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Formative Research for the National HIV Stigma and Discrimination Pre-campaign Development

Qualitative Research Report

Prepared for:

Australian Federation of AIDS Organisations (AFAO)



napwa national association of
people living with HIV/AIDS

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EXECUTIVE SUMMARY

1 EXECUTIVE SUMMARY

1.1 Objectives and Methodology

In recognition of the complexity of the task in of addressing HIV stigma and discrimination, AFAO and, its member organisations, have undertaken a phased approach to the development of a social marketing campaign. This approach will be implemented over a 12-18 month period.

The final activity to be undertaken within Phase 1 of the project was formative research via a series of focus groups and in-depth interviews with gay men / men who have sex with men who do not identify as gay (MSMs) regarding discriminatory or prejudicial attitudes and experiences. The overall aim of the research task was to explore HIV related stigma and discrimination among positive and negative gay men and men who have sex with men but do not identify as gay (MSMs). This will assist AFAO with a solid understanding of the issues from the perspective of this audience, and will assist in informing the development of a social marketing campaign brief and eventual campaign.

The specific objectives of the research were formulated following a Development Group meeting at which various reviews on existing literature and information were presented. This report has been structured to include a section on each of the research objectives as they were outlined in the document provided following this meeting.

The initial round of research consisted of 11 discussion groups and 4 in- depth interviews with men who have sex with men but do not identify as gay (MSMs). Each group was approximately 2 hours in length and consisted of 6-8 respondents. The sample for the discussion groups was segmented according to age, HIV status and was conducted in metropolitan and regional locations across four states. Each in-depth interview was of approximately 45-50 minutes duration. Two of these were completed face-to-face and two by telephone. Multiple methods of recruitment were used to recruit respondents including specialist qualitative research recruitment agencies, advertisements in gay publications and contact through organisations.

A subsequent round of research specifically targeting HIV positive men aged 35 years and younger followed. This consisted of 6 in-depth interviews conducted by phone, 4 face-to-face in-depth interviews, 1 mini-group discussion consisting of 4 respondents and a paired in-depth interview. Respondents for this latter round of research were recruited primarily through HIV organisations.

1.2 Detailed Findings

Awareness, attitudes and experiences of HIV stigma and discrimination

Issues of HIV related stigma and discrimination were not raised spontaneously as specific areas of concern among gay men in groups consisting of HIV negative men. In fact, younger HIV negative

men did not even raise the topic area of HIV as a current issue of concern at all. Older HIV negative men were more likely to spontaneously raise the issue of HIV in relation to prevention and disclosure in sexual encounters. Spontaneous issues of concern raised by HIV negative men consisted of homophobia, especially in regional areas, and the impact of various changes to Mardi Gras, and places such as Oxford St in Sydney. These latter issues tended to lead to discussions surrounding the concept of a 'gay community', specifically the necessity and cohesiveness of 'gay community' in the current day. Lack of equal legal rights was also spontaneously raised as an issue of concern for some men in metropolitan areas.

In contrast, stigma and discrimination related to sexual encounters, prevention and disclosure were the single most important issue raised as a spontaneous area of concern for gay men in groups involving HIV positive men. Some of these men immediately identified feelings of rejection and helplessness when engaging with other men both online and in physical situations.

One of the key findings from the research was the notable differences in awareness and knowledge of HIV among different groups of men. These differences have a direct impact on attitudes to HIV related stigma and discrimination. Broadly, awareness and knowledge of HIV was directly dependent on age and personal knowledge and experience of someone who was HIV positive.

The lack of knowledge about HIV among some younger men in their early 20s, beyond prevention messages of using condoms, was markedly apparent. Awareness and knowledge of HIV was higher among men who were aged in their late 20s and older, although these men differed a great deal in their attitudes towards HIV positive men depending on their personal experience. Those who claimed to have little or no personal experience of anyone living with HIV were often openly negative and discriminatory in the way they discussed PLHIV.

When asked about stigma and discrimination in relation to HIV, most HIV negative men admitted that there was a stigma associated with HIV, although were more reluctant to identify any forms of discrimination towards HIV positive men. It was certainly not believed that discrimination towards PLHIV was any more severe than that directed towards other gay men due to factors such as ethnicity, age, physical appearance, fashion and preferred sexual behaviours.

HIV negative men had difficulty in providing a definition of what they perceived as stigma and discrimination, however, there was a great deal of consistency between the reported attitudes and behaviours of some HIV negative men and the definition provided by Link and Phelan ¹, cited in the literature review. Most HIV negative men readily admitted to being aware of a labelling and stereotyping of HIV positive men among gay men generally. Many younger men, in particular,

¹ Bruce G. Link, and Jo C. Phelan. 2003. Conceptualizing Stigma. Review- article. November 28. <http://arjournals.annualreviews.org.dbgw.lis.curtin.edu.au/doi/abs/10.1146/annurev.soc.27.1.363?prevSearch=HIV+stigma&searchHistoryKey.>

believed they could identify someone as HIV positive by their physical appearance, strongly believing in the stereotype of an older, thin man with sunken cheeks. While not as apparent among older HIV negative men, there was a strong recognition that this was the accepted physical stereotype. Many readily articulate an 'us and them' attitude, with some HIV negative men openly claiming they refuse to engage with HIV positive men electronically via the Internet, and try to avoid physical associations with these men. The language used to describe HIV positive men clearly differentiates these men from being the same as negative men, as they are in different 'clubs' or different 'teams'.

Status loss and discrimination occurs on multiple levels, but is typified by HIV being one of the key factors with which potential sexual partners are chosen. For many HIV negative men, this would be the only factor on which a potential sexual partner would definitely be excluded from consideration. Changes in power relations, specifically loss of power by HIV positive men, was highlighted by the language used by HIV negative men in describing HIV positive men. It was common to identify HIV positive men as 'unclean', and to liken sexual interactions with HIV positive men to 'loaded guns', 'playing Russian Roulette' and 'poison'. Whether conscious or not, this language likens HIV positive men to criminals, and as a criminal would be marginalised from mainstream society and stripped of certain rights, so are some HIV positive men in the view of others.

Positive men indicated that within the gay community, discrimination largely occurred in potential or realised sexual situations rather than elsewhere. This discrimination occurred with both physical rejection, and within the language used to ask about sero-status, with many believing there was an increase in prevalence of other men asking "are you clean?".

Fear relating to potentially contracting HIV from unprotected sexual activities was undoubtedly one of the key underlying factors contributing to HIV stigma and discrimination. However, it was apparent that this fear was in many cases applied to non-intimate activities as well. In turn, fear of HIV is driven predominantly by lack of knowledge with this being the key driver behind the stigma expressed by younger men. Lack of knowledge combined with limited personal experience of anyone who is HIV positive results in very limited information and references on which to develop attitudes. This means that many HIV negative men, particularly younger men, base all their attitudes and behaviours toward PLHIV on the preventative education and social marketing materials they had been exposed to over the years. Continuous messages of prevention, and no information about other more positive experiences of HIV, result in some men only having the knowledge that HIV is something to avoid at all costs. A number of HIV positive men also identified that continuous prevention messages and the absence of any 'good news' about PLHIV has been one of the key factors in some attitudes among the gay community changing for the worse.

This is the social environment in which younger HIV positive men must then face when learning about their diagnoses.

HIV positive men identified that the main area in which they experience stigma and discrimination was in sexual and personal relationships. The majority of HIV positive men openly discussed rejection from prospective partners once they disclosed being HIV positive. Other identified that their HIV status was often a source of a discussion and 'warning' in social situations, such as at a venue, prior to even the possibility of sexual relationship occurring. Some likened this to social ostracism, and identified that this intensified the negative feelings, such as shame, they had towards themselves. Some HIV positive men felt that the word 'disclosure' contributed to the shame experienced by some men. It was seen to imply that HIV status is a secret that men should be ashamed of.

The potential for social ostracism was identified as the worst possible consequence of disclosure for younger men. For some, this was worse than the feelings of rejection by individuals. Disclosing to an individual was seen to run the real risk of quickly becoming common knowledge in the "gossipy" social circles of young gay men.

