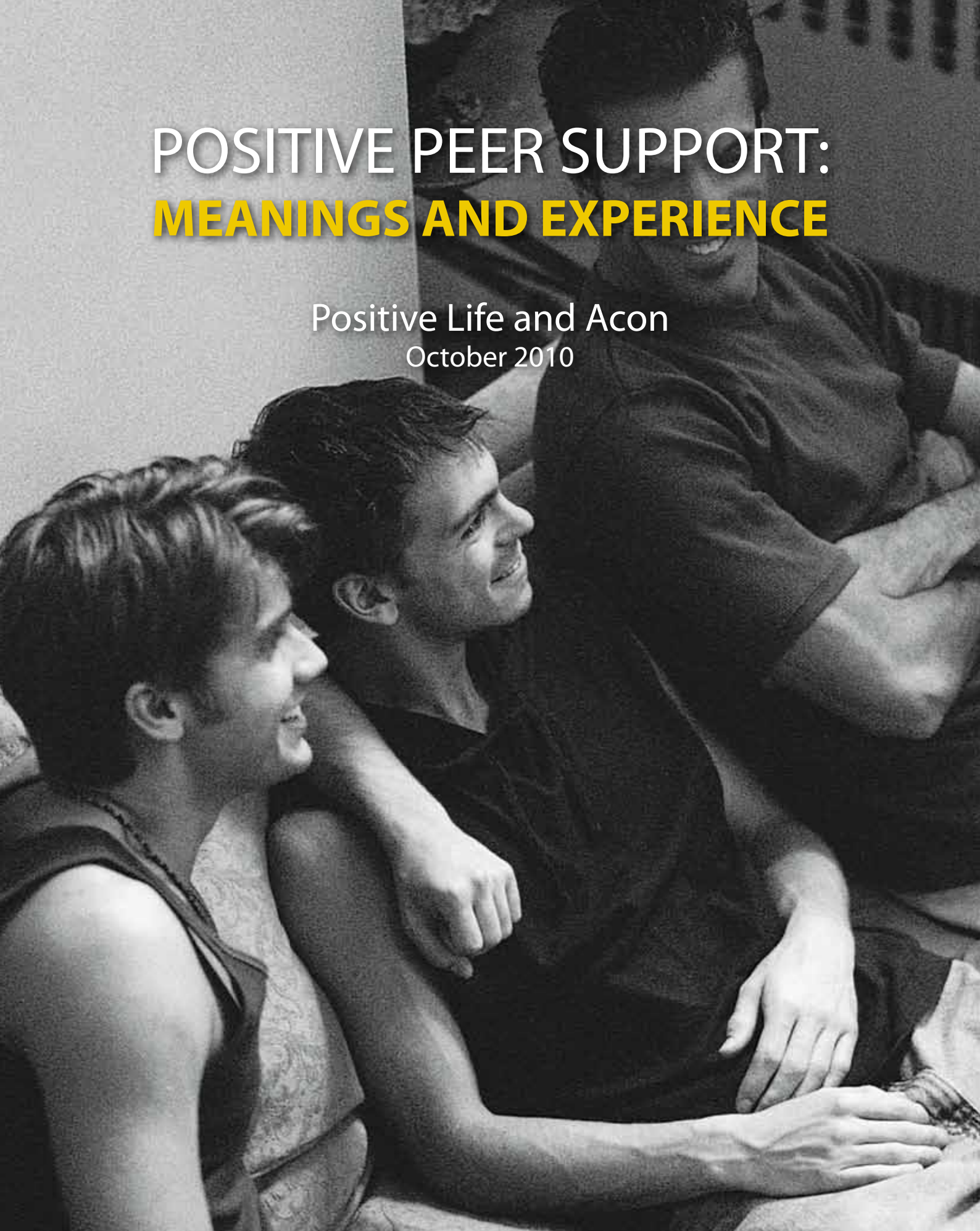


POSITIVE PEER SUPPORT: MEANINGS AND EXPERIENCE

Positive Life and Acon
October 2010





Published by Positive Life NSW Incorporated
PO Box 831
Darlinghurst
NSW 1300
Australia
www.positivelife.org.au

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ISBN: 978-646-55650-5

1. Social Sciences
2. Social Services and Welfare
3. Health

Acknowledgements

Thank you to the following people and organisations for their contributions to the research:

- Positive Life NSW
- ACON
- The participants of the focus groups and online survey for sharing their time and experiences.

Brown, G. (2010) **Positive Peer Support: Meanings and Experience**. Western Australian Centre for Health Promotion Research, Curtin Health Innovation Research Institute, Perth, Western Australia.

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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.





1.0 Project aim and methods

1.1 Background

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.

Although peer support programs for PLHIV have been running for a long time, it has always been difficult to measure their effectiveness or to gather evidence to guide future development of the programs.

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.

1.2 Project aim

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.

1.3 Project methods

The project took a participatory approach. We worked closely with the programs and gathered information from a range of sources. We sought feedback from program facilitators, held discussion groups with program participants and conducted an online survey for all peer support participants (past and present). The research was conducted over five phases as outlined 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

1.4 Workshops with program staff and facilitators

During phases 1 and 2, we reviewed and developed draft objectives for the peer support strategies and guided the development of the research methods in consultation with program staff and facilitators (See the reports for phase 1 and 2 for more details). We developed eight draft objectives, which the peer support programs are believed to be meeting. These objectives guided the ensuing phases of the research.

Draft program objectives

1. Increase in reported HIV peer connectedness
2. Increase in indicators of support from and to other HIV-positive people
3. Increase in background/foundation knowledge for living with HIV and where to find it (health literacy)
4. Increase in range of skills and approaches regarding living with HIV*
5. Increase in confidence/experience in living with HIV*
6. Increase in quality of life/wellbeing indicators
7. Increase in proportion of group participating contributing to other HIV-positive organisations/ programs
8. Identifying and mapping the issues and responses by people with HIV attending peer programs

*Living with HIV for the purposes of the above objectives is focused on indicators of social connectedness, relationship management, confidence in HIV status disclosure management, advocacy for and management of own health needs, accessing information and staying up to date (linked to Obj 3 above), accessing support and advice from HIV-positive peers, accessing support and advice from HIV-negative peers, resilience in responding to challenges and stigma, and independence beyond formal services.

1.5 Focus groups

The focus groups had two purposes:

1. To develop a deeper understanding of the diverse experiences and perspectives of PLHIV in NSW concerning:
 - The meaning and role of peer and social support generally
 - The meaning and role of current peer support programs (facilitated, structured and opportunistic) conducted by ACON and Positive Life
 - Feedback on current programs, approaches and models of peer support
 - Recommendations for focusing or improving current initiatives and recommendations for new approaches or models.
2. To support the development of an online survey to investigate the program objectives and to test the ideas from the focus group discussions with a broader sample.

We conducted four focus groups in May 2009 at the Positive Life offices and there were a total of 25 participants. 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	

1.6 Online survey

The online survey questions were guided by the draft program objectives and the process indicators developed during phases 1 and 2. The online survey incorporated a range of 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

The survey was then reviewed based on initial analysis of the focus group data, and questions were adapted or added. The draft survey was 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 newspaper *Sydney Star Observer* 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. Participants remained anonymous.

1.7 Limitations

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 was 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.



2.0 Focus groups

This chapter provides a detailed description of the key themes drawn from the focus group discussions and the qualitative feedback from the online survey.

The analysis focused on:

- The meaning and role of peer and social support generally
- The meaning and role of current peer support programs conducted by ACON and Positive Life
- Feedback on current programs, approaches and models of peer support
- Recommendations for focusing or improving current initiatives and recommendations for new approaches or models.

2.1 The meaning and role of peer and social support

The focus group participants generated considerable discussion about the meaning of peer support and the role it plays in their lives. Participants spoke about peer and social support from a range of sources, including friendships and networks, organised social events, ongoing peer support groups and other formal and informal contexts. For most participants, support from other PLHIV is viewed as very important, but it is not the only source of support.

The main themes that arose include:

- Peer support as an experience of connection, validation and reduced isolation
- Peer support as gaining and sharing credible advice, knowledge and experience
- HIV-positive peers as part of a friendship network.

These three themes are interrelated and were discussed in each focus group. The way participants discussed these themes related to how they see themselves and their situation, and this was often linked to concepts such as years living with HIV or general experiences of isolation and stigma versus connection and support.

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

All participants described or agreed that peer support is an important part of meeting emotional needs of feeling connected, validated and less isolated. However, for some participants this is an ongoing issue, while for others it is seen as a stage that they will or have moved through in a period after diagnosis and may occasionally need another boost.

I found it, for me, was so important to access people who were positive after I was diagnosed and just be in the same room as people. When I went to the first Genesis group it was unbelievable, you know, it just, it really made all the difference. My fears just began to melt away. (Focus group 3)

Going to a group or a session, or whatever you want to call it, all of the people that are in a similar position to you, makes life a lot easier. It's, I guess, that kind of safe place element, and there's people from different walks of life that are in for that specific situation, being HIV positive. And they're similar, as what you are, so there's kind of a joint interest. (Focus group 4)

Many participants spoke about monitoring what they said or disclosed in social situations. There was an experience of relief of not having to either avoid topics or explain everything when with HIV-positive peers.

I find to tell somebody that you have HIV is a bit of an event and so most of us just don't tell everybody straight away, so therefore we spend a lot of our time socially being very guarded. Because even though you might be in a group of friends, there might be some of those people that don't know about your status. So just for the simple comfort of being in a group and socialising where that's not an issue, that you don't have to be guarded and if there is something that comes up in a conversation that concerns HIV, then you know, it gets woven into the conversation and it's not a big deal. (Focus group 1)

Many men spoke about experiences in which they felt their HIV-negative friends or family (if they knew) did not know how to support them. The reactions tended to be sympathy and often over reactions about their health and mortality, rather than the empathy and credible advice they felt they received from other positive people. A minority of men described negative or stigmatising reactions from friends and many felt there was a level of gradual distancing from acquaintances once they found out.

Participants with strong social networks made direct comparisons to good HIV-negative friends who provided support, but noted this was not the same as being able to speak openly with other HIV-positive people. However, for some this meant developing friendships with HIV-positive people, for others this was not a prerequisite.

I can talk to my close friends about everything, and they do understand to some degree, but, you know, they can't really totally know what I'm going through. They try and be supportive ... But, you know, I've met a few people through this, having HIV and the people I do talk to about, you know, don't break down with them or anything like that. It's just a little bit of support. I might say I'm down or I feel like this, but it's more about the journey with them ... It is easier to talk to some people that are HIV cause they can understand, you know, it's having to take medication and I, well do feel like there's stigmas and things like that, but that doesn't necessarily mean we're going to be the bestest of friends or anything. (Focus Group 2)

A number of participants felt they received less judgment and more pragmatism from other PLHIV.

For instance, I got syphilis at the same time that I was diagnosed, which the HIV-positive people that I knew said, oh it's alright, you can get over it with a shot of whatever. Whereas my negative friends would go, oh syphilis, that's really dirty, or whatever. Or they wouldn't say anything at all, they just go, oh okay. (Focus Group 3)

The comments from the online survey were consistent with those above, including statements such as "That I am a part of a group", "A sense of commonality, understanding, validation" and "The empathy and understanding means you do not have to explain yourself. It also gives you the feeling you are not on your own."

There was little mention of the capacity of online forums to meet peer support needs in the focus groups, but this was mentioned more often in the online survey.

2.1.2 Peer support as gaining and sharing credible advice, knowledge and experience

Credibility

A key component of peer-based programs is the capacity for peers to provide advice that is seen as credible and based in the same experience. This was a strong component of how men described peer support. The person presenting the advice has a large influence on how it is received. Participants often compare the same information coming from a health professional, family member or friend against that coming from an HIV-positive peer.

I think that it's sort of like a fine line between advice and lecturing... it depends who it's coming from. I mean if my mum starts talking to me about HIV I'll go, "stop lecturing me". If it's just a random friend I'll think it's probably a bit weird if they didn't ask me, if I didn't know where it was coming from. Whereas if it was coming from a positive person I'd just take it as useful advice... the tone in the voice obviously. I mean if your doctor talks down to you then you're not going to be happy, just as if a HIV positive person said to you, oh why did you go and do that, or whatever and you will just tell them to shut up. But I just find that subconsciously I listen more to what they [HIV positive] have to say than to what my negative friends would say because I think there's experience there. (Focus group 3)

Overall, there is a general trust and engagement with health professionals, however for some there is a huge amount of information to absorb and hearing how other HIV-positive people integrate the information or deal with issues allows them to more easily cut through. There is also a sense of men, particularly those more recently diagnosed, looking for credible confirmation of the advice they receive from health professionals.

Because the other person's actually taking it. As opposed to maybe a doctor that can tell you side effects and things, but you can hear about somebody's actual lived experienced and that's so valuable. (Focus group 4)

Participants in focus group 2, all of whom had attended Genesis, expressed an experience of credibility and honesty from other PLHIV that they did not achieve or expect with a health professional.

I think with that it's, you know, they're there in a medical capacity whereas with going to a group like that, it's all about everyone, their experiences, not just, you know, take this tablet this'll happen and that'll happen and it'll make you feel better in two weeks or three weeks and these could be some of the side effects or whatever. But when you get into a group you're hearing everybody else as well. It's just, it's totally different. It's just, you can listen to their experiences, share your experiences and, you know, things like that. (Focus group 2)

We could swear and we could be talking about drugs, you know, and they kept it real and we could be trusting as well, obviously being honest, you know ... a doctor can't do that. You know, so doctors just, I guess that would make you feel more like they're just doing their job, you know. Because they can't be real. (Focus group 2)

The term 'empathy' was commonly used and often compared to 'sympathy'. There was a strong reaction against support that feels patronising or pitying and a belief that HIV-positive peers understand the experience and so have more credibility.

Meeting other people who actually understand what you are going through, because other people will often be quite condescending and say, "Oh I know it's tough" and all that sort of stuff where they really have no idea what you are dealing with on a day-to-day basis. (Focus group 1)

Knowledge

The term 'knowledge' was used often. However while this included information on treatments and other medical information about living with HIV, it was primarily used as a synonym for hearing experiences, learning tips on managing HIV and staying well, as well as stories about dealing with disclosure and discrimination. It was also associated, particularly with the newly diagnosed, with building confidence, gaining options for solutions to problems, and gaining a more accurate perspective about living with HIV.

