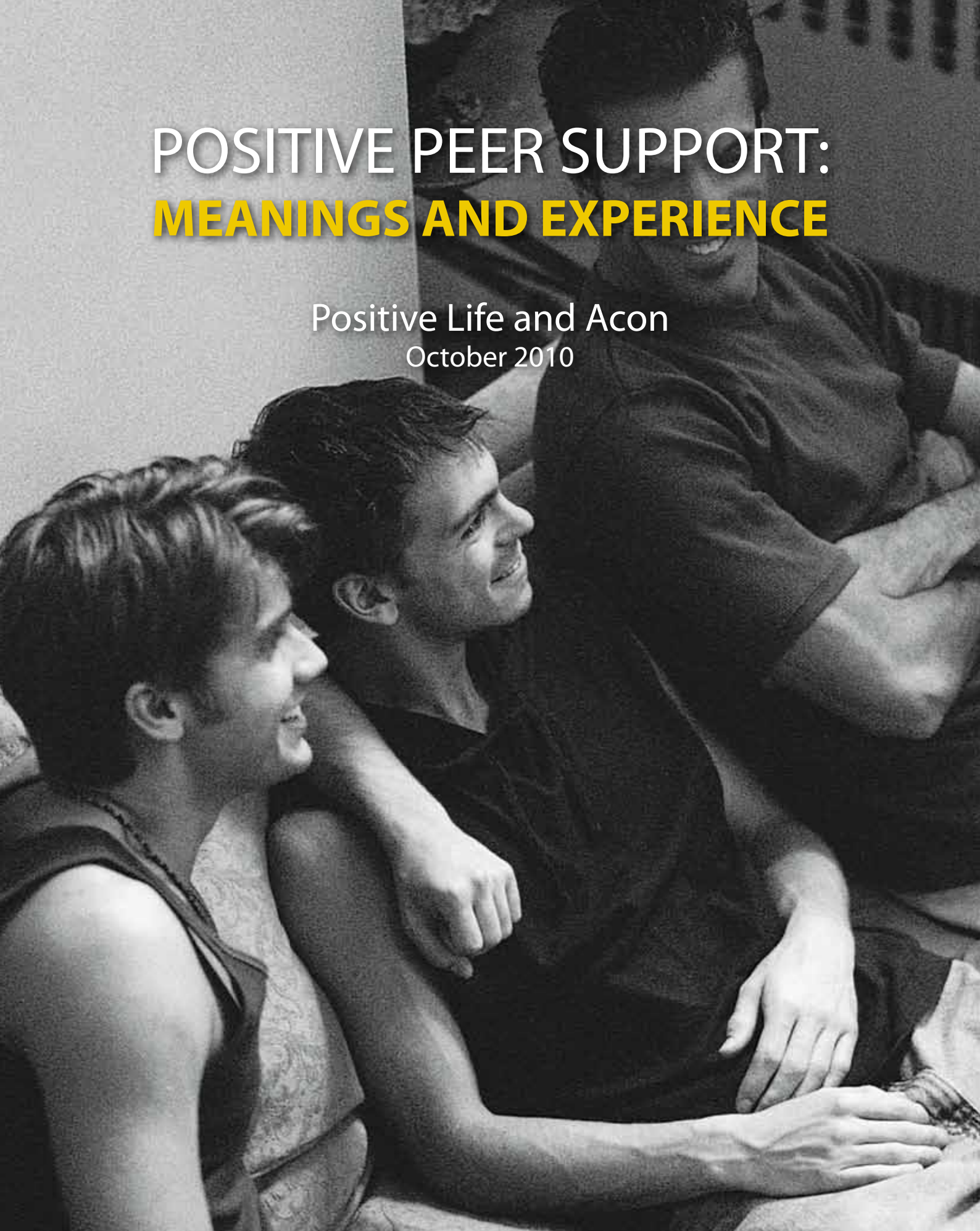


POSITIVE PEER SUPPORT: MEANINGS AND EXPERIENCE

Positive Life and Acon
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Research summary

Peer education and support has been a key component of Australia's community response to HIV since the early 80s. A vital component of this has been the peer support programs initiated by and for people with HIV (PLHIV). These programs have developed and evolved over many years, adapting and changing as needs changed.

Positive Life NSW and ACON currently support a range of complementary peer support programs for PLHIV. These programs are offered as structured workshops, facilitated support groups, discussion groups and informal social support opportunities.