Within the broad topic area of stigma and discrimination, positive experiences were essentially about when stigma and discrimination did not occur where it may have. There were many instances in the group discussions where both HIV negative and HIV positive men were openly surprised at others within the group being in a sero-discordant relationship. Where this occurred, the resultant discussion about how such a relationship could be successful appeared to have a strong positive influence over pre-existing attitudes. Finding a 'peer group' of other PLHIV appeared to also be a very positive experience for many, as did becoming active and participating in projects related to promoting a positive image of PLHIV.

One of the key barriers to combating the factors that contribute to HIV stigma and discrimination will be in overcoming the impact on knowledge and attitudes of the continuous prevention message that have been the only source of knowledge on HIV for many men. Trying to balance more 'positive' messages about PLHIV, while still having messages of prevention, will be a challenge. Other particular barriers have been identified as challenging and changing the established vernacular and overcoming the self-stigmatisation and discrimination that causes HIV positive men to live in secrecy, therefore allowing the issue to be self-perpetuating.

Reasons why HIV related stigma and discrimination appear to be increasing

The research findings suggest that a confluence of factors is responsible for increases in HIV stigma and discrimination. Change has occurred in a number of inter-related areas, resulting in stronger changes in attitude than may have otherwise occurred. Broad social factors, such as social and legal acceptance among the wider community, have resulted in gay men no longer identifying a need for a cohesive 'gay community'. This has had implications for HIV losing value as a binding force for a 'gay community' that is no longer seen as needed. Similarly broader social

acceptance means that specific social spaces in which men need in order to socialise as openly 'gay' are not as necessary, with many clubs and venues now being seen as 'for both' heterosexual and homosexual people. This has resulted in less direct social exposure and personal experience between HIV positive and HIV negative men

Changes to physical spaces have occurred at the same time that the online social networking environment has evolved. This has now become one of the key mediums in which gay men meet each. The anonymity offered by online interaction results in users being able to 'voice' opinions in an online environment that they may not do in face-to-face situations. It is easier to discriminate online based on specific characteristics, including HIV, than it is in a face-to-face environment. There is no doubt that the ease in which sero-sorting² can occur online, through checked boxes in a person electronic profile, has contributed to this being a more acceptable practice in physical situations as well. Both HIV negative and HIV positive men practice sero-sorting, both online and in physical situations.

There was very limited spontaneous mention of any criminal prosecutions regarding HIV. Even when prompted there was no direct link to criminal prosecutions and attitudes to PLHIV. However, the language used regarding HIV, positive men feeling they need to keep their status a secret to avoid consequences, along with the legal obligation to disclose their HIV status in certain circumstances was perceived to reinforce the perception of criminalisation among both HIV negative and HIV positive men.

The nature of the disease has also changed considerably with the advent of new medications. When diagnosed now, men are told that HIV is a manageable chronic condition, therefore they do no longer have to prepare themselves and others for illness and death. In a sense being able to 'live with HIV' seems to mean that there is no reason to tell others (unless engaged in sexual relations), meaning that less people are aware of others with HIV, and therefore do not get to know men with HIV.

The social environment in which young positive men exist perpetuates the need to maintain a degree of secrecy about HIV. Younger negative men have limited understanding and knowledge about HIV. Often, their only knowledge is of HIV is based on social marketing campaigns that carry simple prevention messages. Younger HIV positive men felt that these campaigns only served to reinforce ignorance and negative attitudes by the simplicity of message, and to promote stereotyping in the creative approaches they used.

² The terminology of sero-sorting was not used spontaneously by respondents in the research. Only on prompting were some aware of the meaning of this terminology, with very few using it to describe their own behaviour.

Influence of HIV on attitudes and behaviours to sexual partners and relationships

It was claimed that HIV status had more of an influence on long term partner selection than casual partner selection, regardless of age or status. Three broad groupings of attitudes and behaviours in regards to casual sexual partners emerged among HIV negative men. The first group were those that claimed they would **never** have sex with someone they believed could possibly be HIV positive, with this attitude being mostly driven by ignorance. The second group was those who would **unknowingly** have sex with someone they knew to be HIV positive, but readily engage in casual, one-off, sexual encounters in certain situations, such as at SOPVs, beats and saunas, without asking someone's HIV status. In a sense these men demonstrated a 'don't ask, don't know, don't care' attitude, although they claimed to always use condoms in these instances. There was a significant number of HIV negative men within the group discussions who were part of the last group of those who claimed to be comfortable with having sex with HIV positive men. These men tended to either have previous personal **experience** of a sero-discordant relationship or to have friends involved in such a relationship. Only this latter group would even consider the possibility of a long term relationship with someone who was HIV positive.

Very few of the HIV positive respondents within the group discussions claimed to discriminate for casual partner selection based on HIV status. Some did admit that they had reached a point where they specifically targeted other HIV positive men to minimise the impact of rejection. Some did identify that they may find the issue of always needing to have protected sex in a long term sero-discordant relationship difficult.

It was identified that one of the more frightening elements to being HIV positive for younger men was the perception that they now had a diminished pool of potential casual and long term partners. Those without partners found it difficult to imagine sero-discordant relationships from both a physical and emotional perspective.

The overwhelming majority of the HIV negative men felt that it should be the responsibility of HIV positive men to disclose their HIV status, thereby taking responsibility regarding transmission. Most expected that this should occur as soon as it was understood that sex would likely occur, regardless of whether sex would be protected or not. In contrast, all HIV positive men felt that they were unfairly burdened with this responsibility. HIV positive men felt that legal obligation to disclose, should others be at risk, had resulted in negating any responsibility of HIV negative men to protect their own health, and had contributed to criminalising HIV in the eyes of both HIV positive and HIV negative men. Both of these impacts were perceived as contributing to stigma and discrimination by HIV negative men. They were also seen to have increased the shame, secretiveness and self-discrimination that HIV positive men practice against themselves.

The issue of disclosure was discussed extensively within the group discussions. It was identified that this was identified as one of the key areas in which HIV positive men could benefit from assistance. This could be an area for future strategies for organisations.

The inclusion of sero-discordant couples within the research identified a number of key learnings that could be used moving forward. The most important of these was that knowledge of a sero-discordant couple is one of the key educative experiences for young men to overcome some negative assumptions they have towards HIV.

Support strategies

HIV positive men all had experienced and strongly endorsed the use of professional advice and social networks as a means of support in living with HIV. However, few men identified specific support that was aimed at building resilience to discrimination. It was felt that agencies tended to focus on ensuring all basic physical and mental needs were met (and had to due to limited funding), rather than on providing 'tools' to enable men to live more confidently in the community. It was identified that there is a need for support strategies to include practical 'skills' to assist men in dealing with issues such as disclosure, living with limited funds, taking care of general health, and the building of social support systems with other HIV positive men with whom experiences can be shared.

This last point was strongly endorsed by many HIV positive men, however many identified that the 'theory' behind the idea of building social networks had been tried and met with little success due to the reluctance of other HIV positive men to engage with the concept.

One of the key issues with building support through social networks with other HIV positive men was the difficulty in identifying with many of the people who frequented events and organised sessions at various organisations. It was experience younger HIV positive men that these events were often 'uninspiring'. They could be very difficult for younger men and those who were recently diagnosed to be part of as they were often attended mainly by older HIV positive men who appeared ill. Rather than find 'positive' support, younger men find their 'fears' of how people may see them and of what impact HIV may have on them, are reinforced.

The second phase of research that was conducted with younger HIV positive men confirmed this finding as well as identifying some other relevant issues. The first of which is the reluctance of younger HIV positive men to allow HIV to have a focal point in their lives or become part of their identity. The second involved a real fear of others disclosing their HIV status through gossip, and it then becoming part of their public identity in the broader social environment. The last issue was the suitability of events in terms of time and focus for young people with both employment and other social commitments.

However, this does not mean that the support strategy of building social networks is not valuable. In fact, support networks were identified as being critical in building confidence and resilience in HIV positive men. All the HIV positive men that exhibited confidence and claimed attitudes of resilience to discrimination in the research, appeared to be strongly linked to the support networks of family and friends. Those that lived alone and/ or claimed to have little support and acceptance from family and friends appeared to feel the impact of stigma and discrimination from others within the gay community to a far greater extent.

Four different approaches to dealing with stigma and discrimination were identified in the research, some more 'healthier' than others. Some men felt the best was to be '**out and proud**', and advocated openly disclosing their HIV status whenever relevant was the best approach. This seen to removed the element of self discrimination from any situation. Others maintained a policy of **non-disclosure**, unless absolutely required by law. Still others tried to surround themselves socially and sexually only with **other HIV positive** people, and a small few had chosen the approach of **reclusiveness**. This latter group claimed to avoid developing of any sort of relationship with others.