It then goes past just the medical, the condition, whatever the hell you want to call it, the disease, whatever... and there's actually then, you start talking to people and you find different people's experiences. And I mean some of that comes from, you know, other issues, such as sexuality... status... circumstances, whatever, but, yes you are there for a common need, but you then actually, you know, from a peer support point of view, you see people that are at different stages and then, in dealing with the situation. (Focus group 4)

Comparison

A strong theme across all the focus groups is that HIV-positive peer support (whether it is formal or informal) acts as a point of comparison, an opportunity where they can compare themselves with their peers. This may be peers at a similar "stage" such as those living with HIV for similar length of time or a different "stage" such as having been on medication for a longer period of time. The comments generally are more related to comparing themselves to gain perspective rather than seeing others necessarily as role models. For those more recently diagnosed, this includes gaining a more accurate perspective or challenging their fears and assumptions.

It gives you a comparison point ... it's interesting to meet other people and find out what their experiences are. And there's the way in which you can actually help each other out, maybe not necessarily doing anything in particular, like consciously, but there's something unconscious there of, okay, you're getting that they're in the same situation, how have they dealt with it, talking to them, what's their thoughts on it. (Focus group 2)

I think one of the best things I got out of Genesis was to actually see somebody who had been diagnosed at the outset of AIDS and HIV, and to see that they are still living a healthy full life now ... and to actually see somebody who was diagnosed in the initial stages still living, breathing, no visible lesions that they depict in movies... To see that they can still function as a normal thinking human being was the best possible thing to take from that. (Focus group 4)

To meet other Pos people, find out a range of views on particular topics & to see how others view what is going on in life. (Online survey)

Advice through social interaction

The nature of peer support means gaining advice or understanding through social interaction. Informal discussions with other PLHIV are seen as important sources of information.

[I was] working out whether I should change my medication and things like that. So it was that sort of two-way discussion, you know, saying well what you are on, what's your effects? How are you finding your medication and that sort of thing. And it's so helpful. You can find out things that you could never really find out from medical doctors just from talking to other people. (Focus group 4)

There is universal agreement that the opportunity to provide some support to others is beneficial. As described earlier, there is little indication that participants are looking for role models as such, but rather an exchange of experiences from which they could draw advice, perspective and support.

I find when I went to the Genesis program ... I was at a different stage. I was a lot more comfortable with things ... there was other people in the group that were at a very different stage, as I phrase it, well, the freak out stage. And, yeah, I know I honestly felt like I was doing a little bit of peer support with some people, not seriously in the group situations but I guess in a couple of individual conversations. We had that little, maybe splinter off from the group, and I guess, you know, that was my experience at the time...I was at a different stage that I felt I could help. (Focus group 4)

If they find out you're positive and they ... see a more senior positive person, they'll suddenly want to, there's some people who will want to suck you dry. You know [those] who have just been newly diagnosed. If you meet them socially and really just like all they want to do is ... want you to talk, they want to know so much. (Focus group 3)

It has positive results such as being able to discuss issues surrounding current treatments, and any trials that may be going on. It is also a way of helping people with issues to see a bigger picture, and to help people gain positivity through example (online survey)

2.1.3 HIV-positive peers as part of a friendship network

All participants recognise and affirm the benefits of having close friends who are HIV positive as a concept. However participants tend to be in one of two groups:

- Those that want to meet PLHIV with the hope that they will be able to develop close friendships with them
- Those that see close friends and HIV-positive peers as separate, and building a network of HIV-positive friends is not a goal.

Participants identified a number of benefits of having a network of friends who are HIV positive, such as an assumed understanding of the same experiences. However the way the experiences were described differs considerably depending on time living with HIV. For example, those living with HIV longer term (more than 15 years) tend to describe the major social and cultural experiences they have been through over the past 15 or 20 years, the loss of friendship networks, and the long-term living with HIV as a chronic illness. For many in this group, close friends with HIV had all passed away, or those who they felt would have been ongoing close friends. For many (but not all) of these men, friends with HIV are certainly the preferred option.

They're in the same boat and when you're with close friends I guess you talk a bit more in depth and a bit more intimately about stuff, you know, can be a bit more real. And maybe I wouldn't talk about it anymore than I do at After Hours, I don't know. But when it's someone you know really, really well it's different. (Focus group 3)

The social aspect of the social support is equal to a peer support. That whole network has pretty much gone haywire for most of us. (Focus group 1)

Participants who were recently diagnosed tend to see ongoing friends with HIV as a bonus rather than a preferred option. The concept was consistently described as friends first and then HIV. This group wants to know and interact with people with HIV, but those peers becoming part of their social network because of HIV status is not a priority.

Many participants in the focus groups felt it is good just to talk without having to develop friendship or build extra expectations. For a minority this is about confidentiality and stigma (particularly in rural areas), but for most there is a trust that confidentiality would be respected but they are not interested in friendships whose basis is grounded only in HIV. These participants tended to also speak of other close friends who knew their HIV status and were generally supportive.

I go to my friends just for boo friggity hoo, you know, if like I'm stressed. You know, and that's what I'd go to my friends for, you know, and sort of have a glass of wine together, something like that... But as far as I'd go to the Positive Living Centre, that would be just things I didn't understand and that's how I actually got through it. (Focus group 2)

The internet was not raised often, but when it was, it was generally in regard to similar contexts of peer interactions without the need for ongoing friendship.

However, as described above, there is a consistency of view that social interactions with HIV-positive friends or networks are seen as easier than other social situations.

You don't have to do the great, the grand expectations ... You don't have to spell it out. So that communication a lot easier when you don't have to say, oh I have to go here because, and I go there because ... Less explanation and less disclosure about the complexities of your personal situation... far easier among people who are already [HIV positive]. (Focus group 4)

For some there is a move towards mostly HIV-positive friends as the explicit fear of negative reaction, broken confidentiality, or the burden of having to counsel friends through the disclosure process, encourages avoidance when compared to the easier communication with other PLHIV.

Just that however long it is ... of waiting for them to sort of get in the right place you know, back to sort of where they were before about how they treat me. And also just disclosure issues, I don't really want the whole world to know, I can't trust them as much as I can HIV-positive people. My friends who are HIV positive I can trust them with that information and I feel that I can't quite trust other people with that information. (Focus group 3)

However, concern about disclosing to family and friends is not always about rejection but often about over reactions, requiring the HIV-positive person to take on a role of counselling family and friends. This provides a disincentive to access support from other networks and an incentive to build a network of friends and support of PLHIV.

I pretty well dropped all my friends who weren't positive and I didn't tell any of them I was positive when I was diagnosed. And then slowly they've fallen away and now all my closest friends are positive and I feel it's still important enough for me that they're the only people I completely relax with and most in common with. I've got some really close friends I've known for 20 years or so who I still, I don't know if I can be bothered telling them I'm positive. And it's still sort of there and every four or five months they text me and say, "what are you doing?" And I think they think I'm on crystal or something and I almost prefer them to think that. I still don't want to go through that whole cycle of counselling old friends about my diagnosis and then you know, before there's any sort of payback for me down the line about some potential support that they might give me. (Focus group 3)

Younger gay men (under 35) tended to speak more about a mix of gay and straight friends than did the older men. This is not to say that both groups did not have a mix – but the younger men were more likely to refer to straight friends as close friends.

Some of the men with friends who have HIV indicated there is a difference between the conversations they might have with these friends and what they might discuss in groups. Occasionally, participants mentioned a reluctance to disclose even to HIV-positive people they know because of the concern of changing the nature of the friendship or obligation for support. The opportunity for peer support groups in this context provides an opportunity to have discussions in a contained context.

I've got a couple of close friends that said "Oh did you know XYZ was positive?" I had no idea. I know kind of probably about 15 guys you have parties and stuff together and I had no idea that they were positive. I haven't told them yet. Like, you know, it just hasn't really come up in conversation and to be honest I don't really want that conversation. I just can't be assed with it. I'd just rather just be mates with them or whatever, so I guess groups gave me an opportunity to ask the questions and that people didn't necessarily know [me], there was kind of that disassociation of like who I was. Like I guess in a little bit of a way kind of like anonymity. I could just ask questions. I could just get information and whatever, rather than have to go through the friendship.

2.2 The meaning and role of organised peer support programs (facilitated, structured and opportunistic) conducted by Positive Life and ACON

When focus group participants discussed the meaning and role of types of organised peer support approaches, as well as specific organised peer support programs, the focus of the discussions tended to gravitate to groups and workshops, with some referring to informal settings such as social events or campaign discussion groups. There was strong discussion about the differences between what was beneficial and what was not – but this was most focused when talking about different programs and services rather than talking about peer and social support generally.

The different programs are well understood by participants. All focus groups 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. However there was, at times, minor confusion about the name of specific programs. Generally, participants see them all as having their different purposes and place, even if they do not access them.

It's obvious in a group you can talk and be as open and honest you want and that environment is set up for that. Whereas if it's someone at Planet Positive, if you got to deep and meaningful you'd probably scare people off because you're there to have a drink and a good time, so you probably want to talk about more light-hearted things. So they're different kind of set up scenarios ... Deep and meaningful can happen anywhere and sometimes the peer support groups can be boring as all bat shit or get out of control and people talk about nothing ... or end up with conflicts and fights ... so they've both got their pluses and minuses.

Table 3 summarises the focus group participants' descriptions of different peer support programs.

Table 3: Focus group participants' descriptions of peer support programs

Structured Workshops (almost exclusively Genesis)	<ul style="list-style-type: none"> • Focus on information and intense bringing up to speed – but much of the information is about other stories and experiences as much biomedical and treatments information • Intensive experience of both information and gaining a clearer and more accurate perspective about life with HIV • Often described as an experience that rapidly reduced feelings of fear and isolation • Rarely spoke about needing to 'make friends' as such but more to meet and talk to other HIV-positive people – reducing the sense of feeling alone and fear for the future • Facilitator was discussed but not as much as in facilitated groups
Facilitated groups (mainly 729 and After Hours, some mention of Nexus, and only minor mention of other one off discussion groups due to lower familiarity)	<ul style="list-style-type: none"> • Generally consistent understanding of the facilitated groups being targeted for men who have been diagnosed for different amounts of time – but a fair diversity of what those "amounts" were (i.e. – under/over 1 year, 5 year, or 10 year etc) • A stronger presence / focus on the facilitator • The role of the facilitator was regularly raised and discussed • There were differences in group expectations for the type of social interaction that would occur depending on the numbers at the group, its format and the topic or purpose
Social Events (Planet Positive, but also socialising after groups or workshops, and Luncheon Club)	<ul style="list-style-type: none"> • Space to have informal, light-hearted conversations without the worry of having to explain • A sense of ease and relief • Not necessarily a peer support conversation but more a supportive peer environment

Although the issue of stigma and discrimination within the focus group participants' lives is ever present, none spontaneously spoke about the peer support programs directly assisting them in this area or suggested that peer support programs should be working with this issue. Stigma is seen as something to be managed, endured, challenged or ignored depending on their life circumstances, and many spoke about the benefit in discussing the issues informally with fellow program participants. However few linked this to peer support programs directly, indicating a more indirect influence when discussing experiences and solutions to problems or disclosure issues.

In discussions about workshops such as Genesis, the participants' descriptions were fairly consistent and indicated expectations were met or exceeded. Although most participants attending facilitated groups offered similar descriptions, there were differences in some of the underlying expectations.

Participants described tensions between:

- Building an ongoing social network and gaining perspective and comparison,
- A regular service experience of peer support to keep well and on track verses an occasional pit-stop experience,
- A focus on information dissemination and a focus on social interaction, and
- Diversity and uniformity of experience, stages and 'headspace' of participants in programs.

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

2.2.1 Tension between building an ongoing social network and gaining perspective and comparison

There is a difference between reducing isolation (which relates to building networks) and not feeling like the only one (which relates to a change in perspective). Some participants like meeting other positive people to gain perspective and ideas, and then going 'back to their own life and carry on'. It is seen as a benefit to have a place they can ask questions, share experiences and support others without having to take on these roles (gaining or giving support) within their own friendship networks.

For other participants, facilitated peer support environments are seen as the only locations in their life where HIV can be discussed openly at all or without a sense of anxiety. These men generally see themselves as having few close friends from whom they can gain support around HIV (whether the friends are HIV-positive or not).

This creates a possible tension between:

- Participants wanting to know they can occasionally have a space to gain peer perspective and insight, or particular challenges and gain advice but not looking for friendship, and
- Participants wanting to build or maintain a peer network or interact with group as a social network, who have had similar experiences as a replacement for what has been lost or not developed.

The following quotes provide examples of this diversity. This first participant, who was diagnosed in the past five years, moved to Sydney to be closer to supportive networks and, having achieved this, considers himself to be moving on from the groups.

I mean, so it was like move to Sydney, that's where the support is and that, so I went to Genesis, that was fantastic, you know, just to meet similar guys in the same area, went to Planet Positive and all that type of thing, and I suppose my needs have sort of adjusted, you know, it was great meeting new people and all that type of thing. I still like meeting new people. Most of my friends are HIV positive, due to these groups ... but it's just that I've taken the next step and sort of, I don't go as much as I used to. You know, the reasons of being, you know, work, too busy and all that type of thing. (Focus group 4)

Whereas this participant was not looking for friendships and felt he already had a network of friends.

I was just looking for a bit of guidance and direction, you know, and just to get on with stuff.

Interviewer: So it sounds like you'd like some guidance and to hear some stories but was there a sense of wanting to meet other people on a more friendship basis - was that part of it?

No, not necessarily. I just wanted to know, to hear other stories so it's not just all about me and my life's not over and where to go from there and see how other people cope, what they've gone through, and what they've done. Just I think the more knowledge the better (Focus group 2)

Whereas this participant, who has been living with HIV for over 10 years, used the groups on an ongoing basis to catch up with friends as well as a basis for other socialising networks.

So I look on the 7-2-9 and what I have tended to met people or who have reconnected with people, gone out and done something specific or just know that I occasionally meet them once a month, at least ... so I have used it as a bouncing set to more specific peer support. (Focus group 1)

This is consistent with many comments collected through the online survey:

The positive people I know are acquaintances in the main. I tend only to have contact through the support groups. (Online survey)

They are the closest thing I have to a social life, otherwise I would be a total hermit. Sometimes they are also a conduit for useful or interesting information. (Online survey)

Within the focus groups, participants diagnosed in past few years tend to want to hear and share experiences but are not looking for friends, whereas those participants living with HIV longer tend to want more ongoing social interaction and friendships. However this simple distinction could be misleading. When compared to other comments made by the participants, the key discriminator may be more related to what network of friends and support the person believes they already have or have developed, their experiences of living with HIV and other priorities in their life.