Positive Life and ACON collaborated to review the mix of peer support models and approaches being used, support the development of effective evaluation to build an evidence base for these programs and review the effectiveness of the peer support programs and make recommendations for further development. Positive Life and ACON contracted the WA Centre for Health Promotion Research to support the review program.

The research project, which is part of the broader Peer Support Review program, aimed to:

- Support the review of peer support models and programs
- Review the effectiveness of peer support programs for PLHIV
- Support the development of effective evaluation tools to evaluate peer support programs for PLHIV.

The project was conducted over five phases as described in Table 1.

Table 1: Project phases

Phase	Description	Date	Status
Phase 1	Workshop to define and agree objectives and evaluation approach	January 2009	Completed
Phase 2	Workshop to finalise model and develop and validate evaluation tools for use within programs	March 2009	Completed
Phase 3	Implement review and evaluation approaches	Focus group discussions (May 2009) Online Survey (June to August 2009)	Completed
Phase 4	Review data and report development	June to October 2009	Completed
Phase 5	Presentation of results to Positive Life/ACON Feedback of results to participants Follow up data collection	Present results (January 2010) June 2010 Follow up online survey (July 2010)	Completed Pending Planned

This report focuses on Phases 3 and 4, which included four focus groups (25 participants) and an online survey (74 respondents) of people living with HIV (PLHIV).

Methodology

We conducted four focus groups in May 2009 at the Positive Life offices. There were 25 participants and the composition of each group is described in Table 2. Each session lasted one hour and was digitally sound recorded and minuted. The digital recording was transcribed, de-identified and then analysed using NVivo Qualitative Data Analysis to identify major themes. The responses to open-ended questions from the online survey were also included.

Table 2: Focus group participants

	Number of participants	Composition	Attendance at peer support groups
Focus group 1	9	All gay male identified	All participants had attended 7-2-9 and most had attended at least one other program (Planet Positive, After Hours, Luncheon Club, etc)
Focus group 2	3	All gay male identified	All had attended Genesis and some After Hours
Focus group 3	5	All gay male identified	Most had attended After Hours and at least one other program (Planet Positive, After Hours, Luncheon Club, etc)
Focus group 4	8	7 gay men 1 heterosexual woman	Most had attended at least one program (Planet Positive, After Hours, Luncheon Club, etc)
Total	25	24 gay identify men 1 heterosexual woman	

The online survey questions were guided by the draft program objectives and the process indicators developed during Phases 1 and 2 of the research project. The survey incorporates questions specific to PLHIV and peer support programs, as well as the General Wellbeing, Psychological and Social Domains from the World Health Organisation's Brief HIV Quality of Life Questionnaire (WHOQoL HIV BREF)¹ and the General Self Efficacy Scale (GSES).² It was later reviewed and revised based on initial analysis of the focus group data and then reviewed for face and content validity with a small group of PLHIV.

The final survey was placed online using the SurveyMonkey platform. The link to the online survey was promoted through ACON and Positive Life programs, email lists, publications and in advertising in the weekly *Sydney Star Observer* newspaper from June to August 2009.

Eighty-six people commenced the survey and, of those, 74 met the intended criteria and completed the majority of survey questions. Most respondents are male (96%), Australian Caucasian (86%), gay (86%) and aged 40 years and over (81%). The largest proportion work full time (40%), while a third are on a disability support pension. See Table 4 (page 42) for more detail.

There are a number of limitations to the study which should be considered when interpreting the results. The focus groups participants were recruited primarily from current or recent program participants who were able and willing to attend the discussion groups in inner city Sydney.

The online survey was promoted through a range of strategies. However, participants were self selected and all but one of the participants were male and gay or bisexual identified. The sample is not, therefore, a representative sample of all PLHIV in NSW.

1 Department of Mental Health and Substance Dependence (2002) WHOQOL HIV BREF World Health Organization Geneva, Switzerland.

2 Jerusalem M, Schwarzer R. (1992). Self-efficacy as a resource factor in stress appraisal processes. In R Schwarzer (Ed), Self-efficacy: Thought control of action (pp 195-213). Washington, DC: Hemisphere.

Focus group summary results

The analysis of the focus group data and open-ended questions in the online survey was focused around:

- The meaning and role of peer and social support
- The meaning and role of current peer support programs conducted by Positive Life and ACON
- Feedback on current programs, approaches and models of peer support.

The focus group participants generated considerable discussion about the meaning of peer support and the role it plays in their lives. For most participants, support from other PLHIV is viewed as very important, but it is not their only source of support.