Sharing of Spaces

Aside from ease of sero-sorting, one of the key learning about the sharing of online space was the number of different interpretations of the various profile descriptors that men had. There did not appear to be a consistent interpretation across ages or HIV status of what was meant by open description of wanting 'bareback only', or what is meant when someone's profile reads 'Always', 'Never', 'Needs discussion' in regards to using condoms. This could strongly impact on perpetuating issues of discrimination as learning that someone is HIV positive after interpreting the different descriptors as them implying they were HIV negative, would reinforce negative perceptions.

While no respondents in Sydney and Melbourne felt that the various clubs and venues had developed so far to be *only* HIV positive or HIV negative spaces as yet, some HIV positive men identified that there were definitely certain physical spaces in which they were more comfortable. Examples provided included social events specifically for HIV positive men, or fetish clubs where the men seemed more open to enjoying sex with someone who is HIV positive.

Overcoming fears of HIV positive partners is a step by step process for many HIV negative men. The first step in overcoming fear of positive partners for many men was to start talking about HIV; for it to be a topic of discussion in general again rather than something that is not discussed except by prevention campaigns. The next step in HIV negative men in overcoming their fears was in knowing HIV positive men socially. Personally knowing someone with HIV acts to 'humanise' the condition and begin the educative process on other sides to HIV and PLHIV rather than only the need to prevent transmission. Next, knowledge that sero-discordant relationships are able to occur

and do exist is important. The final step in overcoming fears of having HIV positive sexual partners, was for HIV negative men to educate themselves on all the risks associated with sex.

Service organisations

All men within the group discussion, both HIV positive and HIV negative, were extremely positive about the HIV service organisations they were aware of. The key criticism levelled at these organisations by HIV positive was the need for a change in the focus of services to be more about 'health' and 'living with HIV' rather than the current focus on the 'illness'. Although it was recognised that there is a need for providing basic services for those who are very ill, many simply felt that the focus of where funds were being directed needed to change now that medications were changing how people are able to live with HIV. The issue of the system dependency was also raised, with the current focus on illness and services assisting in the creation of a 'welfare dependent' group of HIV positive men. Younger positive men highlighted that the difference between older positive men and themselves was marked because of this reason. Younger men felt that the older positive men tended to feel a sense of entitlement about what they received from organisations.

None of the HIV negative men involved in the group discussions criticised the availability of and access to service providers. Although HIV negative men were limited in their contact, knowledge and experience of service providers, none claimed to feel discriminated against in regard to these providers.

Developing Communications

The research suggests that two broad strategies should be considered in moving forward. One strategy should aim at changing the prevailing attitude among HIV negative men via communications. It is likely that this will need to be a phased process delivering a series of messages over time as even after two hours of discussion, many HIV negative men could not move beyond the prevention message. They see 'HIV' and read 'prevention', whatever else the message may be.

It would be useful to use the idea of sero-discordant relationships across all stages of communications to HIV negative men, as it is personal experience with one of these that seems to have the greatest impact on allowing men to overcome negative perceptions of HIV. However, what is shown about these relationships should fit with each stage

The focus of the first stage of communicating to HIV negative men will need to be one that aims to 'educate' these men about what HIV is and who it affects. The focus will need to be on breaking down the stereotype, for all men, but particularly among younger men who simply do not see HIV as relevant to themselves due to the stereotype. Coupled with this, there is a need for some basic

facts about HIV for this group as currently they have no knowledge apart from a need to prevent HIV.

The second stage could focus on the concept of 'holding a mirror up to men' and showing them their behaviour. Get them to '**reflect**' on their behaviour, and illustrate the ugliness of stigma and discrimination. It was very apparent that the group discussions achieved this for some HIV negative men, with some startled by their own attitudes and behaviours. Focusing on the 'person' who is discriminating will be important in this stage, with some suggestion that men who are HIV – phobic should be parodied, in the manner of the RTA's 'Little Pinky' campaign. There is a need to exercise care in this approach so that credibility of the concept is not rejected by the perpetrators of the unattractive behaviours.

The final stage of the strategy will be to encourage gay men to stop excluding HIV positive men in sexual and social situations – '**promoting inclusiveness and openness**'. Although this is obviously the goal of the whole campaign in terms of overcoming HIV stigma and discrimination, it will only be possible to reach this stage after taking men through the first two phases. To go straight to this type of message will likely result in perceived lack of credibility and would be unlikely to be as effective.

While a broad communications approach aimed at HIV negative men would also reach HIV positive men, a specific service delivery strategy aimed at HIV positive men should also be considered. It is appreciated that the suggestions for a strategy with positive men may already be being implemented within different organisations and that it simply that the men in the research are not aware of them.

Firstly, HIV positive men identified they would welcome support services to direct some funds towards promoting positive and healthy life experiences for HIV positive people – '**health and wellbeing**' – rather than only focusing on the 'illness'. Secondly, the research suggests that one of the most important ways for developing confidence and resilience among HIV positive men would be to assist in the development and maintenance of **social networks**. The question is whether a changed focus in the different events that are organised, to one of positive living and wellbeing, would assist this to occur more so than it does now through greater participation?

The final element that HIV positive men felt was necessary was the implementation of services that focused on assisting with practical **skills** which focused on maintaining an active and 'normal' life, while living with HIV.



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RESEARCH BACKGROUND AND METHODOLOGY

2 BACKGROUND

2.1 Overview

HIV stigma and related discrimination remain key barriers to dealing effectively with the HIV epidemic in Australia and around the world. HIV stigma can deter people at risk from being tested for HIV and deter HIV-positive people from accessing appropriate treatment and care. It also remains the key obstacle for HIV-positive people disclosing their status to friends and family, employers and work colleagues, health care providers, insurance companies, landlords, and sexual partners for fear of being treated less favourably, or being outrightly rejected or abused.

Combating HIV related stigma and discrimination is identified as one of the guiding principles in the National HIV / AIDS strategy. However, it is a complex task. The issue of HIV stigma and discrimination has not been directly addressed through any social marketing campaigns in Australia for over a decade. In addition, the campaigns that have occurred in the past have been largely targeted at the general Australian community. To date, there has not been a national campaign that speaks to gay men who are living with HIV (and their service providers) about confronting the prejudices that exist within the gay community, nor one that speaks to heterosexuals or sex workers also living with HIV.

The Australian Federation of AIDS Organisations (AFAO) is the peak national non-government organisation representing Australia's community based response to the HIV / AIDS epidemic. As a result AFAO is the organisation best positioned to address this issue of HIV related stigma and discrimination.

It is recognised that overcoming stigma and discrimination is a difficult task, and requires careful consideration and long term support for changes to occur in community attitudes and individuals' perceptions of HIV risk. AFAO and its member organisations envisage achieving shifts in ingrained attitudes will require campaign materials to be programmatically supported through concurrent group-work interventions, community outreach and individual counselling, and other community initiatives. Given the complexity of developing the campaign and these supporting elements, the AFAO membership has recommended that this issue be addressed as a priority over the coming 12-18 months.

The first phase of the project is being completed in the 2008-09 financial year. The second phase will be conducted in 2009/ 2010. The key priority currently is the completion of all of Phase 1 elements. To date, the first phase of the project has consisted of:

- a review of domestic and international campaigns, other resources, and existing programs designed to address HIV stigma and discrimination for examination of their strengths and weaknesses;

- a review of the current research literature and existing health promotional materials; and
- the formation of a Development Group from AFAO's and NAPWA's³ membership, staff of the research centres and other key informants.

2.2 The Need for Research

The final activity to be undertaken within Phase 1 of the project was formative research via a series of focus groups with gay men / men who have sex with men who do not identify as gay (MSMs) regarding discriminatory or prejudicial attitudes and experiences. These groups were intended to assist AFAO and the Development Group to understand and 'unpack' the issues and questions on stigma and discrimination identified as needing further understanding following the various reviews. The formative research will assist in the further development of a social marketing campaign brief to inform the development of campaign materials and other program components.

³ National Association of People Living with HIV/ AIDS'

3 RESEARCH OBJECTIVES

3.1 Research Objectives

The overall aim of the research task was to explore HIV related stigma and discrimination among positive and negative gay men and men who have sex with men but do not identify as gay (MSMs). This will provide AFAO with a solid foundation of the issues from the perspective of this audience, and will assist in informing the development of a social marketing campaign brief and eventual campaign.