2.2.2 Tension between peer support as a regular service experience to keep well and on track verses a one off or occasional pit-stop experience

For some participants, peer support is seen as an opportunity to gain perspective and knowledge, and then move on, similar to a pit-stop, while for others it is seen as a regular service to diminish fears, maintain resilience and increase confidence. This is separate to issues of developing friendships. For example, the following quotes are from men who regularly attend peer support groups.

I think you can live with fears often and not really realise and usually after turning up to an After Hours I've managed to square myself in terms of any sort of little worries or fears I've collected about HIV along the way since my last time of being to After Hours. (Focus group 4)

It's not so much about information, it's about, emotionally about HIV, how it is to be positive and I've just felt by listening to other positive people in a group sitting around in a circle, it's made me feel more normal and more reconciled in my life about being HIV positive. Sometimes information has been interesting as well. (Focus group 4)

Attending these groups has helped bring me out of myself if I have been down. Has assisted my personal growth and development through a variety of ways including but not limited to intellectual stimulation, sexual encounters /flirtations, community gossip, an opportunity to let off steam. (Online survey)

Other participants view the peer support programs as something they can tap back into from time to time, like a pit-stop, if needed.

The Genesis program's great, but then there are people out there that need, you know, a little bit more follow up...and ongoing. Because you just sort of fall back into the same things. (Focus group 2)

Although I feel for myself that it's not necessary to involve myself with social networks so to say I think it's still important for the option/s to be there. It gives me the choice to have other coping avenues and that is not only comforting but reassuring. (Online survey)

The support groups also need to assist people to realise that the group is just a 'tool' and not a solution to getting on with your life. They need to stimulate people to become independent, to move their lives forward in a useful and positive way. If you leave the island, you should always feel that you can swim back, knowing that the option is there to leave again. (Online survey)

A minority of focus group participants see peer support programs as exclusively a one-off experience.

I found out like three days before I started my new job ... it was full on and I'm like having all these, I'm trying to learn my new job and so it got too much so I had to tell my boss and then it went on for a couple of weeks and then Genesis started and I went there, bang, I was fine. Didn't need to take the Xanax or anything like that ... I think it was just that experience of Genesis and that's why I really like that and I look back on what I got out of it, exactly what you said, just to know other people's situations and how they've been going through. (Focus group 2)

2.2.3 Tension between information dissemination and social interaction

Social interaction is universally believed to be a key part of the peer support. Many participants discussed the need for social interaction and the human element in the programs is possibly higher priority than formal information dissemination. For the majority it is probably the main reason they continue to attend.

You go to a group it's more human. I can read a story. I can read 15 stories ... versus seeing someone in front of me, maybe, but hearing somebody say it humanises it, as opposed to, you know, an article can give you the information, but a person will actually give you the experience. (Focus group 4)

[I feel it has been a good session] when I get to have a chat with people either during the meeting but it usually happens more so on the smoking break half way between the two sessions. (Focus group 1)

The meaning of social interaction varies a lot. For most it is just having the time to talk informally and allowing the natural conversations to evolve, for others it is the opportunity to build networks. However many admit that if the group were just a space to talk and had no specific topic, they probably would not attend.

I don't really go to After Hours to talk about whatever the set discussion is for that week and I don't think a lot of people there do either. I think that they're really just there to socialise. If there wasn't a topic then the group wouldn't make any sense because people wouldn't have anything to talk about. So it's good that there is a topic because it gives everyone something to talk about and chew the fat ... the topic is the lubricant ... But I think most people just go there for the social side. (Focus group 3)

If you go to Genesis first and get all that information into you, then going to After Hours, you probably won't need much more information because they pump you full of it at Genesis. (Focus group 3)

I didn't know anyone who had been positive for 25 years and so there were two reasons for attending this group. One was just to find out what the hell everyone else is going through, who has been positive for as long as I have ... And then the other reason was for information as well and so it was that social connection, that personal connection ... that's why I also feel that the group, despite the need for structure, needs some flexibility as well. So allow those natural conversations and those natural connections to happen ... often the best part of some nights is the break...but we have had the odd night where some people have been quite into the topic and they have gone really, really well. (Focus group 1)

Generally, there is support for the mixed information and social approach, however a balance that is right for everyone may be difficult to achieve.

We normally have the groups each meeting, one's for two hours and it's good to have a bit of a purpose ahead of time that you are going and that this is going to be the discussion. And what we generally tried to do is devote the first hour to the topic and then you know have our break and then it just goes off a little bit and people splinter off and have different discussions and things like that. I think that it's good that we had a little bit of an agenda because a lot of people only come along when there is a certain topic that they are interested in. And often they are not interested in that more than the social aspect and some people come along because there is going to be some information that they are interested in. But then whatever information is given or the discussion, the formal discussions will often, you know, sort out people into different sub groups and that's when usually we have our drinks and snacks and things and seek out some of – they have a bit more common ground ... So I see no conflict really in sort of having a bit of a set agenda because it only has to be the first half of the night and then you can go off on whatever tangent is natural.

I mean its obvious in a group you can talk and be as open and honest you want and that environment is set up for that. Whereas if it's someone at Planet Positive, if you got to deep and meaningful you'd probably scare people off because you're there to have a drink and a good time, so you probably want to talk about more light-hearted things. So they're different kind of set up scenarios. You know, but deep and meaningfuls can happen anywhere and sometimes the peer support groups can be boring as all bat shit or get out of control and people talk about nothing. You know, like, or end up with conflicts and fights and you end up, you know, so they've both got their pluses and minuses.

There is feedback from all the focus groups that peer support groups need to find a balance between structure and commitment to the topic and remaining flexible to redirect the topic.

Much of this tends to be driven by the tension between discussion topics and education topics, and the challenges of selecting topics that meet the range of needs of participants. Within the focus groups and across focus groups, there are differing opinions on the topics and who should decide them. While there is little consensus on specific topics, and few put forward, what underlies much of this discussion seems to be a frustration among some participants with discussion topics that are either too educational or too repetitive.

With the more structured sessions they are needs specific, need to be, like if somebody needs to know more about medication or are having a problem with disclosure, these are two huge major issues, but it gets a bit tedious after a while ... I'm interested to listen to other people, whatever level they are, but I don't want to hear about it every time. (Focus group 4)

When you are dealing with people who are over 40 and who have had a lot of catastrophe and I think that's why in the meetings a lot of people get stuck into – well just an opportunity to have their voice heard and they will just talk about anything for whatever reason, just to get it off ... But the bottom line is that people are there because they want to feel some sort of social connection which obviously isn't happening outside and it just needs to be a little bit more casual ... Particularly when that break is the highpoint of the evening. (Focus group 1)

People that have been positive for almost 30 years would probably like to talk on issues about getting older and the impact that has occurred and will occur and the impact that this will have getting older. We know what the safe sex message is. (Online survey)

There appears to be tension between those who go knowing the topic, but feel the primary reason is the social interaction, and those who are there specifically for the topic. In these circumstances, the outcome for participants is described as moving away from a peer-based experience towards a formal educational experience. However, some participants value the chosen educational aspect of the discussions and would feel aggrieved if there were a significant change from the plan. A good example is the following interaction from Focus group 1:

Interviewer: So what's it taking away, by pushing it back to the original topic?

Participant: Well, it's taking away the support.

Participant: Well, it's taking away the peerness.

Participant: It's making it like a teacher and pupil.

Participant: But it's also taking away, oh what is the word that I am looking for? Validation.

Participant: It's like coming to an educational session and not peer support.

Participant: Might I counter that by saying that if we had [changed the topic] I would not have felt justified being there.

2.2.4 Tension between diversity and uniformity of experience, stages and “headspace” within groups

There was much discussion about the participants of peer support groups. A significant part of the discussion was related to the theme of diversity or homogenous groups verses uniformity or heterogeneous groups in the peer support group. Diversity relates to different age groups, length of time living with HIV and employment status – which are effectively proxies for the different social experiences of living with HIV discussed earlier. It was assumed the participants would be gay men, but occasionally diversity explicitly included gender and sexuality.

Social events such as Planet Positive and Lunch Club are universally assumed to be open to all and diversity is seen as a benefit in these contexts. Diversity is seen as beneficial in one-off discussion sessions, such as campaign focus groups. Workshops such as Genesis are unchallenged as a program specifically for those who have been recently diagnosed and still coming to terms with a new diagnosis.

The opinions differ in regard to more structured or facilitated programs. After Hours is generally seen as a follow on from Genesis, but has evolved into something else, whereas 7-2-9 is intended to be for those living longer with HIV. The tensions can be summarised as the tension between uniformity, where there is a relatable peerness, and diversity, where there is a mix of different experiences within a broader definition of peer. The dominant theme seems to be more about people at different stages of living with HIV than an exclusively age or time since diagnosis or employment parameter, though these are

proxy indicators. All the focus groups had differing views within them and for some participants they themselves changed their view or had an internal tension between the arguments.

I've always said I wanted a group that's just for me. And I was thinking when you said, let's have a whole range of different groups, I was thinking, well I'd probably would want to go to all of them. Because I would be able to relate to every single individual group as well. So I think T's suggestion is probably the better solution to that, is that the group is inclusive rather than having different groups. But I guess it's to what degree because we do have different groups now. (Focus group 3)

For me, the whole, the concept of the group, the main thing being that you have HIV and the length of time that you have had it. Those are the main parameters of getting to the different groups. But basically for me, it's just an excuse to put people together. So it could be the same thing as you know, you might be a chess club or something and you just have a few things in common and you get together in a group and then you find other people that you have more in common with, within that circle once you get to the group. (Focus group 1)

I was just thinking of my experience of meeting lots of gay guys who are positive and lots of women and straight men who are positive, I really believe that there's far more similarities than differences, from what I've experienced. This is my experience. And I've been quite surprised by that at times and when I've sort of spoken in groups sometimes I've actually had gay guys coming up to me and saying "I experienced that and that and that too" you know. And I'm thinking oh wow, really. So, yeah, to my mind there's a lot more similarities than differences. (Focus group 4 – note – only female participant and received many nods from the rest of the group)

There seems to be an underlying assumption in the focus groups that newly diagnosed generally means a younger age. There was little spontaneous discussion of men in their 40s or 50s being newly diagnosed.

Stages and headspace of participants of peer support programs

Across all the focus groups, participants referred to terms such as "stages" to describe different people's experience with HIV. Generally, someone's "stage" is influenced by a mix of age, time living with HIV, their experience with HIV and their "headspace".

I just sort of see what stages other people are at with it ... And sort of compare that to my own, where I have been or where I might end up. (Focus group 1)

There seems to be two parallel factors happening here. The first is the experience of those diagnosed in the 80s and early 90s whose difference is about an experience they have been through which may have placed them in a particular social experience and situation in 2009. Those diagnosed more recently may not have had this experience or may be of the same generation but have not lived through that experience with HIV.

Most people who have had it for more than 15 or 20 years, you know, it's hard to explain and it's sort of like surviving a holocaust ... the people that I knew when I was diagnosed that I had known for four or five years and I spent a lot of time with, who probably would have gone on to be my lifelong friends; have all gone. So I have found myself at this point in my life without those long-term friends ... People lose a lot of their, just basic social skills. So getting into those groups is a way to sort of sharpen them up I guess ... something that has been a pretty major part of their life and you have got at least one thing in common with at least everybody in the room. (Focus group 1)

The second is the issue of coming to terms with a chronic and transmissible disease, and the implications this has on health, relationships, work and expectations for the future. This takes some time to resolve and incorporate into one's life. 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.

Where Genesis is fantastic when you first come out and you need that information and all that type of thing, so that was the first diagnosed, or six months, a year whatever. But then there's, After Hours, after that, where it's a year to whenever, really, whenever you feel comfortable to move on, really, where I found that fantastic after Genesis because there were the younger guys that were around in my same area who have been diagnosed and then there was older guys, you know, five, six years, hearing their experiences was really great ... I went along to the 7-2-9 group ... there were a couple of guys that like "I've been HIV positive for 25 years" and the discussions and the type of conversations that went on with that group I felt was very fairly dominated by people that were very comfortable with being HIV, they were long-terms of at least 10 plus years and it was all sort of "Well, yeah, we all know each other, and oh there's a couple of new people" sort of thing. And it wasn't really conducive to the idea of me feeling free to express my ideas or actually discuss something from my perspective because all these other people were like well they basically already dealt with that, and they were at a totally different stage. Where with Genesis it was like well we're all sort of fresh in the boat sort of thing and it was much more conducive to actually having an exchange of ideas. (Focus group 4)

So despite the fact that you are both HIV positive, there isn't really that connection because you have been there and done that and they might just be diagnosed. I mean, yes you can help them out, but then you are being the support, rather than them. (Focus group 1)

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.

The concept of headspace was raised a number of times across the focus groups. Headspace was presented as a tension between a sense of positive, confident thinking and being independent, and a sense of uncertainty, isolation, need and pessimism. Many men spoke about moving through these headspaces and time is a dominant factor, but it was discussed as a one-way journey. However when men spoke about actual experiences, it appears to be more of a continuum in which people move back and forth. It is in this context that peer support groups are more about a regular dose that helps people keep their perspective and sense of connection on track. It was suggested that some people are "stuck" in a negative headspace and there was some recognition of depression and mental health concerns. Some of these comments include inherent stereotypes and generalisations:

People who are very long-term survivors, there's a mix of two people. A lot of them want recognition and acknowledgement; we have survived this bloody long. And it's very important and some of them want to tell their story and sometimes we don't capture that and others don't hear them and that's one group. We have another group that's long-term survivors. They have been through hell, they have heard it so many times they say come on let's pass/move on ... so there is a slight mix there. (Focus group 1)

There was much discussion about the mixing of participants in different stages and headspaces, and the advantages and disadvantages of this. There was no consensus and many had conflicting thoughts.