The three main themes that arose during the discussions are drawn from the qualitative data:

1. Peer support as an experience of connection, validation and reduced isolation

- Peer support is an important part of meeting emotional needs of feeling connected, validated and less isolated.
- Peer support environments (whether formal or informal) provide a relief from social situations where participants feel they have to monitor themselves and an opportunity to openly discuss their life without having to explain their HIV status.
- Access to peer support is an ongoing need for some, but for most it is a stage that they will or have moved through in a period after diagnosis and may occasionally revisit to get another boost.

2. Peer support as gaining and sharing credible advice, knowledge and experience

- Peer support provides a point of credible comparison, where people can compare themselves to others at the same or different “stages” of coming to terms with HIV.
- Gaining ‘knowledge’ was used to explain a desire to hear experiences, get tips on managing HIV and staying well, and stories about dealing with disclosure and discrimination.
- It provides an opportunity to build confidence, gain options for solutions to problems, gain a more accurate perspective about living with HIV, and more accurate expectations for the future.
- The opportunity to provide some support to others is beneficial. Participants look for an exchange of experiences from which to draw advice, perspective and support.

3. HIV-positive peers as part of a friendship network

- Participants recognise and affirm the benefits of having a network of friends who are HIV-positive.
- For some, there is a preference for mostly HIV-positive friends driven by any or a combination of issues such as fear of negative reaction and distancing behaviour; broken confidentiality; self monitoring in social situations; and the burden of having to counsel friends through the disclosure process.
- Recently diagnosed participants tend (but not exclusively) to describe friends with HIV as a bonus, rather than a preferred option.
- Occasionally participants mentioned a reluctance to disclose to PLHIV they know because of the concern of changing the nature of the friendship or obligate support.
- Peer support groups provide an opportunity to have discussions in a contained context that does not impact on other friendships.

These themes are connected and relate to how participants see themselves and their situation. This is often linked to concepts such as years living with HIV or general experiences of isolation and stigma versus connection and support.

The meaning and role of organised peer support programs conducted by Positive Life and ACON

The different programs are well understood by participants. All focus group participants talked about and compared examples of structured workshops (such as Genesis), facilitated groups (such as 729 and After Hours) and less formal social environments (such as Planet Positive). Generally participants see them all as having their different purposes and environments, even if they do not access them.

There are differences in some of the expectations from peer support and the following tensions were noted:

1. Building an ongoing social network versus gaining perspective and comparison

- Some participants like to meet other PLHIV to gain perspective and get ideas, and then go “back to their own life and carry on”. Peer support is seen as an opportunity to ask questions, share experiences and support others outside their established friendship networks.
- For others, facilitated peer support environments are the only location where they can discuss HIV openly or without a sense of anxiety.
- Generally, participants who were diagnosed in past few years attended peer support to hear and share experiences, not look for friends, while those living with HIV longer tend to want more ongoing social interaction and friendships. However, the key discriminator may be more related to the type of friends and support the person believes they already have and other life priorities.

2. Peer support as a regular service experience to keep well and on track verses a one off or occasional pit-stop experience

- Some participants see peer support as an opportunity to gain perspective and knowledge and then move on, similar to an occasional pit-stop, for others it offers a regular service to diminish fears, maintain resilience and increase confidence.
- A minority view peer support programs as exclusively one-off experiences.

3. Information dissemination versus social interaction

- Social interaction is universally believed to be a key part of peer support. Social interaction is often higher priority than information dissemination and, for the majority, it is probably the main reason they continue to attend.
- Many participants admit that if the group were just a space to talk and had no specific topic, they would probably not attend.
- Generally there is support for the mixed information and social approach; however a balance that is right for everyone may be difficult to achieve.
- The groups need to find a balance between structure and commitment to the topic on one hand and remaining flexible to allow the topic to be redirected on the other.
- There appears to be tension between those that go along knowing the topic, but feel the primary reason is the social interaction, and those that go specifically for the topic.
- There appears to be frustration among some participants with discussion topics that are either too education focused or too repetitive.

4. Diversity versus uniformity of experience, stages and “headspace” within groups

- A tension exists between uniformity, where there is a relatable peerness, and diversity, where there is a mix of different experiences.
- Participants used terms such as “stages” and “headspace” to describe different people’s experience with HIV. Generally, “stage” is influenced by a mix of age, time living with HIV, experience with HIV and “headspace”. “Headspace” was presented as a continuum between a sense of positive, confident thinking and being independent verses a sense of uncertainty, isolation, need and pessimism.