Prior to the research commencing a review of previous domestic and international campaigns and other resources, literature and health promotional materials was undertaken. This assisted in narrowing the research issues that are to form the research objectives. Following a Development Group meeting at which the findings of these reviews were presented, the developmental group members prepared a set of questions, scenarios and priority issues on which the qualitative research was to focus. AFAO provided a document detailing these.

As a result, the research objectives were defined as:

To understand the attitudes and experiences of HIV-positive and HIV-negative gay men/MSM regarding HIV stigma and discrimination, by:

- exploring awareness and attitudes towards HIV related stigma and discrimination within the gay community;
- identifying and articulating what Australian HIV-negative and HIV-positive gay men define as stigma and discrimination;
- exploring the factors that contribute to HIV related stigma and discrimination in a range of day-to-day life situations: professional, personal, sexual and interactions, and with service providers;
- exploring instances and experiences of stigma and discrimination and identifying the 'burning issues' of discrimination in HIV-positive gay men/MSM lives (where it occurs and is most negative);
- understanding both the positive and negative experiences of PLHIV regarding their HIV-positive status (public and private interactions); and
- identifying barriers to combating factors contributing to HIV-related stigma and discrimination.

To investigate why HIV-related stigma and discrimination has become a priority issue in recent years, by exploring the impact of:

- increases in the number of cases of criminal prosecutions for HIV transmission;
- the increased media coverage of these criminal prosecutions;
- an increase in the practice of 'serosorting', and whether this has widening of the "sero-divide" between HIV-positive and HIV-negative gay men; and
- the increased use of online sexual spaces (online dating and chat sites) and the change in the dynamics of disclosure/discussion of serostatus on these sites. (Has this become an ingrained sexual culture that is supporting and enabling people to discriminate? And is this seen as a good or a bad thing?)

To explore attitudes and behaviours regarding (new) sexual partners and/or relationships and the role of HIV in relation to this, by:

- exploring the attitudes of HIV-negative gay men/MSM towards those living with HIV and understand how they interact with HIV-positive men in their community (i.e. what interactions, negotiations there are, and what prejudices and discriminatory behaviours exist);
- exploring the attitudes of HIV-positive gay men/MSM towards partner selection with regard to HIV status—both casual and regular partners; and
- exploring gay men's perceptions of 'responsibility' regarding HIV transmission. Is it a shared responsibility or are HIV-positive men unfairly burdened with the responsibility to not transmit HIV to their partners?

To understand gaps in the existing support strategies for HIV-positive gay men—such as social networks and professional advice—and understand how these could be improved on as a means of building resilience to discrimination, by:

- exploring the types of support strategies, networks and professional advice that men who are subject to HIV stigma and discrimination may currently engage with and why;
- investigating positive gay men's own sense of confidence and resilience in dealing with stigma in their (working) lives;
- identifying what strategies do positive gay men use to cope with stigma and discrimination? Are there common themes?; and
- obtaining a clearer understanding of younger HIV-positive gay men not wanting to disclose in social settings, and their perceptions about a lack of contact with other positive gay men and subsequent support.

Obtain a clearer understanding of the experiences of HIV-negative gay men who use sexual spaces that are shared with HIV-positive gay men (i.e. online – Manhunt, Gaydar etc, shared physical spaces – sex on premises venues, clubs, sex parties etc) and the learning experiences which take place, by:

- understanding if there is a gap between HIV-negative gay men's own knowledge about, and self-efficacy in, condom use and protecting themselves. (Some research indicates that gay men with increased anxiety and limited skills have lower levels of self-efficacy, and confidence in protecting themselves with HIV-positive partners);
- identifying how HIV-negative gay men overcome their fear of positive partners; and
- identifying what strategies do they undertake in partner selection.

Investigate gay men's perceptions of the AIDS service organisation with which they interact or know about—in particular their local AIDS Council and PLWHA organisation—as to whether people from either HIV status are adequately and appropriately served by these organisations, by:

- obtaining a clearer understanding of whether there is a subliminal or obvious level of stigma and discrimination within the HIV sector service providers i.e. AIDS councils and PLWHA organisations;
- understanding the attitudes and actions of key service providers when it comes to interactions with HIV-positive gay men/MSM; and
- identifying those attitudes and behaviours that are most able to be re-set, and those that are more ingrained and resistant to change.

In addition, the research was required to provide insight into the potential communication strategies for the future social marketing campaign.

4 RESEARCH METHODOLOGY

4.1 Overview

Two rounds of research were conducted. The main body of fieldwork, the first round, consisted of 11 discussion groups and 4 in-depth interviews with men who have sex with men but do not identify as gay (MSMs). Each group was approximately 2 hours in length and consisted of 6-8 respondents. Each in-depth interview was of approximately 45-50 minutes duration. Two of these were completed face-to-face and two by telephone.

Due to limited representation of HIV positive men aged under 35 years of age within the main body of fieldwork, a second round of research specifically targeting this group of men was conducted. This round of research consisted of 6 in-depth interviews conducted by phone, 4 face-to-face in-depth interviews, 1 mini-group discussion consisting of 4 respondents and a paired in-depth interview. Respondents for this latter round of research were recruited primarily through HIV organisations.

4.2 Sample

Achieved sample for main body of fieldwork - Round One

Group	Age	Status	Location	State
1	Under 30	Negative	Sydney	NSW
2	Over 35	Positive		
3	Mix	Mix Status – Experience of sero - discord relationships		
4	20–35 years	Mixed	Lismore	
5	Under 30	Negative	Bendigo	VIC
6	Mix	Positive	Melbourne	
7	Over 30	Negative		
8	Over 35 years	Positive	Adelaide	SA
9	Under 30	Negative	Adelaide	SA
10	22-58 years	Mixed / sero–discord group	Gold Coast	QLD
11	Over 30	Negative	Brisbane	QLD

Sample for Round Two

Depth	Method	Respondent Age	Respondent location
1	Telephone	30-35	Melbourne
2	Telephone	25-30	Adelaide
3	Telephone	30-35	Melbourne
4	Telephone	25-30	Adelaide
5	Face-to-face	25-30	Perth
6	Face-to-face	30-35	Perth
7	Face-to-face	20-25	Perth
8	Face-to-face	25-30	Perth
9	Telephone	20-25	Perth
10	Telephone	30-35	Regional Victoria

Groups	Method	Respondent Age	Respondent location
1	Mini group (4 respondents)	25-35	Brisbane
2	Paired in-depth	20-30	Sydney

The research program for Round two was designed to be flexible to cater for geographic dispersion of respondents and the reluctance to participate in a group situation.

4.3 Exclusions to the Research

As with any research of this nature attempts were made to exclude from the research anyone working in marketing or research, as well as any person working for HIV organisations. Despite this, there were a small number of men who worked in marketing in unrelated areas and a couple of volunteers for organisations involved in the research.

4.4 Recruitment of Respondents

Multiple methods of recruitment were used. These included:

- Advertisements about the research in gay publications in Sydney, Melbourne and Adelaide:
 - advertisements in both Sydney and Melbourne described the research as being on current issues in the gay community. This was done to disguise the specific issue under discussion and ensure that the sample was not skewed towards only those who were willing to engage with the issue. This was particularly important with groups among negative men. The advertisement placed in Blaze (an Adelaide publication) stated that the research was on HIV discrimination, as this ad was specifically aimed at recruitment

of positive men. HIV negative men in Adelaide were recruited using other means (see below).

- Recruitment via IQCA recruitment specialists:
 - recruitment via random selection from commercial databases of people who have identified as willing to be contacted for market research. A recruitment screener was completed to ascertain suitability for the group.
- Assistance offered through organisations:
 - various local organisations distributed copies of the advertisements and publicised the research via email networks. Those interested were provided with a phone number to call and were recruited to appropriate groups after responding to the recruitment screener.
- Existing contacts:
 - GfK Blue Moon had recently completed another study that required research with MSMs. Some of these respondents identified that they would be willing to undertake similar research in the future and were happy for their contact details to be kept on file. These respondents were invited to participate in this research. Four interviews were completed.

The recruitment screener used in Round One to ensure that potential respondents fulfilled demographic criteria is appended (Appendix A).