The one at ACON, the age group was more varied whereas the one in Newtown they're all probably around my age and older, whereas I found where the age difference was like 20s, 30s, 40s, it was a lot better ... I think that the younger group sort of brought it up a bit. Mate, that's just the way I saw it. But the ones that are older, as well as being HIV, they've got other stuff that's going on as well and their headspace, to me it sort of brought it down a little bit, and the activities that they wanted to do were a lot different to the ones that most of the people that around our age or younger wanted to do, you know what I mean? The, that was the only thing I found. And I don't know, I just say they're more friendly. For me it was friendlier with the age mix in there, it was better. (Focus group 2)

Having a skewed mix is universally believed to be ineffective. It is believed that either the whole group should be homogenous or the diversity should be more evenly spread. The most common example is a group in which one participant is in their 20s and the balance of people are over 40. This is seen to result in an isolating experience, whereas if there were a more even spread of ages, then the atmosphere would be more conducive to the benefits of sharing different experiences.

2.3 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.

Do not need or would not access peer support

Some participants in the online survey do not see themselves as someone who would access groups, particularly something they view as a support group. This is sometimes associated with assumptions about the 'peerness' of the group participants and a resistance to identify as being "needy".

Throughout my life I have never been a big attendee of "groups" so little has changed. (Online survey)

Not really interested: if I had diabetes I wouldn't go to a diabetes support group. (Online survey)

Peerness of other participants

Some focus group and online survey participants feel that other participants are in a different stage or headspace to them, and that this is experienced or assumed to be a barrier to being able to relate to the other participants. This includes, but is not entirely driven by, some underlying generalisations about participants of peer support groups or programs.

Existing peer support groups don't seem to attract the same sort of people as me - seem to be mostly people with HIV long term, generally older and don't work full-time. I don't fit into that category. (Online survey)

I often find it hard to relate to the group. Matching personal situations and being able to relate to others whose circumstances are vastly different to my own. Also finding that groups seem to have a sense of helplessness about them. (Online survey)

Behaviour of other participants

When participants spoke about challenges with other participants it was generally in the context of facilitated groups rather than social events or structured workshops. The members of groups are thought to have the capacity to “make or break a group”, and so can have a positive or detrimental effect. Group members who dominate the discussion were regularly raised, though no one identified themselves as being a dominant group participant. The tension between being heard, reliving the past or hijacking the agenda verses moving on or staying on topic was often raised.

I think that each person comes along with the expectation that their personal issues will be addressed. They either try to impose their agenda on the rest of the group, or stop attending. The key is to make the gatherings enjoyable, while giving everyone the possibility of some ongoing input. (Online survey)

Some participants felt that pre-existing social networks had been established through the group and that this made it more challenging for new participants to engage, as the group could be interpreted as a clique.

I think these groups you're talking about have been well established, and it was probably the reason why I didn't go ... I know some of the guys that have had HIV for 20 years and I'd be just walking into that environment and feeling like really a little bit left out in the cold because they've got a social network now. That's almost like a club environment for them and when new me comes in, it's a threatening sexual intimidation and they're being cliquy and you've got to break into that. (Focus group 4)

There are a handful of people who tend to be at most groups & love to hear their own voice, remind us of their past glory's & consistently, frequently highlight their self importance. (Online survey)

Topics not considered relevant

The online survey participants provided more specific suggestions and recommendations for topics for peer support programs. These should be interpreted in the context of the results from the online survey in section 3.8. The key feedback from the online survey and in the focus groups is about the range and diversity of topics related to broader life in the context of living with HIV and less emphasis on issues specific to HIV. Suggestions include more emphasis on:

- Healthy living related topics or other more general topics not specifically related to HIV but discussed in the context of living with HIV (individual suggestions included topics such as healthier living, building social connection, aging, starting a business)
- Redirecting and achieving life goals, independence or perspective
- Skill sharing among participants.

There are also topics seen to be conducted too often. Participants requested less focus on:

- The “safe sex message”, however contextual issues of acknowledging that unsafe sex happens or issues of managing disclosure are important
- Issues of living on pensions, Centrelink and resumes, particularly from those participants who are working.

These comments include those from many participants who have not attended facilitated or structured peer support programs in the past six months.

Rural and regional participants

The challenges for rural and regional participants to participate in peer support were raised mostly in the online survey, which had a much broader geographic reach. The issues were also raised in the focus groups.

The key issues are access and connection with other PLHIV. For people travelling considerable distances, or time on public transport, the need for the session to be relevant and useful is higher than someone in inner urban areas who are perceived to have easier and more frequent access. In this context it is not only an issue of distance, but also the investment of time, energy and overcoming any anxiety or other barriers to feel warranted.

When you attend a workshop environment in rural areas you have to travel a long distance and often leave the workshops having heard about a topic you are not that interested in, have to fill in an appraisal form and go home without having spent any quality time with other poz people which could have been more useful and rewarding. (Focus group 3)

The issue of online peer support did not come up regularly in the focus groups, although it was more often referred to in the online survey. Online support is generally considered as possibly useful for others, but only occasionally referred to as useful to self. While online support could be useful for information and comparison, the inference is that face-to-face peer experiences are required to achieve the experience of connection, validation and reduced isolation.

2.4 Group facilitator skills and expectations

Most discussion about peer support program facilitation focused on the ongoing facilitated groups as opposed to the structured, social or other peer support environments. 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. Overall, the social events are seen as either well conducted or, where there were issues, they were believed to be outside the control of the facilitator (such as comments about peerness of participants at social events). There is reasonably frequent mention of the value of the break in the facilitated groups as being a key part of the event, if not the most important part. The focus groups 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.

What makes that session good is allowing people just to talk or allowing people to be quiet if they want to be quiet ... creating an environment whereby you're going from a group information giving opportunity to ask questions, but then you go to more of a facilitated peer support ... you had two peer support workers, we'll call them that, and I mean it was just an opportunity to talk about whatever you wanted to talk about. And letting it go off tangent, letting it go where people wanted it to, but still keeping it kind of on track. But without actually going, no, no, no, we're talking about disclosure, you can't talk about that ... letting people talk or some people just want to sit there and listen. And I think a good facilitator identifies that within a group and knows when to tell one person to, well not tell them, but you should tell them to shut up a bit more which is fine, okay. (Focus group 4)

As indicated in the above quote, there is recognition across the focus groups and online survey that this flexibility and allowing the discussion to go on tangents could and does become problematic. Where it crosses the line is difficult to define or agree on, but managing this is seen as key to the skills of the facilitator. The underlying issue seems to be about individual versus group need, and gauging if the issue is the right issue to discuss and explore as a peer group or is better responded to on a one-on-one basis.

Each person is going to want to divulge a little more information than others, and if they feel that that person needs to talk, okay, it may not be a beneficial subject for the group to actually listen to, but they would say “Okay, we’ll deal with that later” and they would make a point of seeking that person out for one-on-one rather than having it monopolise the whole group. Whereby having one person becoming very monotonous in a discussion would then mean three or four people are then looking out the window and not actually focussing on what they’re there for. So, I suppose a good facilitator is a good reader of people and a good reader of situations. (Focus group 4)

Group facilitation also needs to have an awareness that some issues for individuals need to go to a more personal level - i.e. it shouldn’t be seen that everything has to happen within the group. If an individual is seen to have a need for other help or support, it should be given to him outside the dynamics of the group. (Online survey)

Facilitators are effectively being 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)
- Ensure the group does not move into a therapeutic context.

The challenge for facilitators is considerable and these comments highlight the need to have strong facilitation skills and more than one facilitator where possible.

A facilitator who is HIV positive is seen as very important for their ability to provide empathy and have the insight to effectively facilitate the issues. However there was more emphasis on the skills and experience of the facilitator, rather than their HIV status. In this context, HIV status is seen as only one component of a facilitator’s experience and insight. This is consistent with the feedback from the online survey.

If you’ve got a facilitator who’s actually positive and been down that road and can give you once again empathy rather than sympathy, they have a greater understanding for what people are going through and they also have a greater understanding that each person is going to react differently to the situation. (Focus group 4)



3.0 Online survey results

This chapter provides a detailed analysis of the online survey data commencing with an overview of the respondents, followed by an analysis of the questions by program objective. We also analyse the process indicators about the peer support programs and the themes that arose from the focus groups.

3.1 Description of the online sample

Most respondents who completed the online survey are male (96%), Australian Caucasian (86%), identified as gay (86%) and aged 40 years and over (81%). The largest proportion (40%) work full time, however a third (33%) are on a disability support pension. Half the respondents live alone (51%) and most described themselves as single (69%). See Table 4 for details.

The year of diagnosis ranges from 1981 to 2008, with an average of 1996 and a median of 1999. Six respondents did not disclose their year of diagnosis. The respondents' date of diagnosis is grouped as prior to or after 1996, the year that highly active antiretroviral therapy was introduced, in Table 5. More than half the respondents had been diagnosed with HIV during or after 1996.

A third of respondents had participated in HIV peer social events in the previous six months, 23% in facilitated groups and 20% in structured workshops. Nine respondents (12%) have participated in the peer support review focus groups. For the purposes of analysis, some peer support programs were grouped into facilitated groups, social events and structured programs. More than half of the sample had participated in one or more program in the past six months (see Table 6 for full details).

Table 4: Demographics of online survey respondents

Variable	Categories	Frequency	Percentage
Age	18-29	4	5.4
	30-39	10	13.5
	40-49	24	32.4
	50-59	29	39.2
	60-69	7	9.5
	Total		74
Gender	Male	70	95.9
	Female	3	4.1
	Transgender	0	0
	Total	73	100
Sexuality	Gay	63	86.3
	MSM	7	9.6
	Heterosexual	3	4.1
	Total	73	100
Employment	Full time	29	39.7
	Part time	9	12.3
	Student	1	1.4
	Newstart	2	2.7
	DSP	24	32.9
	Other	8	11.0
	Total	73	100
Postcode	2000 to 2099	41	55.4
	2100 to 2999	33	44.6
	Total	74	100
Living arrangement	Alone	38	51.4
	With partner	12	16.2
	Share	24	32.4
	Total	74	100
Relationship status	Single	48	68.6
	In a relationship	22	31.4
	Total	70	100
HIV status of partner	HIV negative	14	63.6
	HIV positive	8	36.4
	Total	22	100
Ethnicity / Cultural background	Australian / Caucasian	64	86.5
	Asian	3	4.1
	European	6	8.1
	Torres Straight Islander	1	1.3
	Total	74	100

Table 5: Year of diagnosis of online survey respondents

Response	Frequency	Percent
Diagnosed before 1996	29	42.6%
Diagnosed in 1996 or after	39	57.4%
Total	68	100%

Table 6: Programs accessed by online survey respondents in previous six months

Program type	Program name	Respondents*	Percentage of total sample
Facilitated groups		17	23.0
	7-2-9	13	17.6
	After Hours	7	9.5
	Nexus	1	1.4
Social events		23	31.1
	Planet Positive	13	17.6
	Social meals (e.g. Luncheon Club, Karumah, Northern Rivers etc)	16	21.6
	PosHet events	1	1.4
Structured program		15	20.3
	Pos Retreat	11	14.9
	Genesis	4	5.4
Online forums in Australia		8	10.8
Online forums internationally		4	5.4
Positive Living Centre		11	14.9
Campaign development discussion groups / focus groups		13	17.6
Focus groups for this peer support review		9	12.2
Any listed program		39	52.7

*Respondents may have participated in more than one program.

3.2 Analysis by program objectives

The following analysis is based on the core objectives for the peer support programs identified in the staff workshops.

Objective	Section
1. Increase in reported HIV peer connectedness	3.2.1
2. Increase in indicators of support from and to other HIV positive people	3.2.2
3. Increase in background / foundation knowledge for living with HIV and where to find it (health literacy)	3.2.3
4. Increase in range of skills and approaches regarding living with HIV*	3.2.4
5. Increase in confidence / experience in living with HIV*	3.2.5
6. Increase in quality of life / wellbeing indicators	3.2.6

3.2.1 HIV peer connectedness (Objective 1)

Respondents were asked a series of questions about HIV peer connectedness, including the number of HIV-positive friends they could talk to about living with HIV and the contexts in which these conversations might happen.

The majority of respondents (92%) knew at least one person living with HIV that they can talk to. Although the numbers were small and should be interpreted with caution, 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 ($p < .05$, Table 8) but no difference on general health domain.

Those who attend facilitated groups are more likely to have higher numbers of positive friends who they can talk to about living with HIV ($p < .05$, Table 9). However there is no difference in number of HIV-positive friends between those who attend structured or social events and those who do not attend.

Table 7: Do you have friends with HIV that you can talk to about living with HIV?

Response	Frequency	Percent
None or none that I can talk to	5	7.7
1 or 2 HIV positive friends	26	40.0
3 or more HIV positive friends	34	52.3
Total*	65	100.0

*All those respondents who reported no HIV positive friends were 40 years or over, diagnosed 1996 or after, and 4 of the 5 lived in post code under 2100.

Table 8: ANOVA analysis of friends with HIV that I can talk with

Do you have friends with HIV that you can talk to about living with HIV?	Quality of Life: General Health <i>mean</i>	Quality of Life: Psychological <i>mean</i>	Quality of Life: Social Domain Average <i>mean</i>	Self Efficacy Scale Averaged <i>mean</i>
None or none that I can talk to	3.1	1.9	2.0	2.0
1 or 2 HIV+ friends	3.6	3.3	3.2	3.0
3 or more HIV+ friends	3.7	3.4	3.4	3.1
Total	3.6	3.3	3.2	3.0
ANOVA	$p = .430$	$p = .001$	$p = .021$	$p = .000$
	$F(2,57) = .857$	$F(2,59) = 7.543$	$F(2,57) = 4.156$	$F(2, 57) = 11.246$

Table 9: Friends with HIV that I can talk with by attendance at facilitated peer groups

Do you have friends with HIV that you can talk to about living with HIV?	Attended facilitated groups: 7-2-9, After Hours, Nexus <i>n (%)</i>		
	Attended in past 6 months	Did not attend in past 6 months	Total
$p = 0.014$			
None or none that I can talk to	3 (18%)	2 (4.1%)	5 (7.7%)
1 or 2 HIV+ friends	2 (12.5%)	24 (49.0%)	26 (40.0%)
3 or more HIV+ friends	11 (68.8%)	23 (46.9%)	34 (52.3%)
Total	16 (100%)	49 (100%)	65 (100%)

The settings in which these discussions take place is most likely to be with other HIV-positive friends, with friends generally and then workshops, peer support groups and HIV-positive social events. It is uncommon for these discussions to occur online among the respondents in the survey (Table 10).