- Many men spoke about moving through “headspaces” in a one-way direction based on time. However when men spoke about actual experiences, it appears to be a continuum in which people may move back and forth.
- There seems to be two parallel factors: Those diagnosed in the 80s and early 90s difference is about an experience they have been through and those diagnosed more recently who may not have had this experience.
- The other point of difference is coming to terms with a chronic and transmissible disease, and its implications on health, relationships, work and expectations for the future. This takes some time to resolve and so those who have recently been diagnosed (in the last year or two) are in a different headspace to those diagnosed five or six years ago, or those diagnosed 20 years ago.
- There are similarities in the experiences, but there are also marked and clear differences that impact on a sense of peerness and on a sense of what is wanted or expected from peer support programs or peer environments. This creates a real dilemma as it is not simply about age, time since diagnosis, employment or even broader sexuality and gender, but is about all these aspects.

These four tensions are relevant to some extent in the all the peer support programs, but were most explicitly discussed in relation to facilitated groups.

Why PLHIV do not attend peer support programs

The comments in the online survey about the reasons for not attending peer support programs were consistent with those of the focus groups. The main feedback can be grouped as follows:

- Do not identify as someone who needs or would access peer support, or felt they had accessed what they needed
- Peerness of other participants was questioned, particularly in relation to what stage or headspace they were assumed to be in
- Behaviour of some participants was seen as dominant, negative, or other generalisations
- Topics were assumed not to be relevant to their life or experiences
- Could not access due to distance, regional or transport issues.

Generally the reasons for not participating are a mix of these factors.

Group facilitator skills and expectations

- Facilitators are required to simultaneously facilitate or manage group and individual needs; identify individuals that may benefit more from one-on-one discussion; continue active facilitation during the breaks to support social interaction and possibly extended social interaction; and ensure the group does not move into a therapeutic context.
- Generally there is recognition of the different facilitation approaches required for an information provision session, which is generally seen as focused and led, and a peer support session which is seen as more fluid or facilitated.
- The focus group participants identified the need for high-level facilitation skills to find the middle ground – a mix of not only the way groups are facilitated and conducted, but also the skills required by the facilitator.
- An HIV-positive facilitator is seen as very important to be able to provide empathy and have the insight to effectively facilitate the issues. However, there was more emphasis and discussion about the skills and experience of the facilitator than HIV status.
- Facilitators need to have strong facilitation skills and more than one facilitator should be present where possible.

Online survey summary results

The online survey summary findings are divided into program objectives and process indicators.

HIV peer connectedness (Objective 1)

- Most respondents knew at least one person living with HIV that they could talk to (93%). Those who attend facilitated groups are more likely to have higher numbers of HIV-positive friends who they can talk to about living with HIV (Table 9).
- On average those who have multiple friends with HIV achieved more positive scores on the psychological and social domains of the WHO Quality of Life Scale as well as the general self efficacy scale compared to those with few or no HIV-positive friends (Table 8) but no difference on general health domain.

Support from and to other HIV positive people (Objective 2)

- The clear majority felt they were mostly or completely supportive to their friends with HIV (90%), however only 65% felt their HIV-positive friends were supportive to them (Tables 12 and 13).
- Those with more friends with HIV were no more likely to indicate they were supported or provided support than those with only one or two friends with HIV.
- The more respondents felt their HIV-positive friends were supportive towards them, the more likely they were to score higher on the psychological, social and general wellbeing domains of the WHO Quality of Life Scale as well as the self efficacy scale.

Background / foundation knowledge for living with HIV and where to find it (health literacy) (Objective 3)

- The majority of respondents feel either mostly or completely confident to form a good relationship with their healthcare provider (88%) and feel they have the skills and resources to make treatment decisions (80%) (Table 15).
- Confidence in knowledge about HIV to manage their health is more varied (72% felt mostly or completely confident). Those who do not feel confident scored lower on the psychological and self efficacy scales (Table 16).
- Most respondents (60%) could name three or more health and community services where they could gain help if they needed it, while 22% did not name any (Table 17).
- Those who had attended any peer-based social or support programs in past six months were more likely to nominate a higher number of services and those who had not attended were the most likely to nominate none (Table 18).

Skills, confidence and experience in living with HIV* (Objective 4 and 5)

Objectives 4 and 5 relate to a range of sub factors included in the phrase 'living with HIV' on which the peer support initiatives should achieve.