Given the difficulties in reaching younger HIV positive men using the above recruitment strategies in Round One, respondents for Round Two were sourced through HIV organisations. All respondents to this round of research were contacted by a member of the local service provider to ask if they would participate in the research. With permission, their contact details were then provided for the researchers to make a time and date to conduct the interview.

4.5 Service Providers

The initial research brief indicated a need for the research to include service providers. On discussion with AFAO, it was determined that this piece of research should focus solely on the perceptions of HIV negative and HIV positive men. This allowed the sample to be increased to cater for different age groups and geographic locations. It was also believed that given the time of year it may be difficult to include service providers in the research in a cost efficient manner, such as a workshop, within the available timeframe for research.

4.6 Discussion Guide

A semi-structured discussion guide was prepared in consultation with the AFAO prior to the conduct of the research. This was approved by AFAO prior to use. A copy of the guide is appended (Appendix B).

4.7 Analysis

Qualitative research deals with relatively small numbers of respondents and explores their in-depth motivations, attitudes, feelings and behaviour. The exchange of views and experiences among participants is relatively free flowing and open, and as a result often provides very rich data that can be broadly representative of the population at large.

Findings were analysed using a thematic analysis model, whereby participant views and opinions are analysed to find common themes and patterns. In qualitative research, the findings are not based on statistics. The research findings are interpretive in nature and are based on the experience and expertise of the researchers in analysing the discussions using a thematic model.

The analysis included a full review of each of the target audiences, in terms of identifying any commonalities or patterns of factors that influence attitudes and behaviours relating to stigma and discrimination, and in how these may be successfully overcome by some men. From this, we developed descriptions of different types of men that share similar attitudes and behaviours, and / or have shared similar experiences.

4.8 Research Timing

The fieldwork for Round One research was conducted from 21 to 28 May, 2009. The fieldwork for Round Two was conducted from 7 July to 5 August, 2009.

4.9 Structure of this Report

This report has been structured to include a section on each of the research objectives outlined in Section 3. This structure will allow readers to access findings on the specific areas of interest as they were specified by members of the Development Group. As a result there is some repetition as certain issues are discussed under more than one area. In addition, sections have been cross referenced where possible. The second round of research has been incorporated into relevant of the report. Where findings were consistent with other, no differentiation between the younger HIV positive men and other respondents have been made.



DETAILED FINDINGS

5 CURRENT ISSUES CONCERNING GAY MEN

5.1 Overview

As the majority of respondents were not aware of the general topic of the discussion group prior to the conduct of the research (discussed in Section 4.4), each focus group commenced with a general discussion about current issues concerning gay men. This section of the discussion had multiple purposes. Firstly, it assisted in establishing group rapport and encouraging individuals to engage with the discussion as they were able to raise specific issues of concern to themselves. Secondly, it assisted in identifying how important and relevant issues of HIV stigma and discrimination, and related issues, were to different groups among other concerns they may have. Spontaneous mention of HIV, stigma and discrimination in this area of the discussion was taken to indicate higher relevance of the issue.

Broadly, issues of concern differed according to geographic area and HIV status of respondents. These are discussed where relevant below.

5.2 Homophobia

Homophobia and lack of anonymity were the key issues of concern raised in the groups discussions in regional areas, with some of these respondents having suffered verbal and physical abuse due to their sexuality. Respondents identified coming out as gay in a regional town was difficult due to a lack of anonymity. Once an individual had openly told people about their sexuality, it was perceived that this automatically became part of their public identity in other non-related areas of their lives, such as the workplace and social situations. It was perceived that they ceased to be known by only their name, instead their identity was always supplemented by also being gay. Most expressed a dislike for what they saw as a label and accompanying expectations about their personality.

"It's like... 'That's Dave. He's gay', not just 'That's Dave'."

"I get asked at least twice a day by clients if I'm gay. You just get sick of it, what does it matter? But it's a small town..."

It was largely perceived that this lack of anonymity was not such an issue in metropolitan areas such as Sydney and Melbourne. In a regional area, the lack of anonymity accompanied by both latent and overt homophobia, was seen to result in gay men moving in small social circles where everyone knew everyone.

"We all know each other, or have heard of each other"

"There's just no men! We all know each other...thank god for the uni students. Some new men each year."

5.3 Gay Community

The remaining regional group involved both HIV positive and HIV negative men. While HIV, and HIV discrimination, was spontaneously raised as an issue in this group another more general issue was the demographic divide, in terms of age, that resulted from men in their 20s and 30s moving away to major metropolitan areas of Sydney and Melbourne. This was seen to result in the establishment of two very different gay communities in regional areas. One community was seen to consist of young men in their early 20s, and the other consisted of men in their late 40s and 50s and above who may have come back to their local area after spending time in Sydney or Melbourne.

The issue of a 'gay community' was raised via a number of different avenues by respondents in metropolitan groups. Discussions about Mardi Gras and the changes that had occurred over the years, led onto more detailed conversation about changes in the 'gay community' and its lack of cohesiveness in current times. Some respondents claimed that 'gay men' did not seem to want to be involved in the 'gay community' anymore, however, this was more likely to come from those who were very active with different organisations. Others, who were not involved with organisations, were more likely to claim to be part of the general community rather than a specific gay community.

The issue of a lack of 'gay community' was spontaneously raised in regard to events like Mardi Gras and places like Oxford Street. Whereas Mardi Gras was once a demonstration of gay pride and a means of raising the issue of acceptance among the broader community, most respondents identified that the activism that was associated with the early years of this event is no longer needed. As a result the purpose of the event was perceived to have changed significantly. It was seen as a means of keeping gay issues in people minds, as well as offering a good party for both gay and straight people. Some actively criticised the event as a simple marketing tool for various commercial organisations.

Similarly, Oxford Street is no longer perceived to be place predominantly for gay men and women. Instead, most identified that Oxford Street is now more 'straight' than 'gay'. For some, this meant that it no longer offers a sense of safety and security as a place where they can be themselves. Some respondents even reported incidents of 'gay bashing'. It certainly is no longer seen as a place for the 'gay community'.

"You used to be able to walk into the Courthouse and know everyone, or at least know that everyone was gay. Now, there's people out of it everywhere, and most of them are straight. Young kids".

"Oxford Street's changed. We went last year and although I haven't been for 20 years or so, it's not what it used to be...it's frightening. I remember feeling safe when we went there before, now I, it was like, let's get out of here...."

While it was recognised that the changing role of events like Mardi Gras was positive in that it illustrates a greater social acceptance of gay people by the wider community, it is also indicative of why the notion of a 'gay community' is not seen to apply as much as it did a decade or more ago. Broader social acceptance no longer means there is a need for activism. Similarly, this acceptance means that gay men and women can feel comfortable in a broader range of places than Oxford Street.

"It's not a strong community...it is not unified...people are part of the community when it suits them."

"We're less under threat."

"You're welcome in any bar so you don't have to be in the same bar as other gay men."

"I'm more comfortable at almost any other bar and club than anywhere on Oxford St. The places I go out to aren't straight or gay."

5.4 Equal Rights

Metropolitan respondents were also more likely to raise issues related to equal legal rights, such as marriage. However, it was generally acknowledged that progress had been made in this area over time and would likely continue. There was some negativity expressed about how when it came to government benefits, gay couples were now legally 'de facto' couples, however they still did not have the choice to have a legally recognised marriage.

5.5 Relationships and HIV

Spontaneous mention of HIV was markedly different between groups. Younger, HIV negative men in both regional and metropolitan areas did not raise HIV as a current issue of concern at all, although some did bring up the topic of STIs generally. Among these groups, there was no spontaneous discussion of issues of HIV disclosure. In regards to relationships, the key issue of concern for this group was faithfulness and a lack of men (in regional areas). In contrast, older HIV negative men groups were more likely to spontaneously raise the issue of HIV in relation to prevention and disclosure in sexual encounters.

Among groups involving older HIV positive men, sexual encounters and the issues of prevention and disclosure were the most common spontaneously raised issue of concern. Some of these men immediately identified feelings of rejection and helplessness when engaging with other men both online and in physical situations. While later discussion identified other areas in which these men may feel stigmatised or discriminated against due to being HIV positive, spontaneous concern focussed only on relationships, both casual and long term, and the issue of disclosure. Although these issues are discussed in detail throughout this document, the fact that it was the key concern raised by many HIV positive men illustrates the importance and impact of discrimination in relationships in the lives of these men.