Table 10: In which settings do these discussions about living with HIV take place?

Response	Never	Rarely	Sometimes	Many times	Most/all of time	Total*
Friends generally	7 (11%)	18 (29%)	31 (49%)	5 (8%)	2 (3%)	63 (100%)
Family	26 (42%)	15 (24%)	16 (26%)	5 (8%)	0 (0%)	62 (100%)
With other HIV-positive friends	2 (3.2%)	7 (11%)	27 (44%)	20 (32%)	6 (10%)	62 (100%)
With friends I have met through ACON/Positive Life programs	13 (23%)	12 (21%)	16 (28%)	8 (14%)	8 (14%)	57 (100%)
While at workshops	14 (25%)	7 (12%)	16 (29%)	11 (20%)	8 (14%)	56 (100%)
While at peer support groups	15 (26%)	7 (12%)	16 (28%)	10 (18%)	9 (16%)	57 (100%)
Online	20 (35%)	15 (26%)	17 (30%)	3 (5%)	2 (4%)	57 (100%)
While at social events for people with HIV	13 (23%)	12 (21%)	16 (28%)	10 (18%)	6 (10%)	57 (100%)
While at HIV related information forums	14 (24%)	13 (22%)	16 (28%)	7 (12%)	8 (14%)	58 (100%)

*Between 11 and 17 respondents did not answer each question. 11 of these respondents did not answer the number of friends with HIV question or reported they did not have any HIV-positive friends they could talk to about HIV.

Table 11: Range of discussion settings referred to by respondents*

Workshops	Support groups	Online sites	Social events	HIV-related information forums
<ul style="list-style-type: none"> • ACON (4) • AFAO focus group (1) • Albion Centre (1) • Genesis (7) • Healthy Life + (1) • Phoenix (4) • Peer support training (1) • Positive Life (3) • Poz Het (2) • Retreat (2) • Treatments (1) • Words to say it (1) 	<ul style="list-style-type: none"> • 7-2-9 (12) • ACON (5) • After Hours (7) • Ankali (1) • CSN (1) • Luncheon Club (2) • NRAHS/ACON-NR organised (1) • PLC (3) • PozNeg Group (1) • Poz Het (1) • Retreat (1) • Sanctuary 7-2-9 – 12 	<ul style="list-style-type: none"> • Bareback RT • The Body - 2 • Dudesnude (1) • Email (1) • Gay chatrooms and websites generally (4) • Gay.com (1) • Gaydar (8) • Gaypoz (1) • HIV forums (1) • Manhunt (6) • NORCOWAM plwha (2) • Poz.com – 3 • Samesame (1) 	<ul style="list-style-type: none"> • 7-2-9 (2) • ACON (1) • BGF (1) • Dance party (2) • Dance – Northern Rivers • Fairs (1) • Gatherings of friends (3) • Genesis (1) • Luncheon club (2) • NR Luncheon Club • Planet Positive (12) • Pos Life drinks (1) • PozHet (1) • Retreat (1) • Xmas Party PLC (1) 	<ul style="list-style-type: none"> • 7-2-9 (1) • ACON (1) • ACON treatments by sea (2) • ACON NR treatments (1) • AFAO Pos Services Forum (1) • The Body (1) • Regional HIV Forum (1) • Garvan Futures Update (3) • Genesis (2) • Hep C (1) • PLC (1) • Positive Life (1) • Poz Het (1) • Sex Pigs Forum (1) • Smoking (1)

*Some respondents indicated they had not attended for some time.

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

Respondents were asked to indicate their degree of agreement to the following statements:

- I believe I am supportive to my friends living with HIV
- My friends living with HIV are supportive towards me.

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 ($p > .05$).

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 ($p < .05$). However, the numbers were small with significant numbers not completing the questions and should be interpreted with some caution (Table 14). There was no statistical difference in the proportion who felt they were less supportive towards their HIV-positive friends.

Table 12: I believe I am supportive to my friends living with HIV

Response	Frequency	Percent
Not at all	0	0
A little	2	3.9
Moderately	3	5.9
Mostly	15	29.4
Completely	31	60.8
Total*	51	100.0

*23 respondents did not answer this question, 11 of whom did not answer the number of friends with HIV question or reported they did not have any HIV positive friends they could talk to about HIV.

Table 13: My friends living with HIV are supportive towards me

Response	Frequency	Percent
Not at all	2	3.8
A little	7	13.5
Moderately	9	17.3
Mostly	27	51.9
Completely	7	13.5
Total*	52	100.0

*22 respondents did not answer this question, 11 of whom did not answer the number of friends with HIV question or reported they did not have any HIV positive friends they could talk to about HIV.

Table 14: ANOVA analysis of my friends support me by quality of life domains and self efficacy

Response	Quality of Life: General Health <i>mean (n)</i>	Quality of Life: Psychological <i>mean (n)</i>	Quality of Life: Social Domain Average <i>mean (n)</i>	Self Efficacy Scale Averaged <i>mean (n)</i>
Not at all or a little	2.6 (9)	2.1 (9)	1.9 (9)	2.3 (9)
Moderately	3.6 (7)	3.6 (8)	3.1 (8)	3.1 (8)
Mostly or completely	3.9 (33)	3.6 (33)	3.6 (33)	3.2 (32)
Total	3.6 (49)	3.3 (50)	3.2 (50)	3.0 (49)
ANOVA	p = .001	p = .000	p = .000	p = .000
	F (2,46) =8.817	F (2,47) =16.759	F(2,47) =25.894	F(2, 46) =13.739
Test of homogeneity of variances (Levine Statistic) showed no significant differences in the variances.				

3.2.3 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 with their healthcare provider (80%) (Table 15). With such a high proportion, there is no significant difference on other variables such as age, year of diagnosis or program access ($p > .05$).

However 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). Those with more recent diagnosis are less likely to feel confident. There is no clear difference in age or program accessed.

Table 15: Health literacy confidence

	Not at all or a little <i>n (%)</i>	Moderately <i>n (%)</i>	Mostly or completely <i>n (%)</i>	Total <i>n (%)</i>
How confident do you feel in forming good relationships with your healthcare provider?	0 (0%)	8 (11.6%)	61 (88.4%)	69 (100%)
To what extent do you feel you have enough knowledge about HIV to manage your health?	7 (10.3%)	12 (17.6%)	49 (72.1%)	68 (100%)
Do you feel you have the skills and resources to make treatment decisions with your health care provider?	2 (2.9%)	12 (17.4%)	55 (79.7%)	69 (100%)

Table 16: ANOVA analysis of knowledge about HIV to manage your health

To what extent do you feel you have enough knowledge about HIV to manage your health?	Quality of Life: Psychological <i>mean (n)</i>	Self Efficacy Scale Averaged <i>mean (n)</i>
Not at all or a little	2.4 (7)	2.3 (7)
Moderately	3.1 (10)	3.0 (10)
Mostly or completely	3.4 (45)	3.1 (43)
Total	3.2 (62)	3.0 (60)
ANOVA	p= .008	p= .004
	F (2,59) =5.277	F(2, 57) =6.200
Test of homogeneity of variances (Levine Statistic) showed no significant differences.		

Most respondents (60%) could name three or more health and community services where they could gain help if they needed it. Just over one-fifth (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 ($p < .05$) (Table 18). There is no significant difference on the basis of confidence in having enough knowledge to manage health or in living in the metropolitan or regional areas.

Table 17: Number of health or community services named

Response	Frequency	Percent
0	16	21.6
1	6	8.1
2	8	10.8
3	8	10.8
4	7	9.5
5	9	12.2
6	20	27.0
Total	74	100.0

Table 18: Number of services nominated by attendance at any listed peer program in past six months

p=.003	Attended in past 6 months <i>n (%)</i>	Did not attend in past 6 months <i>n (%)</i>	Total <i>n (%)</i>
No services nominated	2 (5.1%)	14 (40.0%)	16 (21.6%)
1 or 2 services nominated	10 (25.6%)	4 (11.4%)	14 (18.9%)
3 or 4 services nominated	8 (20.5%)	7 (20.0%)	15 (20.3%)
5 or 6 services nominated	19 (48.7%)	10 (28.6%)	29 (39.2%)
Total	39	35	74 (100%)

Respondents could name up to six health and community services. Table 19 provides an overview of the range and order of services nominated by respondents.

Table 19: Range of services nominated by respondents

Service	First	Second	Third	Fourth	Fifth	Sixth	Total
ACON	19	12	9		5	1	46
ACON Northern Rivers	1	2					3
ACON Mid-North Coast	1						1
BGF	4	8	5	5	4	2	28
Positive Living Centre	3	3	2	4	6	4	22
Positive Life	5	9	10	5	1		19
Albion St Clinic	3	4	3	4	4	1	19
Ankali			1	2	4	1	8
St Vincent's Hospital			2	3		3	8
GP	4		2				6
SHAIDS Clinic (NRAHS)	3	2					5
Taylor Square Clinic	3	1					4
CSN		1	1	1			3
HIV doctor		3					3
Stanford House				1	1	1	3

Service (continued)	First	Second	Third	Fourth	Fifth	Sixth	Total
Area Health Service HIV community care teams		1		1			2
PozHet	1				1		2
Redfern Community Health	1		1				2
RPA Sexual Health Clinic			2				2
7-2-9					1		1
Clinic 16	1						1
Darlinghurst Com Health						1	1
Eye clinic		1					1
Food Support Network					1		1
Former GP/HIV Clinician in Sydney				1			1
G&L Counselling Service			1				1
gay press						1	1
Government new Health Plus department	1						1
GP (S100 prescriber/HIV Doctor)	1						1
Griffith NSW	1						1
HALC				1			1
HIV 24 hour info line				1			1
HIV Community Team			1				1
IBAC	1						1
IMC RPAH Camperdown 2050	1						1
John Hunter Hospital	1						1
Karumah Positive Living Centre				1			1
Lifeline	1						1
Local community clinic at hospital				1			1
local sexual health service				1			1
Mardi Gras			1				1
Men & Family Centre Lismore						1	1
Miami Sexual Health Clinic	1						1
Mid-North Coast Sexual Health Service/ Clinic		1					1
My HIV Specialist when I can find him					1		1
my S100 prescriber/Dr			1				1
Northern Rivers Community Legal Centre			1				1
onq human resources				1			1
Parramatta sexual health clinic				1			1
Polly's				1			1
Positive Support Network, Gosford						1	1
QPP					1		1
QUAC				1			1
RPA hospital				1			1
RPA IBAC						1	1
Sexual Health Clinic at Gosford Hospital	1						1
The Body website						1	1
Tropical Fruits		1					1
Websites						1	1
No other services nominated	16	22	30	38	45	54	
Total respondents	74	74	74	74	74	74	

3.2.4 Skills, confidence and experience in living with HIV* (Objectives 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. Some of these factors overlap with other objectives and are summarised in Table 20, which shows the section where the results are presented.

Table 20: Living with HIV sub factors and location of analysis

Sub factor	Location
1. Relationship management	3.2.4 – but only in limited context of disclosure of HIV status and safe sex negotiation
2. Confidence in HIV status disclosure management	3.2.4
3. Resilience in responding to challenges and stigma	3.2.4
4. Accessing support and advice from non HIV+ peers	3.2.4
5. Advocacy for and management of own health needs	Health literacy objective 3.2.3
6. Accessing information and staying up to date	Health literacy objective 3.2.3
7. Accessing support and advice from HIV+ peers	Support from HIV positive peers objective 3.2.2
8. Social connectedness	Quality of life and Self efficacy scale 3.2.5
9. Independence beyond formal services	Quality of life and Self efficacy scale 3.2.5

Table 21 provides an overview of the results of the key questions for sub factors 1–4 noted in Table 20. The following sections discuss each of these questions in more detail.

Table 21: Key questions related to living with HIV sub factors 1–4

	Not at all n (%)	A little n (%)	Moderately n (%)	Mostly n (%)	Completely n (%)	Total n (%)
Has having HIV made you feel less sexually attractive?	9 (14.3%)	18 (28.6%)	13 (20.6%)	12 (19.0%)	11 (17.5%)	63 (100%)
How confident are you to talk about safe sex?	0 (0%)	5 (8.1%)	17 (27.4%)	18 (29.0%)	22 (35.5%)	62 (100%)
How confident are you in deciding when and how you disclose your HIV status?	5 (8.2%)	6 (9.8%)	19 (31.1%)	15 (24.6%)	16 (26.2%)	61 (100%)
How confident do you feel in dealing with HIV-related stigma and discrimination?	10 (14.9%)	15 (22.4%)	17 (25.4%)	15 (22.4%)	10 (14.9%)	67 (100%)

Sexually attractive

More than half of the respondents (57%) felt moderately or stronger that having HIV had made them feel less sexually attractive (Table 19). However those respondents who had not attended social support events in the past six months were more likely to report that HIV had made them feel less sexually attractive than those who attended social programs ($p < 0.05$). There is no difference on the basis of other peer support programs, number of friends who are HIV positive, age, year diagnosed or postcode.

Table 22: Has living with HIV made you feel less sexually attractive by attendance at social events (Planet Positive, Social Meals, Poz Het events)

Has living with HIV made you feel less sexually attractive p=.003	Attended peer social events in past 6 months <i>n (%)</i>	Did not attend peer social events in past 6 months <i>n (%)</i>
Not at all	5 (21.7%)	4 (10.0%)
A little	12 (52.2%)	6 (15.0%)
Moderately	4 (17.4%)	9 (22.5%)
Mostly	1 (4.3%)	11 (27.5%)
Completely	1 (4.3%)	10 (25.0%)
Total	23 (100.0%)	40 (100.0%)

To complement these results, it should be noted that less than 20% of the survey respondents who answered the quality of life questions indicated they were satisfied with their sex life (Table 23).

Table 23: Satisfaction with sex life (from Quality of Life scale)

How satisfied are you with your sex life?	Frequency	Percent
Very dissatisfied	11	18.0
Dissatisfied	17	27.9
Neither satisfied nor dissatisfied	22	36.1
Satisfied	8	13.1
Very satisfied	3	4.9
Total	61	100.0

How confident are you to talk about and/or ask for safe sex?

Nearly two-thirds (65%) reported feeling mostly or completely confident to talk about safe sex. Those who are less confident tended to score lower on the psychological and social domains of the quality of life scales, however there is no difference on the self efficacy scale. There is no significant difference on basis of attendance of peer support programs, number of friends with HIV, when diagnosed with HIV, age or postcode.