- Less than 20% of respondents are satisfied with their sex life. Most (57%) feel that having HIV makes them feel less sexually attractive.
- Respondents who attended social support events in the past six months were less likely to feel HIV had made them feel less sexually attractive than those who did not attend social programs.
- Two thirds (65%) of respondents reported feeling mostly or completely confident to talk about safe sex. Those who are less confident tend to score lower on the psychological and social domains of the quality of life scales.

- Half of the respondents (51%) feel confident in deciding when and how they disclose their HIV status. Those who feel more confident are more likely to have attended peer based social events in the past six months and have more friends with HIV.
- The majority feel confident to disclose their HIV status to their regular partner (70%), their friends (60%) and to their general practitioner (89%). Less than half of respondents (47%) feel confident to disclose to casual or new sexual partners.
- More recently diagnosed respondents tend to be the least confident in disclosing to family, work and friends. Younger participants are the least likely to have confidence disclosing at work.
- A quarter of participants reported experiencing HIV related stigma or discrimination in the previous 12 months.
- The level of confidence in dealing with stigma and discrimination is evenly distributed with only 36% feeling mostly or completely confident. Those who attended peer support programs in the past six months were no more or less likely to feel confident in responding to stigma and discrimination
- Those who indicated that support from family and straight friends has no or limited use to them are more likely to have attended a peer support program in the past six months.
- There are small but significant indications that those who feel support from gay friends is very important generally have higher average scores on the social domain and self efficacy scales than those who feel support from gay friends is of limited use.
- Indications may be that people who are less connected to a range social support structures are more likely to have attended a peer support program in the past six months.

Quality of life and wellbeing indicators (Objective 6)

- There are indications that those who accessed facilitated peer support programs in the previous six months averaged lower scores on the general, psychological and social domains of the Quality of Life scale, however there is no difference for the general self efficacy scale. There are no significant associations between the quality of life domains of self efficacy scale and men who had attended other types of peer programs in past six months.
- Facilitated groups tend to reach those who are feeling less socially or psychologically supported elsewhere.

Process indicators

- Almost all respondents rated gaining support from other PLHIV as important or higher (86%), but more participants gave higher priority to support from gay friends.
- Nearly two-thirds feel that being able to give support to other PLHIV is very important or essential (65%).
- Sharing stories and experiences is seen as having some importance, with experiences about managing HIV being the most likely to be viewed as very important or essential.
- The perceived importance of spending time with people who have lived with HIV for a similar amount of time, making friends through peer support groups or socialising with people they had met through peer support groups is fairly evenly spread across "limited use" to "very important."
- There are some areas where participants diagnosed before or after 1996 differ. Sharing stories and experiences about 'disclosing HIV status', 'HIV and sex', and 'HIV and relationships' as well as topic focused groups generally are significantly more likely to be highly valued by participants diagnosed after 1996 than those diagnosed prior to 1996.
- Gaining information on particular issues is seen as having some importance for almost all participants however those attending facilitated groups and older age groups are most likely to highly value managing health and wellbeing.

- The most highly rated aspects of running and facilitating peer support programs are:
 - A place where group members feel comfortable and safe to talk about their experiences
 - Well-facilitated discussion that stay on topic and time
 - A coordinator with strong and effective group discussion facilitation skills.
- One-off workshops to discuss a topic, being able to decide the topic and groups that meet monthly to discuss a topic are more likely to be highly valued by people diagnosed after 1996.
- Respondents who attended facilitated groups are most likely to value groups that meet monthly to discuss specific topics. Men who did not attend facilitated groups are more likely to view this as unnecessary or of limited use.

Table 49: Program objectives and inferences from focus group and online survey data

Objective	Focus groups	Online survey
Increase in reported HIV peer connectedness Increase in indicators of support from and to other HIV-positive people	Peer support described as an experience of connection, validation and reduced isolation	Respondents of peer support programs in previous six months are more likely to have higher numbers of friends with HIV with whom they can talk to, and are more likely to have received from and provided support to HIV-positive friends
Increase in background / foundation knowledge for living with HIV and where to find it (health literacy)	Peer support programs described as gaining and sharing credible advice, knowledge and experience.	Respondents of any peer support programs are more likely to be able to name multiple services for support and information
Increase in range of skills and approaches regarding living with HIV	Not assessed	Not assessed
Increase in confidence / experience in living with HIV	Peer support programs described as gaining and sharing credible advice, knowledge and experience.	Respondents of social peer support programs in the previous six months are more likely to feel confident in deciding when and how they disclose their HIV status and less likely to feel HIV makes them feel less sexually attractive
Increase in quality of life / wellbeing indicators	Peer support described as an experience of connection, validation and reduced isolation	Indications that the facilitated groups are reaching those who are less likely to feel connected to or supported by a range social support structures outside of the peer support programs
Increase in proportion of group participating contributing to other HIV positive organisations / programs	Not assessed	Not assessed
Identifying and mapping the issues and responses by people with HIV attending peer programs	See general themes and results	See general themes and results