While potential rejection was a concern for younger HIV positive men in regards to both causal and long term relationships, of equal value were potential shame and embarrassment that they would feel. While these feelings no doubt exist among older HIV positive men, they were not as openly discussed as they were among younger men. Further, most younger HIV positive men tended to fear the potential for the person who rejected them to tell others about their HIV status as much as the actual act of being rejected.

A critical part of the shame and embarrassment that the younger men felt was in regard to getting HIV. Those who were newly diagnosed identified that they felt as others felt that they must be 'stupid' to be able to get HIV with all the education about prevention that occurs.

"Your embarrassed because its stupid. All of us could have prevented getting HIV, there is no excuses. We were just young and stupid, thinking that it would never happen to me."

However, they all identified that ignorance had a role to play. Like themselves, their peers have a perception that it will not happen to them.

"Other people think how could you be so stupid. But they think its because you slept with someone who looks like they have HIV. They don't; think about the guy they're bare backing that night would have HIV....they'll think your stupid but do the same thing as what you did."

6 ATTITUDES AND EXPERIENCES OF HIV STIGMA AND DISCRIMINATION

6.1 Awareness and Knowledge of HIV

One of the key findings from the research was the notable differences in awareness and knowledge of HIV among different groups of men. Levels of awareness and knowledge of HIV have an impact on attitudes to stigma and discrimination. Broadly, awareness and knowledge was dependent on:

- age; and
- personal association with HIV.

Please note, the following discussion is based on the broad trends that emerged from the group discussions. Obviously individuals differ according to their own experiences.

Younger HIV Negative Men

The lack of knowledge about HIV among some younger men in their early 20s was markedly apparent in the group discussions. They openly talked about people with AIDS, rather than HIV, and readily discussed how it was easy to identify men with AIDS by their physical appearance. It was often assumed that men with AIDS 'looked sick', with most describing a stereotypical image of an older thin man with sunken cheeks.

These men were aware of prevention messages of using condoms in regards to HIV/ AIDS, but generally had little knowledge of the topic apart from this. Very few knew someone with HIV /AIDS, and most admitted to not having discussed it with other people previously. A couple of the groups were clearly uncomfortable when it became apparent that some of the discussion would focus on HIV. Even those with some personal experience of HIV, such as having a friend who is HIV positive, were often reluctant to engage in the discussion within the group situation.

Reluctance and discomfort in discussing HIV within the group situation, and more broadly in everyday life, appeared to be based on a number of perceptions:

- association with illness and death;
"I'm young. I'm 20. I don't talk about death with my friends."
- lack of perceived risk as the 'stereotype' image they held suggested that they were unlikely to encounter someone with HIV, and very unlikely to engage with them sexually;
"I'm into young, hot guys. I just don't know anyone with HIV and I'm not going to have sex with them if I did."
- lack of perceived relevance due to being currently involved in relationships and / or claiming that they would always use condoms with someone new; and

"I've been with my partner for two months. We got tested for everything, so we know that we are alright...it really isn't relevant to me."

- the general 'invincibility' of youth.

"Those things don't happen to people my age. Things are different now than what they used to be"

Older HIV Negative Men

Awareness and knowledge of HIV was higher among men who were aged in their late 20s and older, although these men differed a great deal in their attitudes towards HIV positive men depending on their personal experience. Compared to younger men, older negative men did not refer to AIDS in isolation, but also talked about HIV. They were less likely to perceive that they would be in a monogamous relationship for a long time, as some younger men in relationships did, and did not tend to believe that HIV status could be determined by physical appearance. While many older negative men claimed to not place themselves in a position of risk by always using condoms, most also claimed to be regularly tested for STIs including HIV.

Older negative men also tended to be more aware that HIV was now a manageable condition through use of medications. While this meant that they were less likely to perceive HIV as necessarily resulting in death, as younger men did, they also recognised that the effect of the medications can also impact on quality of life.

"It no longer being a death sentence...everyone has realised you can still lead a long and normal life."

"It still isn't great. Some people suffer so much from medications...you don't want to shit through the eye of a needle every morning for the rest of your life."

That said, some older negative men did admit that after having been careful and taken regular tests over the years, they had gotten a bit lax in regards to always having protected sex. For some it was a sense of, 'if it hasn't happened by now, then it is unlikely to', and for others it was more the possibility of feeling that they had already reached an age where the impact of HIV managed by medications would not reduce their life span considerably.

"Well I'm nearly 50, if I get it now I'll probably get 15 years still, so I'd be 65 when I'd probably die anyway."

Despite generally having higher awareness than younger men, there will still some older negative men who had little personal experience of knowing someone with HIV, still tended to be openly negative and have little empathy for people who contract HIV in the current environment.

"If you knew someone who'd got it through unprotected sex you would see them as stupid."

Positive Men

Attitudes of positive men towards HIV were many and varied. Some displayed a strong resilience and confidence in living with HIV, while others expressed experiencing numerous difficulties in many areas of their lives which had led to severe mental and physical hardship. Later sections discuss these in detail. This section aims at providing an understanding of how positive men perceive the attitudes of negative men towards HIV (not to people with HIV).

Some HIV positive men claimed to have experiences of negative men lying about their status so they could have unprotected sex with positive men. It was perceived that these men were motivated by two very different reasons.

Firstly, HIV positive men felt that some negative men did not feel that there were any real consequences to contracting HIV now that medications enabled the majority of men to manage the condition. Effectively, the medications were seen as a motivator for men who would prefer to *'get it over with'* (contract HIV) so that they could then make the choice to not use condoms in the future. There was also some discussion about 'infection parties' occurring in the US. Most referred to these men as 'bug chasers', although not all were aware of the phrase.

Not surprisingly, HIV positive men were quick to criticise HIV negative men trying to get HIV. Older positive men felt that the impact of the medications on quality of life was not understood. That is, some negative men were not aware of the associated conditions, side effects of the medications, and that medications do not work for everyone.

"Your body is like a chemical waste dump."

"I've had a triple by-pass because of the medications, problems with my liver and kidneys...people don't die from AIDS now but they die from AIDS related diseases. What's the difference?"

Younger HIV positive men were more likely to believe that these negative men did not understand the mental and emotional implications of contracting HIV. Those who were more recently diagnosed tended to express both disbelief and anger that any HIV negative man would knowingly risk having unprotected sex with someone who was HIV positive. They could not understand why someone would actively place themselves in the same mental and emotional situation as where they currently found themselves.

The second reason identified for why HIV negative men were seeking out positive men to have unprotected sex with was the idea of playing 'Russian Roulette'. Some positive men claimed to have experienced younger men asking for unprotected sex for the sense of danger, excitement and adrenalin, from the possibility of contracting HIV. Notably, some young HIV negative men claimed to know others who acted in this manner.

It was claimed that these younger men saw having sex with HIV positive men as being like playing Russian Roulette with a gun, or even a form of 'Extreme Sex'. This identifies how negative men who engage in this behaviour view HIV positive men, that of having the potential to kill such as a loaded gun or as a deliverer of a lethal poison. In effect, they identify all HIV positive men as potential criminals.

Older HIV positive men were very quick to criticise young men's attitudes to HIV. Apart from the specific instances of men deliberately trying to contract HIV, HIV positive men also identified a lack of knowledge among young men in regards to HIV and its perceived severity. They identify that a resurgence in barebacking is based on younger men no longer being fearful of HIV, the availability of PEP, and assumptions about what people with HIV look like.

"Thinking of the Grim Reaper campaigns, people have don't know about all that stuff or they seem to have forgotten it."

"The under 25s only think they can get it from men who are bald with beards and wear leather."

"They don't think they can get it from someone their own age who looks like them."

"Because people with HIV don't look unhealthy anymore, like they're not always gaunt and sick looking."

"You can just take a pill for it (PEP) if you think you're at risk."

Younger HIV positive men agreed that younger men tended to not fear contracting HIV, however, they believed that this was based purely on ignorance rather than it now being seen as less severe than in the past. Younger positive men could easily recall their own perceptions about HIV prior to contracting it, and believed that their HIV negative peers most likely did not think about HIV at all in relation to the men they normally engaged in unprotected sex with. That is, although they may theoretically be aware that you can not tell that someone has HIV by their appearance, it is not generally even considered as a possibility when having sex with someone of similar age to themselves. The possibility of contracting HIV is simply not a real consideration, it is instead an 'abstract' concept that happens to others.