Table 24: Confidence to talk about or ask for safe sex

How confident are you to talk about or ask for safe sex	Frequency	Percent
A little	5	8.1
Moderately	17	27.4
Mostly	18	29.0
Completely	22	35.5
Total	62	100.0

Table 25: ANOVA: Confidence in talking about safe sex by Quality of Life Domain

How confident are you to talk about or ask for safe sex	Quality of Life: Psychological <i>mean (n)</i>	Quality of Life: Social Domain Average <i>mean (n)</i>
A little	2.4 (5)	2.4 (5)
Moderately	3.0 (17)	3.1 (17)
Mostly	3.3 (18)	3.2 (18)
Completely	3.7 (22)	3.6 (21)
Total	3.3 (62)	3.2 (61)
ANOVA	p= .007	p= .038
	F (3,58) =4.408	F(3,57) =2.993
Test of homogeneity of variances (Levine Statistic) showed no significant differences.		

Confidence in HIV status disclosure management

Half of respondents (51%) feel confident deciding when and how they disclose their HIV status (Table 26). Those who feel more confident generally have more friends with HIV and have attended peer-based social events in the past six months ($p < .05$), and generally scored higher on the psychological and social domains of quality of life and on the self efficacy scale ($p < .05$) (Tables 26, 27 and 28). There is no difference on attendance of other types of peer support groups.

Table 26: Confidence in deciding when and how to disclose HIV status

How confident are you in deciding when and how you disclose your HIV status?	Frequency	Percent
Not at all	5	8.2
A little	6	9.8
Moderately	19	31.1
Mostly	15	24.6
Completely	16	26.2
Total	61	100.0

Table 27: Confidence in disclosing HIV status by attendance at social events

How confident are you in deciding when and how you disclose your HIV status? p=.016	Attended peer social events in past 6 months <i>n (%)</i>	Did not attend peer social events in past 6 months <i>n (%)</i>	Total <i>n (%)</i>
Not at all or a little	0 (0%)	11 (28.2%)	11 (18.0%)
Moderately	7 (31.8%)	12 (30.8%)	19 (31.1%)
Mostly or completely	15 (68.2%)	16 (41.0%)	31 (50.8%)
Total	22 (100%)	39 (100%)	61 (100%)

Table 28: Confidence in disclosing HIV status by friends with HIV

How confident are you in deciding when and how you disclose your HIV status? p=.012	No HIV+ friends or none that I can talk to n (%)	1 or 2 HIV+ friends n (%)	3 or more HIV+ friends n (%)	Total n (%)
Not at all or a little	3 (75.0%)	6 (25.0%)	2 (6.3%)	11 (18.3%)
Moderately	0 (0%)	6 (25.0%)	12 (37.5%)	18 (30.0%)
Mostly or completely	1 (25.0%)	12 (50.0%)	18 (56.3%)	31 (51.7%)
Total	4 (100%)	24 (100%)	32 (100%)	60 (100%)

Table 29: ANOVA: Confidence to deal with stigma and discrimination by quality of life and self efficacy

How confident do you feel in dealing with HIV-related stigma and discrimination?	Quality of Life: Psychological mean (n)	Quality of Life: Social Domain Average mean (n)	Self Efficacy Scale Averaged mean (n)
not at all or a little	2.4 (11)	2.4 (11)	2.5 (11)
moderately	3.3 (19)	3.3 (19)	3.1 (18)
mostly or completely	3.6 (31)	3.5 (30)	3.2 (31)
Total	3.3 (61)	3.2 (60)	3.0 (60)
ANOVA	p= .001	p= .000	p= .001
	F (2,58) =8.667	F(2,57) =9.627	F(2,57) =7.652
Test of homogeneity of variances (Levine Statistic) showed no significant differences			

The majority of respondents feel mostly or completely confident to disclose their HIV status to their regular partner (70%), their friends (60%) and to their general practitioner (89%) (Table 30). While 45% of respondents feel mostly or completely confident disclosing to family, a third of the sample (33%) do not feel at all confident. The majority only feel a little or not at all confident to disclose their status to people they work with (61%), however 18% feel completely confident to disclose in this context. Disclosing to casual or new sexual partners is more evenly distributed, with only around half feeling confident to disclose their status in this context (47%).

Respondents diagnosed before 1996 tend to be more confident in disclosing to family, work and friends than those more recently diagnosed. Indications are for a similar trend for disclosure to casual partners; however the figures are too small to calculate significance. There is no significant difference on accessing of peer support programs or on post code.

Table 30: Which people do you feel confident disclosing your HIV status to?

	Not at all n (%)	A little n (%)	Moderately n (%)	Mostly n (%)	Completely n (%)	n/a n (%)	Total n (%)
Family	23 (33%)	6 (9%)	5 (7%)	13 (19%)	18 (26%)	4 (6%)	69 (100%)
Friends	5 (7%)	13 (19%)	8 (12%)	18 (26%)	23 (34%)	1 (2%)	68 (100%)
General practitioner	2 (3%)	2 (3%)	3 (4%)	8 (12%)	53 (77%)	1 (1%)	69 (100%)
Regular partner / relationship	2 (3%)	3 (4%)	4 (6%)	11 (16%)	37 (54%)	11 (16%)	68 (100%)
Casual / new sexual partner	6 (9%)	13 (20%)	9 (14%)	12 (18%)	19 (29%)	7 (11%)	66 (100%)
Work or study	27 (41%)	13 (20%)	1 (2%)	6 (9%)	12 (18%)	7 (11%)	66 (100%)

NB: Between 5 and 9 respondents did not answer each question.

Table 31: Disclosure of HIV status at work by year diagnosed

p=.040	pre 1996 n (%)	1996 to 2004 n (%)	2005 onwards n (%)	Total n (%)
Not at all or a little	10 (47.6%)	17 (77.3%)	10 (90.9%)	37 (68.5%)
Moderately	0 (0%)	1 (4.5%)	0 (0%)	1 (1.9%)
Mostly or completely	11 (52.4%)	4 (18.2%)	1 (9.1%)	16 (29.6%)
Total	21 (100%)	22 (100%)	11 (100%)	54 (100%)

Additional comments in the online survey tend to include explanations of when respondents did or did not disclose depending on context. Most of these statements concerned rejection in social or sexual contexts.

If I am just having casual safe sex, I would not necessarily disclose my status. However, if I am looking to tie down myself into a relationship, then certainly I will disclose my status. It is very important to the other person ... and to me too! (Online survey)

When I disclose my status I always get rejected. (Online survey)

Resilience in responding to and stigma and discrimination

A quarter of respondents reported experiencing HIV-related stigma or discrimination in the previous 12 months (Table 32). Online survey comments tend to focus on disclosure in sexual and relationship issues, or organisational discrimination, particularly when accessing services in outer suburbs or rural areas. Respondents mainly reported being moderately confident in dealing with stigma and discrimination (Table 33) and is not dependant on whether they experienced stigma or discrimination in the past 12 months.

Table 32: Experiences of stigma and discrimination in past 12 months

Response	Frequency	Percent
Yes	18	26.1
No	51	73.9
Total	69	100.0

Table 33: How confident do you feel in dealing with HIV-related stigma and discrimination?

Response	Frequency	Percent
Not at all	10	14.9
A little	15	22.4
Moderately	17	25.4
Mostly	15	22.4
Completely	10	14.9
Total	67	100.0

Those who attended peer support programs in the past six months are no more or less likely to feel confident in responding to stigma and discrimination. There is also no difference on age categories, relationship status or number of friends with HIV.

Those who feel mostly or completely confident to deal with stigma and discrimination average higher on the psychological and social domains of quality of life and on the self efficacy scale than those who feel less confident ($p < .05$) (Table 34). There are indications that those diagnosed more recently are less confident to deal with stigma and discrimination, but the sample is too small to calculate statistical significance.

Table 34: ANOVA: Confidence to deal with stigma and discrimination by quality of life and self efficacy

How confident do you feel in dealing with HIV-related stigma and discrimination?	Quality of Life: Psychological mean (n)	Quality of Life: Social Domain Average mean (n)	Self Efficacy Scale Averaged mean (n)
Not at all or a little	2.7 (22)	2.8 (22)	2.7 (21)
Moderately	3.4 (15)	3.1 (15)	3.1 (14)
Mostly or completely	3.8 (24)	3.7 (23)	3.3 (24)
Total	3.3 (61)	3.2 (60)	3.0 (59)
ANOVA	p= .000	p= .002	p= .000
	F (2,57) =10.243	F(2,58) =7.299	F(2, 57) =8.955
Test of homogeneity of variances (Levine Statistic) showed no significant differences			

Accessing support and advice from HIV-negative peers

Most respondents rate support from gay friends as very important or essential, while support from straight friends also rates strongly. Support from family is equally rated as important and unnecessary (Table 35).

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 than those who see support from family or straight friends as important or essential ($p < .05$). There is no difference between importance of support from gay friends and attendance at peer support programs. However, there are small, but significant, indications that those who feel support from gay friends is very important or essential generally have slightly higher average scores on the social domain and self efficacy scales than those who feel support from gay friends is of limited use ($p < .05$). 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.

Table 35: How important to you are the following

	Unnecessary n (%)	Of limited use to me n (%)	Important and useful to me n (%)	Very important and useful to me n (%)	Essential n (%)	Total n (%)
Gaining support from family	14 (23%)	13 (22%)	11 (18%)	14 (23%)	8 (13%)	60 (100%)
Gaining support from gay friends	0 (0%)	9 (16%)	13 (23%)	20 (35%)	15 (26%)	57 (100%)
Gaining support from straight friends	1 (2%)	18 (30%)	21 (35%)	14 (23%)	6 (10%)	60 (100%)

NB: Between 5 and 14 respondents did not answer each question.

Table 36: Gaining support from family and straight friends by accessing peer support programs

	Gaining support from family (p= .022)		Gaining support from straight friends (p= .044)	
	Attended peer support programs in past 6 months <i>n (%)</i>	Did not attend peer support program in past 6 months <i>n (%)</i>	Attended peer support programs in past 6 months <i>n (%)</i>	Did not attend peer support program in past 6 months <i>n (%)</i>
Unnecessary or of limited use to me	21 (55.3%)	6 (27.3%)	16 (42.1%)	3 (13.6%)
Important and useful to me	8 (21.1%)	3 (13.6%)	15 (39.5%)	6 (27.3%)
Very important and useful to me or essential	9 (23.7%)	13 (59.1%)	7 (18.4%)	13 (59.1%)
Total*	38 (100%)	22 (100%)	38 (100%)	22 (100%)

*Between 5 and 14 respondents did not answer each question. Importance of gaining support from gay friends showed no significant association with accessing support programs.

Table 37: ANOVA: Gaining support from gay friends by quality of life and self efficacy

	Quality of Life: Social Domain Average <i>mean (n)</i>	Self Efficacy Scale Averaged <i>mean (n)</i>
Unnecessary or of limited use to me	2.7 (9)	2.6 (9)
Important and useful to me	3.0 (13)	3.1 (13)
Very important and useful to me or essential	3.4 (35)	3.2 (34)
Total	3.2 (57)	3.1 (56)
ANOVA	p= .032	p= .006
	F (2,54) =3.672	F(2,53) =5.553
Test of homogeneity of variances (Levine Statistic) showed no significant differences.		

3.2.5 Quality of life and wellbeing indicators (Objective 6)

The general wellbeing, social and psychological domains from the WHO HIV Quality of Life survey¹ and the General Self Efficacy Scale² were included in the online survey. Both these scales have been shown to be highly reliable across populations and strong internal consistency scores.

All the domains of the WHOQOL HIV BREF Quality of Life scale were assessed for their applicability and priority within the study. To reduce the size of the survey, only the social, psychological and general wellbeing domains were used. Therefore the survey does not measure all aspects of quality of life as assessed by the WHOQOL HIV BREF instrument.

Table 38 provides a general picture of the diversity of the scores among the online survey respondents. In these figures, 1 is a low score and 5 is a high score. A key intention here is to produce a baseline which can be assessed in six months' time. The online sample was divided by various demographic and program participation variables and the average and distribution of the scores were compared using one way analysis of variance (ANOVA).

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.

Table 38: Summary results for quality of life domains and self efficacy scale

<p>Quality of Life: General health and wellbeing</p> <ul style="list-style-type: none"> • How would you rate your quality of life? • How satisfied are you with your health? 	
<p>Quality of Life: Psychological Domain</p> <ul style="list-style-type: none"> • How much do you enjoy life? • How well are you able to concentrate? • Are you able to accept your body and appearance? • How satisfied are you with yourself? • How often do you have negative feelings such as blue mood, despair, anxiety, depression? 	
<p>Quality of Life: Social Domain</p> <ul style="list-style-type: none"> • To what extent do you feel accepted by the people you know? • How satisfied are you with your personal relationships? • How satisfied are you with your sex life? • How satisfied are you with the support you get from your friends? 	
<p>General Self Efficacy Scale</p> <ul style="list-style-type: none"> • I can always manage to solve difficult problems if I try hard enough • If someone opposes me, I can find the means and ways to get what I want • It is easy for me to stick to my aims and accomplish my goals • I am confident that I could deal efficiently with unexpected events • Thanks to my resourcefulness, I know how to handle unforeseen situations • I can solve most problems if I invest the necessary effort • I can remain calm when facing difficulties because I can rely on my coping abilities • When I am confronted with a problem, I can usually find several solutions • If I am in trouble, I can usually think of a solution? • I can usually handle whatever comes my way 	

Attending peer programs and Quality of Life Domain and Self Efficacy Scale Scores

There are indications that those who have accessed facilitated peer support programs in the previous six months have average lower scores on the psychological and social domains of the Quality of Life scale, however there is no difference for the general self efficacy scale (Table 39). There are no significant associations between the quality of life domains of self efficacy scale and men who have attended other types of peer programs in past six months. There is also no significant difference on the basis of age, year diagnosed, relationship status or post code.

The indication may be that the facilitated groups tend to reach those who feel less socially or psychologically supported elsewhere.