Summarised recommendations arranged by theme

Aims and objectives

Review the peer support objectives for the purpose of developing consistent objectives across all peer and social support opportunities.

Ensure newly developed objectives focus on the experiences, challenges and solutions of living with HIV included in both peer and social support environments.

Research

Repeat the online survey in 2010 to provide relevant data that can be examined over time.

Conduct a separate analysis of the surveys submitted by HIV-negative partners and heterosexuals with HIV.

Review research on stigma and discrimination, consider its implications for people with HIV and develop an appropriate framework to address this issue in peer support settings.

Model

Ensure objectives include indicators that support new or infrequent participants in peer support models and reorient some programs to a higher proportion of regular educational perspectives of living with HIV and subsequent focussed discussion sessions and social interaction.

Survey attending participants to understand at what level they are interacting with the group, i.e., determine who knew the topic beforehand, who attended for the topic and who attended for social interaction regardless of the topic.

Facilitation

Upon review of the objectives consider the facilitation skills required to facilitate the various groups.

Ensure that all discussion groups have two facilitators present to manage the conversation and group dynamic.

Evaluation

Review and enhance process indicators that monitor social interaction, facilitation issues and general environment for program sessions.

Full list of recommendations

Recommendation 1

Review the peer support objectives and process indicators for consistency with the research findings.

Recommendation 2

Repeat the online survey by July 2010 to provide follow-up data on relevant items.

Recommendation 3

Refocus the program objectives to include the creation of an environment for sharing experiences, challenges and solutions in living with HIV. Investigate an increased emphasis in programs on achieving changes in perspective and outlook, indicators of self efficacy and social connectedness generally, and increase in HIV-positive peer networks rather than friendships.

Recommendation 4

Develop clear objectives and strategies to enhance and sustain the benefits from the social interaction component of programs (be it during a break or other contexts).

Recommendation 5

Investigate the reorientation of some programs to a higher proportion of one-off topic discussions.

Recommendation 6

Refocus the objectives to include indicators of an environment relevant to new or infrequent participants.

Recommendation 7

Review the approach to facilitation of the different peer support groups to incorporate the social environments, program objectives and facilitation skills required to achieve these objectives.

Recommendation 8

Incorporate the explicit opportunity to contribute to peer support and learning experiences within the discussion/focus group program objectives.

Recommendation 9

Investigate the reorientation to a stronger focus on living with HIV perspectives, tips, building self efficacy and confidence.

Recommendation 10

Review the sub themes within the skills, confidence and experience of living with HIV (Objectives 4 and 5) and limit to those areas most likely to be impacted by the peer support programs.

Recommendation 11

Develop a clear definition of the stages of living with HIV, as described by the participants, and the implications for the program objectives and target participants.

Recommendation 12

Develop clear objectives and strategies to enhance and sustain the benefits of the social interaction component of programs (be it during a break or other contexts).

Recommendation 13

Review training and development opportunities to enhance facilitator skills.

Recommendation 14

Ensure a minimum of two facilitators for all discussion group programs.

Recommendation 15

Review and enhance process indicators for program sessions that monitor social interaction, facilitation issues and general environment.

Recommendation 16

Investigate appropriate linkages and cross program support between campaigns to reduce stigma and discrimination and peer support programs.

Recommendation 17

Review other research into the stigma and discrimination of PLHIV in Australia for their contribution to the review of peer support programs.

Recommendation 18

Review the conceptual framework for the programs in light of the research findings to provide focus for the program-specific objectives and approaches.

Recommendation 19

Analyse the feedback of heterosexual participants separately.

Recommendation 20

Analyse the feedback of HIV-negative partners of PLHIV who participated (but not included in the analysis) separately.

Recommendation 21

Survey facilitated peer support program participants to determine who knew the topic beforehand, who attended for the topic and who attended for social interaction regardless of the topic.

Recommendation 22

Repeat the key questions in the online survey to provide some inference of change over time.