The effect of medications was universally raised across all groups with HIV positive men. Men openly discussed with each other the difficulties and discomfort brought on by the medications. Health professionals appeared to have a pivotal role in how men felt towards medications. Those who felt they could be honest and open with their health professionals and could work with them to find the right mix of medication appeared to be more comfortable with discussing HIV as a manageable condition. Those who claimed to be having difficulties with their medications often also expressed that they had taken some time to find a health professional they were comfortable with,

or were still looking. Younger men who had yet to experience medications to any real extent all expressed some trepidation about how they may feel at the time.

6.2 Awareness and Attitudes towards HIV Stigma and Discrimination

Overview

Although many men had difficulty in providing an actual definition for stigma and discrimination, all respondents, regardless of age and HIV status, claimed that discrimination on a range of factors was rampant among gay men.

“Oh, the names we have for each other. We can't not have names and groups, and labels. All gay men do is bitch about other gay men when they're not trying to fuck them.”

Despite the difficulty in defining stigma and discrimination, all respondents could relate instances of discrimination, stereotyping and labelling. The most common factors on which this was seen to occur, aside from HIV, included:

- race,
- age;
- height and weight;
- fashion; and
- preferred sexual behaviours.

Some examples of different forms of discrimination experienced by both positive and negative men that were recounted in the groups included:

- Asian men being told being told to 'go back to China' by other men in saunas, and being more likely to be called a 'slut' or 'Ho' than a Caucasian man if having lots of casual sex;
- older guys being rejected consistently for casual sex, even by men of a similar age;
- younger men being labelled and subject to ridicule if dressing differently than others; and
- being rejected due to physical size, either being a large build, heavier in weight, or a small frame.

When asked about stigma and discrimination in relation to HIV, most HIV negative men admitted that there was a stigma associated with HIV, although were more reluctant to identify any forms of discrimination towards HIV positive men.

Stigma

Most HIV negative men readily admitted to being aware of a labelling and stereotyping of HIV positive men among gay men generally. The extent to which respondents admitted to doing this personally was strongly dependent on the age and personal experience of HIV. Younger men with no personal experience of HIV do not think twice about openly labelling and stereotyping HIV positive men. Some phrases that men had heard to describe HIV positive men included 'leeches', 'diseases queens', 'filth'. At the extreme end of this scale, younger men described the stereotype of HIV positive men as:

Older men who look sick and have sunken cheeks, who frequent bars and beats preying on other men to have unprotected sex with. They also lie about their status on the Internet, or ask to have unprotected sex with negative guys on the Internet so that they could further infect others.

These men readily admitted to having the perception that HIV positive men were 'dirty' or 'unclean'. Some men, at the extreme end of scale, stated that they would be reluctant to be in the same space, such as a club, as someone they knew to be HIV positive. They felt that this would associate them with the negative stereotype they held of HIV positive men, which was something to avoid. Men that hold this stereotype of HIV positive men were unlikely to be aware of anyone they know who is HIV positive. This group of men had little empathy for HIV positive men as they feel that men who contract HIV in today's environment have actively chosen to as they feel it can be prevented through safe sex. There is a strong sense of blame associated with this.

"If you have unprotected sex then it's your fault."

One younger HIV positive respondent claimed that it was common for some of the younger HIV negative men he knew to chant or sing 'He's got the AIDS, he's got the AIDS' when they wanted to demean others, regardless of HIV status. Essentially it was seen as a way of being particularly insulting to others.

The shame and embarrassment that younger HIV positive men reported feeling due to having HIV, appeared to be exacerbated by being very aware that these extreme views are held by other younger men. Many of the younger HIV positive men could distinctly recall that they were very naïve about HIV prior to being diagnosed, with some admitting to holding views similar to those expressed above. It is likely that the negativity that some may feel towards themselves is strongly based in the views and opinions that they held prior to becoming HIV positive. Coupled with this is the keen awareness that they have as to how men who are HIV positive are perceived by some younger men.

Labelling and stereotyping existed among almost all respondents, not just those at the extreme end of the scale of attitudes. Older, negative men, some of whom had some personal experience with people living with HIV, used specific phrases to identify HIV positive men. 'Victim', although used with perceived sensitivity by HIV negative men, was often seen as patronising and pitying by positive men. 'GAIDS' was a term that some positive men in Sydney had frequently heard 'in fun', but still could be difficult to hear. 'In the club' was used by older men, often in a derogatory manner, such as 'Don't go near her, she's in the club'. A variant on this is 'she's got the lurgy'. 'What team are you on?' was used as a phrase by some as a means of ascertaining HIV status. This last phrasing is reminiscent of asking whether a person is gay or straight.

While not as demeaning as some of the labels used by younger men with little personal experience of HIV, the use of phrases such as team and clubs clearly indicate how negative men think of themselves as belonging to a different 'community' than positive men (albeit they would not describe this as community). Although none of the positive men involved in the research embraced the notion that they were of a different 'community' than HIV negative men they clearly felt as if they were. Notably, the vast majority of negative men happily claimed a difference.

Even among some of the most of liberal the HIV negative men in the sample, there was an element of implicit judgement in the way they talked about men with HIV. Often this was related to the way they explained how someone they knew contracted HIV. For example, one man gave an example of a friend who had contracted HIV from his partner because the partner had injected drugs and been promiscuous, while the friend had been faithful. The respondent said *"you can't be judgmental. It's not necessarily from decisions they've made"*. This highlights that there is a strong element of blame that underlies the stigma associated with being HIV positive.

In regional areas and smaller metropolitan centres, HIV negative men perceived that stigma associated with HIV directed from the broader community, was still largely attached to gay men in general. That is, HIV was still often seen as *"(that's) a poofers disease"*. Some of the younger men claimed that this stigma made being gay in a small town or city even more difficult, and reinforced their intent to distance themselves from HIV.

A number of younger HIV positive men felt that it was this attempt to distance themselves from HIV that was the basis for the negative attitudes and behaviours demonstrated by younger HIV negative men, regardless of where they lived. It was believed that many young HIV negative men who are still exploring and establishing their own identity in relation to being gay, tend to be overly critical of PLHIV as they lack any real knowledge of HIV. They only know it as something to prevent and be frightened of. As HIV is still linked to gay men by the broader community, the lack of knowledge and perception of HIV as something to be feared can increase feelings of insecurity and uncertainty when they are dealing with their own emerging gay identity.

One articulated the behaviour of young negative men as being an *"internalised homophobia"*. He identified that this described the attitudes and behaviour that he held towards others when he was HIV negative, and now towards himself now that he was HIV positive. One empathetic HIV positive respondent concluded that the attitudes and behaviour of younger men was not really deliberate, it was only that younger negative men often just did not know better and were still trying to work out their own identity issues.

Discrimination

Interestingly, despite being cognisant of stigma associated with HIV, the majority of negative men did not tend to feel that HIV positive men suffered from discrimination specifically. When the concept of discrimination was raised, most immediately thought of sexual relations and did not see it as discriminating if they chose not to have sex with HIV positive men even with protection. While across the sample there were some examples of sero-discordant relationships, many of these were long term relationships of between 6-27 years. Interestingly, among the younger HIV positive men interviewed in the second round of research who were in relationships, most were in sero-discordant relationships.

Across the sample, there were only a small number of HIV negative men that claimed to not discriminate, and reported to readily engage in casual, and long term, sexual relationships with men who were HIV positive.

The majority likened HIV to being one of the key factors on which they may base a choice of casual or long term partner, but they did not identify this as discrimination. For example:

"I have a list. Young, hot (laughter), tall, has to have hair, well dressed, not Asian, and clean."

"If you want to call it discrimination, then we discriminate all the time when we choose to have sex. You don't have sex with someone you're not physically attracted to, and the moment I found out that someone was positive, I wouldn't be physically attracted to them. It would be like being told to have sex with a gun to my head. Things just wouldn't work like they're supposed to."

"Is it discrimination if people don't want to have sex with HIV positive people?...I've always been a bit concerned about that in the back of my mind."

Rejecting someone for sex on finding out they were HIV positive was simply not seen as discrimination, as it was perceived to be a 'right' to protect oneself by avoiding sexual relations with positive men altogether. This was even the case among by those who admitted they tended to be abrupt in ending the relationship on finding out that the other person was HIV positive.