Table 39: ANOVA: Attending peer programs in previous six months by Quality of Life Domain and Self Efficacy Scale

	Quality of Life: Social Domain Average mean (n)	Self Efficacy Scale Averaged mean (n)
Attended in past 6 months	2.9 (17)	2.8 (17)
Did not attend in past 6 months	3.4 (46)	3.4 (44)
Total	3.3 (63)	3.2 (61)
ANOVA	p= .034	p= .008
	F(1,61)=4.730	F(1,59)=7.624
Test of homogeneity of variances (Levine Statistic) showed no significant differences		

3.3 Process indicators from online survey

Importance of types of support, sharing and information

Importance of types of support

Although almost all respondents rated gaining support from other people with HIV as important or higher (86%) (Table 40), more respondents gave high importance to gaining support from gay friends generally. Almost two-thirds feel that being able to give support to other PLHIV is very important or essential (65%) (Table 40).

There is no significant difference in any of the items in Table 40 when compared on the basis of peer or social support program accessed, age, year diagnosed, or quality of life or self efficacy indicators ($p > 0.05$). While gaining support from and providing support to other PLHIV is almost universally considered important, there is much more diversity in the rating of the importance of developing friendships with people met through HIV-positive peer support groups. The perceived importance of spending time with people who had lived with HIV for a similar amount of time is also fairly evenly spread across the scale, and does not differ on the basis of program accessed, age or year diagnosed.

Table 40: How important to you are the following?

	Unnecessary <i>n (%)</i>	Of limited use to me <i>n (%)</i>	important and useful to me <i>n (%)</i>	Very important and useful to me <i>n (%)</i>	Essential <i>n (%)</i>	Total <i>n (%)</i>
Gaining support from other people with HIV	0 (0%)	8 (13.8%)	24 (41.4%)	16 (27.6%)	10 (17.2%)	58 (100%)
Being able to give support to other people with HIV	0 (0%)	5 (8.6%)	15 (25.9%)	26 (44.8%)	12 (20.7%)	58 (100%)
Spending time with people who have lived with HIV for around same amount of time as me	3 (5.3%)	16 (28.1%)	13 (22.8%)	17 (29.8%)	8 (14.0%)	57 (100%)
Spending time with people with HIV with the same sexuality as me	5 (8.5%)	9 (15.3%)	17 (28.8%)	15 (25.4%)	13 (22.0%)	59 (100%)
Developing friendships with people I met through peer support groups	6 (10.2%)	17 (28.8%)	18 (30.5%)	14 (23.7%)	4 (6.8%)	59 (100%)
Socialising with people I have met through organised peer support groups	6 (10.2%)	16 (27.1%)	24 (40.7%)	10 (16.9%)	3 (5.1%)	59 (100%)
Opportunity to meet a potential partner who is HIV positive	9 (15.5%)	7 (12.1%)	17 (29.3%)	15 (25.9%)	10 (17.2%)	58 (100%)

Sharing stories and experiences

All items in the sharing stories question were seen as having some importance, with managing HIV being the most likely to be viewed as very important or essential. However, sharing stories and experiences about 'disclosing HIV status', 'HIV and sex', and 'HIV and relationships' was more likely to be highly valued by respondents diagnosed after 1996 than those diagnosed prior to 1996 ($p < 0.05$).

Table 41: How important is sharing stories and experiences about:

	Unnecessary <i>n (%)</i>	of limited use to me <i>n (%)</i>	important and useful to me <i>n (%)</i>	Very important and useful to me <i>n (%)</i>	Essential <i>n (%)</i>	Total <i>n (%)</i>
Coming to terms with a HIV positive diagnosis	7 (11.7%)	17 (28.3%)	10 (16.7%)	14 (23.3%)	12 (20.0%)	60 (100%)
Managing HIV	3 (5.0%)	6 (10.0%)	15 (25.0%)	17 (28.3%)	19 (31.7%)	60 (100%)
Disclosing HIV status	5 (8.3%)	9 (15.0%)	20 (33.3%)	15 (25.0%)	11 (18.3%)	60 (100%)
HIV and sex	2 (3.4%)	10 (16.9%)	23 (39.0%)	13 (22.0%)	11 (18.6%)	59 (100%)
HIV and relationships	2 (3.6%)	10 (17.9%)	21 (37.5%)	12 (21.4%)	11 (19.6%)	56 (100%)

Table 42: How important is sharing stories and experiences about:

	Disclosing HIV status (p= .040)		HIV and sex (p= .034)		HIV and relationships (p= .021)	
	Attended peer support programs in past 6 mos. n (%)	Did not attend in past 6 mos. n (%)	Attended in past 6 mos. n (%)	Did not attend in past 6 mos. n (%)	Attended in past 6 mos. n (%)	Did not attend in past 6 mos. n (%)
Unnecessary or of limited use to me	9 (37.5%)	5 (15.2%)	9 (37.5%)	3 (9.1%)	9 (39.1%)	3 (9.7%)
Important and useful to me	4 (16.7%)	15 (45.5%)	7 (29.2%)	15 (45.5%)	5 (21.7%)	15 (48.4%)
Very important and useful to me or essential	11 (45.8%)	13 (39.4%)	8 (33.3%)	15 (45.5%)	9 (39.1%)	13 (41.9%)
Total	24 (100%)	33 (100%)	24 (100%)	33 (100%)	23 (100%)	31 (100%)

Gaining information

The items in the gaining information question are seen as having some importance for almost all respondents, and do not vary on the basis of general wellbeing, social or psychological domains, general self efficacy scale ($p>.05$), or year of diagnosis($p>0.05$) (Table 43). However those attending facilitated groups and older age groups are most likely to highly value managing health and wellbeing ($p<0.05$).

Table 43: How important is gaining information about:

	Unnecessary n (%)	Of limited use to me n (%)	Important and useful to me n (%)	Very important and useful to me n (%)	Essential n (%)	Total n (%)
Treatments or managing side effects	1 (1.7%)	2 (3.3%)	12 (20.0%)	18 (30.0%)	27 (45.0%)	60 (100%)
Managing health and wellbeing generally	0 (0%)	2 (3.3%)	12 (20.0%)	19 (31.7%)	27 (45.0%)	60 (100%)
Other health or support services	0 (0%)	9 (15.3%)	14 (23.7%)	19 (32.2%)	17 (28.8%)	59 (100%)

Coordination and facilitation of peer support programs

Table 44 summaries the responses relating to aspects of running a peer support program from the online survey. The highest results are in bold.

The most highly rated items 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.

For most items, there is no significant difference on demographic, general wellbeing, psychological, social domains or general self efficacy ($p>0.05$). However, one-off workshops to discuss a topic, being able to decide the topic and groups that meet monthly to discuss a topic are more highly valued by people diagnosed after 1996 ($p<0.05$) (Tables 45 and 46).

Table 44: How important to you are these aspects in the running of a peer group program

	Unnecessary <i>n (%)</i>	Of limited use to me <i>n (%)</i>	Important and useful to me <i>n (%)</i>	Very important and useful to me <i>n (%)</i>	Essential <i>n (%)</i>	Total <i>n (%)</i>
A place where group members feel comfortable and safe to talk about their experiences	3 (5.2%)	3 (5.2%)	10 (17.2%)	9 (15.5%)	33 (56.9%)	58 (100%)
Well-facilitated discussions that stay on topic and time	3 (5.3%)	4 (7.0%)	15 (26.3%)	17 (29.8%)	18 (31.6%)	57 (100%)
Discussions that are able to move away from the original topic if that is what some group members are interested in discussing	3 (5.3%)	5 (8.8%)	26 (45.6%)	13 (22.8%)	10 (17.5%)	57 (100%)
A coordinator with strong and effective group discussion facilitation skills	3 (5.2%)	3 (5.2%)	15 (25.9%)	10 (17.2%)	27 (46.6%)	58 (100%)
Having time to talk informally with friends I have met through peer group programs	3 (5.2%)	3 (5.2%)	21 (36.2%)	16 (27.6%)	15 (25.9%)	58 (100%)
A coordinator who is HIV positive	7 (12.3%)	7 (12.3%)	15 (26.3%)	16 (28.1%)	12 (21.1%)	57 (100%)
One-off events where HIV-positive people can talk and socialise	3 (5.3%)	7 (12.3%)	19 (33.3%)	18 (31.6%)	10 (17.5%)	57 (100%)
One-off workshops or discussions for people to discuss a topic	3 (5.3%)	7 (12.3%)	19 (33.3%)	20 (35.1%)	8 (14.0%)	57 (100%)
Being able to decide discussion topics	3 (5.3%)	12 (21.1%)	19 (33.3%)	16 (28.1%)	7 (12.3%)	57 (100%)
Groups that meet monthly for a set number of months	6 (10.5%)	20 (35.1%)	18 (31.6%)	9 (15.8%)	4 (7.0%)	57 (100%)
Groups that meet weekly for a set number of weeks	12 (21.1%)	23 (40.4%)	15 (26.3%)	5 (8.8%)	2 (3.5%)	57 (100%)
Groups that meet monthly on an ongoing basis to mainly discuss or learn about different topics and issues	4 (7.0%)	12 (21.1%)	20 (35.1%)	14 (24.6%)	7 (12.3%)	57 (100%)
Groups that meet monthly on an ongoing basis to mainly talk and socialise informally	4 (6.9%)	16 (27.6%)	19 (32.8%)	10 (17.2%)	9 (15.5%)	58 (100%)
Online forums where you can chat to other people with HIV on any day	8 (13.8%)	25 (43.1%)	8 (13.8%)	7 (12.1%)	10 (17.2%)	58 (100%)
Group members who are all participating in the group for the same reasons	8 (14.0%)	14 (24.6%)	17 (29.8%)	10 (17.5%)	8 (14.0%)	57 (100%)

Table 45: Importance of one-off workshops to discuss a topic by year diagnosed

p=.028	Year diagnosed category	
	Before 1996 n (%)	1996 or after n (%)
Unnecessary or of limited use to me	8 (33.3%)	2 (6.5%)
Important and useful to me	8 (33.3%)	11 (35.5%)
Very important and useful to me and essential	8 (33.3%)	18 (58.1%)
Total	24 (100%)	31 (100%)

Table 46: Importance of groups that meet monthly to discuss a topic by year diagnosed

p=.005	Year diagnosed category	
	Before 1996 n (%)	1996 or after n (%)
Unnecessary or of limited use to me	11 (45.8%)	5 (16.1%)
Important and useful to me	10 (41.7%)	10 (32.3%)
Very important and useful to me and essential	3 (12.5%)	16 (51.6%)
Total	24 (100%)	31 (100%)

Those who attend facilitated groups are most likely to value groups that meet monthly on an ongoing basis to discuss specific topics, and groups that meet for a set number of months. Those who have not attended facilitated groups are more likely to view this as unnecessary or of limited use (Tables 47 and 48).

Table 47: Importance of groups that meet monthly for a set number of months by participation in facilitated groups

p=.015	Attended in past 6 months n (%)	Did not attend in past 6 months n (%)
Unnecessary or of limited use to me	3 (17.6%)	23 (57.5%)
Important and useful to me	7 (41.2%)	11 (27.5%)
Very important and useful to me and essential	7 (41.2%)	6 (15.0%)
Total	17 (100%)	40 (100%)

Table 46: Importance of groups that meet monthly on an ongoing basis to mainly learn about topics or issues by participation in facilitated groups

p=.008	Attended in past 6 months n (%)	Did not attend in past 6 months n (%)
Unnecessary or of limited use to me	1 (5.9%)	15 (37.5%)
Important and useful to me	5 (29.4%)	15 (37.5%)
Very important and useful to me and essential	11 (64.7%)	10 (25.0%)
Total	17 (100%)	40 (100%)







4.0 Discussion and recommendations

4.1 Role and objectives of peer support

Overall there is a high level of consistency between the focus group participants and online respondents about peer support and its role in their lives. The description of peer support as a an experience of connection, validation and reduced isolation, and peer support as gaining and sharing credible advice, knowledge and experience are well supported in the larger online survey.

Certainly the results from the online sample indicate that those respondents who report having multiple friends with HIV with whom they can talk to, and feel they are supported by their HIV-positive friends, are significantly more likely to feel positive psychologically and socially, have higher feelings of general self efficacy and wellbeing, and are more likely to feel confident to manage HIV status disclosure. However the focus group participants raised the issue of some of the complexity in this and the difference between gaining perspective and support from HIV-positive peers and building a friendship network with HIV-positive peers.

The online survey results provide a baseline for measuring achievement of the program objectives but does not provide an indication of improvements. The follow-up survey, yet to be conducted, will be required to provide some level of insight for improvements. We can make some inferences about the objectives from the qualitative and quantitative data, as shown in Table 49.

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.

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

4.2 Challenges in providing peer support programs

The focus group participants and online survey respondents identified a number of challenges that peer support programs face in meeting the needs and expectations of participants. The focus group participants highlighted a number of important tensions that the peer support programs need to navigate and the online survey results reinforce this.

First is the tension between building an ongoing social network and gaining perspective and comparison. While gaining support from and providing support to other people with HIV is almost universally considered important, there is much more diversity in the rating of the importance of developing friendships with people met through HIV-positive peer support groups. However, those who have larger HIV-positive peer networks, on average, rated better on a number of indicators such as self efficacy and psychological outlook. It is difficult to determine at this stage the causal direction if any, as those with stronger self efficacy may be more able to develop strong peer networks or having stronger networks may increase sense of self efficacy and outlook. A minority consider making friends through peer support programs essential.

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).

Second is the tension between a regular service experience of peer support to keep well and on track versus an occasional pit-stop experience. Consistent with this, in the online survey, although sharing of stories, experiences and information about living with HIV is generally considered very important, there are clear differences regarding the preferred format. For example those diagnosed after 1996 are more likely to prefer one-off events and topic-focused events than those diagnosed before 1996.

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.

Third is the tension between a focus on information dissemination and a focus on social interaction. Although gaining information is considered important (topics vary on the basis of year of diagnosis), almost 60% of participants rated having a place where group members feel comfortable and safe to talk about their experiences as essential. More than 50% rated having time within peer support programs to talk informally as very important or essential. The main theme of the feedback regarding topics emphasises less educational and repetitive topics, and more sharing of experience and knowledge related topics. However, the need for social interaction within the peer support program contexts is universal.

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.

Fourth is the tension between diversity and uniformity of experience, stages and 'headspace' of participants in programs. This was more difficult to measure within the online survey. However there is a relatively even spread across the rating of importance for wanting group members who are all participating in the group for the same reasons. There are also differences on the basis of programs accessed across groups with those with stronger social connectedness and psychological outlook (which relates to some of the descriptions of headspace) being less likely to have attended facilitated groups in the past six months. The inconsistent results within the process indicators where some items are associated with age and year diagnosed, some associated with social connectedness, some associated

with self efficacy and psychological outlook highlights the complexity of the issue raised in the focus groups around stages and headspace.

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.

These are significant challenges for a diverse range of programs to navigate. Program facilitators are effectively being 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)
- Ensure the group does not move into a therapeutic context.

The challenge for facilitators is considerable. This highlights the need for strong facilitation skills and more than one facilitator where possible.

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.

4.3 Disclosure, Stigma and Discrimination

Although the issue of stigma and discrimination within the focus group participant's lives is ever present, none spontaneously spoke about the peer support programs directly assisting them in this area, or suggested that peer support programs should be working with this issue. Stigma is seen as something to be managed, endured, challenged or ignored depending on their life circumstances, and many spoke about the benefit in discussing the issues informally with fellow program participants. However few linked this to programs directly, indicating a more indirect influence. There is generally an association between higher confidence in managing disclosure and responding to stigma and discrimination and having higher levels of general self efficacy, feeling socially connected and more positive psychologically. In the online survey, the most common direct reference to stigma and discrimination relates to rejection in social and sexual contexts after disclosure of HIV status.

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.

4.4 Peer support models and approaches

The current peer support and education programs range from formal structured courses through to informal social events. The underlying assumption is that different people may be attracted to and influenced by different environments and approaches in which learning, peer support and social influence can occur.

Phases 1 and 2 of the research indicates that the peer support programs have an underlying theory or assumption that participants move through stages from early diagnosis through to living with HIV for awhile. These are not formal time-based stages, but an acknowledgement of the different stages people with HIV are at in coming to terms and managing HIV, and the stages they go through when building their capacity, self efficacy and expectations of living with HIV. This is relatively consistent with the findings from the focus groups, with the term 'stage' used in mostly similar contexts and meanings.

During phases 1 and 2 of the research project, we also developed a conceptual description of the mix of peer support programs on an axis of time since participants' diagnosis and structure style of the program. The chosen axis focused on the time since diagnosis continuum and the structure of the program. However, this representation may not be an accurate representation of the themes drawn from the focus groups and online survey responses. There needs to be a more nuanced explanation of the "stages", and perhaps more of a focus on the intention of the program rather than its structure.

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.

Further research and evaluation

The PLHIV who participated in the online survey contributed significant time and energy to complete the survey and the majority included additional responses and suggestions in the open-ended questions. The majority of participants identified as gay men. A small number of heterosexuals and HIV-negative partners of PLHIV participated and their feedback may need to be reviewed separately.

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.

This research project raises a number of questions that need further investigation or clarification.

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.



Appendix 1: Positive Life NSW and ACON Peer Support Questionnaire

Positive Life NSW and ACON Peer Support Questionnaire

1. Welcome to the Positive Life / ACON Peer Support Survey

Peer support and education is an important part of Australia's community response to HIV since the early 80's. Some of this has been through informal friendship groups and social networks; some of this has been through peer support programs initiated by and for people living with HIV. These programs have developed and evolved over many years, adapting and changing as needs changed.

ACON and Positive Life NSW are looking at how they conduct peer support and education for people with HIV, what sort of impact the programs have in people's lives, and how they can improve the approach. This survey is one part of this process.

We are asking people in NSW with HIV to complete this survey to assist us in understanding and improving peer support and education programs. Your participation will remain anonymous and will assist greatly in how we improve and provide programs.

The survey is being conducted with the assistance of Dr Graham Brown from the WA Centre for Health Promotion Research and has received Human Research Ethics Approval from Curtin University of Technology.

Please answer as many questions as you feel comfortable. If you would like further information about the survey feel free to contact:

Positive Life:

Lance Feeney Ph: 02 9361 6011 email: lancef@positivelife.org.au www.positivelife.org.au

ACON:

Ian Walker - Ph: 9699 8756 email: iwalker@acon.org.au www.acon.org.au

WA Centre for Health Promotion Research:

Graham Brown - Ph: 08 92662751 email: g.brown@curtin.edu.au

Positive Life NSW and ACON Peer Support Questionnaire

2. First some general demographic questions

1. What is your age?

- <18 years 50-59 years
 18-29 years 60-69 years
 30-39 years 70+ years
 40-49 years

2. Are you.....

- Male Female Transgender Other

3. How do you identify?

- Gay MSM (Men who have sex with men) Bisexual Heterosexual Trans Intersex

4. What is your current employment situation?

- Full-time employed Volunteer Newstart
 Part-time employed Student DSP
 Other (please specify)

5. What is your postcode?

6. What is your ethnic or cultural background

7. What language is spoken at home?

- English
 Other

8. Do you identify as....

- Aboriginal Torres Strait Islander

9. Are you HIV positive?

- Yes No Don't know

10. If Yes, please specify your year of diagnosis?

Positive Life NSW and ACON Peer Support Questionnaire

11. Do you live...

Alone

With a partner

Share

Other (please specify)

12. Do you identify as.....

single

in a relationship

more than one regular partner

Other (please describe)

13. If in a relationship, what is the HIV status of your partner?

HIV negative

HIV positive

Don't know

Positive Life NSW and ACON Peer Support Questionnaire

3. The following questions are about living with HIV

1. Please indicate your level of agreement with the following statements:

	Not at all	A little	Moderately	Mostly	Completely
How confident do you feel in forming good relationships with your healthcare provider?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To what extent do you feel you have enough knowledge about HIV to manage your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you feel you have the skills and resources to make treatment decisions with your health care provider?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

any comments:

2. Which people do you feel confident disclosing your HIV status to:

	Not at all	A little	Moderately	Mostly	completely	n/a
Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People at work or study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General Practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Regular partner(s)/relationship	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Casual/New sexual partner(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please feel free to comment or clarify

3. Have you experienced any HIV related stigma/discrimination, in the past 12 months?

Yes No

please feel free comment or provide details

4. How confident do you feel in dealing with HIV-related stigma and discrimination?

Not at all A little Moderately Mostly Completely

How would you deal with it?

Positive Life NSW and ACON Peer Support Questionnaire

4. These questions are about support from others

1. Do you have friends with HIV that you can talk to about living with HIV?

- No, don't know anyone else with HIV (you can skip to Question 4)
- No, none that I can talk to
- Yes, 1 or 2
- Yes, 3 to 5
- Yes, 5 or more

2. In which settings do these discussions about living with HIV take place?

	Never	Rarely	Sometimes	Many times	Most/all the times
With friends generally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With other HIV positive friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With friends I have met through ACON/Positive Life programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
While at workshops	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
While at peer support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Online	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
While at social events for people with HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
While at HIV related information forums	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Positive Life NSW and ACON Peer Support Questionnaire

3. Please note which of the following settings in the above question you were referring to:

Which workshops were you referring to?

Which support groups were you referring to?

Which online sites were you referring to?

Which social events were you referring to?

Which HIV related information forums were you referring to?

4. Please indicate your level of agreement with the following statements:

	Not at all	A little	Moderately	Mostly	Completely
I believe I am supportive to my friends living with HIV ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My friends living with HIV are supportive towards me ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

any comments:

5. Name up to six health and community services where you could get help if you needed it?(name as many as you can)

-
-
-
-
-
-

Positive Life NSW and ACON Peer Support Questionnaire

5. These questions are about quality of life

1. How would you rate your quality of life?

Very poor
 Poor
 Neither poor nor good
 Good
 Very good

2. Please indicate your satisfaction with the following:

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
How satisfied are you with your health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with your personal relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with your sex life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How satisfied are you with the support you get from your friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. Please indicate your level of agreement with the following:

	Not at all	A little	Moderately	Mostly	Completely
How much do you enjoy life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How well are you able to concentrate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable with your body and appearance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To what extent do you feel accepted by the people you know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Has living with HIV made you feel less sexually attractive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How confident are you to talk about safe sex	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How confident are you in deciding when and how you disclose your HIV status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. How often do you have negative feelings such as blue mood, despair, anxiety, depression?

Never
 Seldom
 Quite often
 Very often
 Always

Positive Life NSW and ACON Peer Support Questionnaire

5. Please indicate your level of agreement with the following:

	Not at all	Hardly true	Moderately true	Exactly true
I can always manage to solve difficult problems if I try hard enough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If someone opposes me, I can find the means and ways to get what I want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is easy for me to stick to my aims and accomplish my goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident that I could deal efficiently with unexpected events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thanks to my resourcefulness, I know how to handle unforeseen situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can solve most problems if I invest the necessary effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can remain calm when facing difficulties because I can rely on my coping abilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am confronted with a problem, I can usually find several solutions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I am in trouble, I can usually think of a solution?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can usually handle whatever comes my way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. How far ahead are you making plans for the future?

- No plans less than 1 year 1 or 2 years 3 to 5 years 5 to 10 years more than 10 years

7. Has planning for the future changed since your diagnosis?

- No - has stayed the same
 Yes - my planning has become shorter term
 Yes - my planning has become longer term

please comment

Positive Life NSW and ACON Peer Support Questionnaire

6. These questions are about the importance to you of different types of suppo...

1. How important to you are the following:

	Unnecessary	Of limited use to me	Important and useful to me	Very important and useful to me	Essential
Gaining support from family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gaining support from gay friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gaining support from straight friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gaining support from other people with HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being able to give support to other people with HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spending time with people who have lived with HIV for around same amount of time as me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spending time with people with HIV of the same gender as me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spending time with people with HIV with the same sexuality as me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Developing friendships with people I met through peer support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Socialising with people I have met through organised peer support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opportunity to meet a potential partner who is HIV positive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How does getting support from other people with HIV help you?

Positive Life NSW and ACON Peer Support Questionnaire

2. How important is sharing stories and experiences about:

	Unnecessary	Of limited use to me	Important and useful to me	Very important and useful to me	Essential
- coming to terms with a HIV positive diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- managing HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- disclosing HIV status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- HIV and sex	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- HIV and relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

3. How important is gaining information about:

	Unnecessary	Of limited use to me	Important and useful to me	Very important and useful to me	Essential
- treatments or managing side effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- managing health and wellbeing generally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- other health or support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

7. These questions are about the running of peer support programs

1. Which of the following peer or social programs have you been involved with in the past 6 months ?

- | | |
|---|--|
| <input type="checkbox"/> HIV positive retreats | <input type="checkbox"/> Online Forums in Australia |
| <input type="checkbox"/> 7-2-9 | <input type="checkbox"/> Online Forums internationally |
| <input type="checkbox"/> After Hours | <input type="checkbox"/> Planet Positive |
| <input type="checkbox"/> Poz Het Events | <input type="checkbox"/> Positive Living Centre |
| <input type="checkbox"/> Genesis | <input type="checkbox"/> Campaign development discussion groups / focus groups |
| <input type="checkbox"/> Social meals (eg Luncheon Club, Karumah, Norther Rivers etc) | <input type="checkbox"/> Focus groups for this peer support review |
| <input type="checkbox"/> Nexus | |

Others - Please specify

Positive Life NSW and ACON Peer Support Questionnaire

2. How important to you are these aspects in the running of a peer group program

	Unnecessary	Of limited use to me	Important and useful to me	Very important and useful to me	Essential
A place where group members feel comfortable and safe to talk about their experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Well facilitated discussions that stay on topic and time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussions that are able to move away from the original topic if that is what some group members are interested in discussing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A coordinator with strong and effective group discussion facilitation skills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having time to talk informally with friends I have met through peer group programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A coordinator who is HIV positive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
One off events where HIV positive people can talk and socialise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
One off workshops or discussions for people to discuss a topic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being able to decide discussion topics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Groups that meet monthly for a set number of months	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Groups that meet weekly for a set number of weeks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Groups that meet monthly on an ongoing basis to mainly discuss or learn about different topics and issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Groups that meet monthly on an ongoing basis to mainly talk and socialise informally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Online forums where you can chat to other people with HIV on any day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Positive Life NSW and ACON Peer Support Questionnaire

Group members who
are all participating in
the group for the
same reasons

Other (please specify)

Positive Life NSW and ACON Peer Support Questionnaire

8. A few final general questions

The following questions are your opportunity to raise any ideas, thoughts and comments that may not have come up in the previous questions.

1. If you attend peer support groups (it may be often or occasionally), why? What do you gain from these groups?

2. If you do not attend peer support groups (or very rarely), why?

3. What would you change about peer support groups that are currently available?

4. What would you keep the same about current peer support groups?

5. We would also like to provide an opportunity for you to provide general feedback on any of the peer group programs we have identified above, or any feedback on other programs that are available or should be conducted or supported. Please feel free to type in any ideas or issues that you would like to add.

9. Linkage question

We would like to invite you to do this survey again in about six months. The next survey will be much shorter than this survey and will significantly assist us in seeing what changes occur over time amongst participants of peer or social support initiatives.

We would like to compare the two surveys, but we want you to stay anonymous. Therefore - we ask that you answer one of the following questions which we will ask again in the next survey, and then we can link the surveys without knowing who you are.

1. What was your mothers maiden name?

2. What was your first pet's name

3. So that we can let you know when the next survey is being conducted again it would be really helpful if you could provide an email address for us to send an email with a link to the survey, or a mobile number to which we can send a text. This email or mobile number will be kept separate from your answers to this survey and is not linked in any way. This is entirely optional and the details will only be used once to let you know the survey is accessible, and then deleted.

email address or mobile number to have a survey link sent to you in six months time:

Positive Life NSW and ACON Peer Support Questionnaire

10. Thank you

Thank you for participating in this survey.

As we explained above, ACON and Positive Life NSW are looking at how they conduct peer support and education for people with HIV, what sort of impact the programs have in people's lives, and how they can improve the approach. This survey was one part of this process.

If you would like further information about this survey or would like to provide more feedback about peer support programs feel free to contact:

Positive Life:

Lance Feeney Ph: 02 9361 6011 email: lancef@positivelife.org.au www.positivelife.org.au

ACON:

Ian Walker - Ph: 02 9699 8756 email: iwalker@acon.org.au www.acon.org.au

WA Centre for Health Promotion Research:

Graham Brown - Ph: 08 92662751 email: g.brown@curtin.edu.au

if you would like to mail your response or other feedback send to (no postage stamp required):

Graham Brown
WACHPR, School of Public Health
Curtin University of Technology
Reply Paid U1987
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