"I shut the window straight away and block them" (online).

“Walk away. That’s all you can do. Walk away” (face-to-face encounter.)

Most HIV negative men tended to define HIV discrimination as deliberately excluding someone from a social circle, or preventing access to services. They did not tend to feel that this occurred since most were aware of a variety of service organisations specifically for HIV positive men, and they were aware of HIV positive men in other social circles.

As is illustrated by the description of reactions and opinions throughout this section, stigmatising and discriminatory language was used consistently within the group discussions even if not explicitly so. Even many open minded negative men, some of whom claimed personal experience with a friend who had HIV, still demonstrated language and behaviour that was indicative of stigma and discrimination, even if this was as subtle as differentiating about how different men had contracted HIV (such as is described above in the section on stigma). Often, throughout discussions, the more open minded men began to identify in themselves the language and behaviours they displayed as being characteristic of discrimination. The process of the discussion group seemed to provide awareness of subtle forms of discrimination that they may not have previously been aware of. This suggests that, at least for some men, raising awareness of the issue will make a start on behaviour change.

Positive men indicated that within the gay community, discrimination largely occurred in potential or realised sexual situations rather than elsewhere. While this occurs in actions of physical rejection (walking away), it also occurred in the language used to ask about sero-status. Some HIV positive men noted an increasing prevalence of other men asking “are you clean?”. All felt this was a highly derogatory and discriminatory word to use, playing negatively on the ego and assuming anyone with HIV is ‘dirty.’

“It’s like Germany in the 1930s – it says if you’re ‘unclean’, that you’re unclean as a human being and you’ll be rejected and discarded straight away. It shows they don’t understand what safe sex is or about the world in general.”

Consistent use and broad social acceptance of language such as this can also lead to self-stigmatisation by HIV positive men. Some HIV positive men readily identified the shame they experienced when consistently rejected on the basis of ‘not being clean’, which could lead on to self hate and stigmatisation.

Aside from sexual situations, other specific areas of discrimination included:

- engaging in ‘normal’ social events, such as a night out due to different financial and health circumstances;
- choice of health professionals such as doctors and pharmacies;
- loss of rights to privacy in some health situations;

- engaging with family members (outside of the gay community); and
- in the workplace.

These areas are discussed throughout this document (see Sections 6.3 and 6.5).

6.3 Defining Stigma and Discrimination

As identified above, HIV negative and positive men had some difficulty in defining stigma and discrimination despite being able to articulate examples of each. The literature review discussed a number of definitions of stigma and discrimination that could be used as a framework for the attitudes described above. It is not the intention of this document to apply these frameworks as a specific model on which to report the qualitative research findings, however there is a great deal of consistency between the findings and the definition provided by Link and Phelan ⁴. Given respondents themselves had difficulty providing a definition, we have used the components referred to in the Link and Phelan definitions, to contextualise the attitudes described in the section above.

Stigma is the social process described by Link & Phelan (2001) as consisting in the co- occurrence of (1) labelling, (2) stereotyping, (3) separating into us and them, (4) status loss & discrimination, (5) power.

Discrimination is a component of stigma and must be considered both in terms of people who practice discrimination and people who experience discrimination.

The descriptions of attitudes and behaviours in the above section illustrate a number of the factors that are seen as necessary to occur for stigma to be seen defined as a social process. HIV negative men label and stereotype HIV positive men. Many readily articulate an 'us and them' attitude, with many HIV negative men avoiding any physical associations with positive men. This is achieved by refusing to engage with HIV positive men even electronically via the Internet, and at the extreme end, not wanting to be at the same physical locations. The language used to describe HIV positive men clearly differentiates these men from being the same as negative men, as they are on different 'clubs' or different 'teams'.

Status loss and discrimination occurs on multiple levels but is specifically highlighted by the description of HIV being one of the key factors with which potential sexual partners are chosen. In

⁴ Bruce G. Link, and Jo C. Phelan. 2003. Conceptualizing Stigma. Review- article. November 28. <http://arjournals.annualreviews.org.dbgw.lis.curtin.edu.au/doi/abs/10.1146/annurev.soc.27.1363?prevSearch=HIV+stigma&searchHistoryKey.>, cited in Stigma & Discrimination Literature Review, Daniel Reeders, Campaign Coordinator, People Living With HIV/AIDS Victoria.

fact for many HIV negative men, HIV status would be the only factor on which a potential partner would definitely be excluded from consideration. Changes in power relations, specifically loss of power by HIV positive men, is highlighted linguistically by the descriptions offered by some HIV negative men. Not only are HIV positive men 'unclean' but sexual interactions with HIV positive men are likened to 'loaded guns', 'playing Russian Roulette' and 'poison'. HIV is the bullet, but the positive man is seen as the person pulling the trigger of the gun, thereby becoming a potential criminal.

As a criminal would be marginalised from mainstream society and stripped of certain rights, so are some HIV positive men in the views of others. Whether they consciously identify this or not, this is indicative of the perspective and the language used by some HIV negative men when discussing HIV and positive men.

Power is also lost by other means. Most positive men identified that once they are known to be HIV positive they appear to lose a right to privacy personally (outside of legal requirements to disclose). Once others are made aware of them being HIV positive, the next question is commonly 'How'? Others feel it is their right to ask. This, in turn, can result in a judgement being passed on that person.

The right to choice is also inhibited in many ways. In terms of healthcare, a number of respondents reported only having limited choices of doctors to see and pharmacies to dispense their necessary medications. Choice of housing is limited when reliant on government benefits, and choice of socialising is limited not only by the perceptions of others, but by the financial and physical capability to participate in the same social situations as physically healthy, working HIV negative men.

"You don't have the money, and you probably shouldn't be out drinking and taking drugs all night. It limits what you can do".

6.4 Factors that Contribute to Stigma and Discrimination

Fear

Fear is commonly cited as one of the key underlying factors contributing to stigma and discrimination toward HIV positive gay men from other gay men. Although most men, especially older men, were well aware that HIV is a manageable condition for many people, the lack of cure means that HIV is still potentially fatal and is seen as something to be feared. At a minimum, it can have substantial impact on an individual's quality of life due to the effect of medications. Not surprisingly, this fear is predominantly related to potentially contracting HIV from unprotected sexual activities, however, the same element of fear of contracting HIV carries through to non-intimate activities.

"I really do....I see it as a loaded gun. I wouldn't hold that to my head and pull the trigger so neither should they."

"The very fact that it's deadly, they (HIV negative men) liken it to be poisoned to some extent..."

Fear also exists of being stigmatised by others should one become HIV positive. For some negative men, the thought of becoming their perceived stereotype of a HIV positive man, reinforced the stigma and discrimination they held far more than the fear of HIV itself. In a sense, the stigma is self-perpetuating as men are driven to distance themselves as much as possible from HIV positive men to reassure themselves that they are not the stereotypes.

"There's another group in their 50s who are long-time HIV sufferers who have physical traits that are apparent to people, and either they don't want to go out in a group or people don't want to be associated with that group because of being stigmatised..."

Lack of Knowledge

In turn, fear of HIV is driven predominantly by lack of knowledge. All HIV negative men know that using condoms will avoid risk of contracting HIV, however, this is all they really know in terms of how to personally protect themselves. Many still see the use of condoms as having an unacceptable element of risk and therefore try and avoid sexual contact with HIV positive men altogether. Most younger men assume they are able to identify men who are HIV positive by physical traits, so therefore tend to make assumptions about sero-status based on this. Older negative men are more likely to be aware that HIV positive men cannot be identified by physical traits, and will use condoms if in doubt. However, most claimed they would avoid the risk of even protected sex if were aware of the other's HIV status.

The lack of knowledge regarding HIV in general was a key driver behind the stigma expressed by younger men. The potentially fatal nature of HIV, and the need to use condoms to prevent getting it, tended to be the extent of knowledge that most younger negative men had. It is simply not discussed by younger gay men (for all the reasons identified in Section 6.1). As a result, these younger men could only base their views and opinions on the limited knowledge they hold – that HIV is something to be avoided.

Personal experience

Reluctance to discuss HIV appears to be strongly linked to personal experience. Men who claimed to not know anyone, or very few people, with HIV held more negative attitudes than those who did personally know someone with HIV. While this was typically younger negative men in their early 20s, lack of personal experience with HIV also strongly influenced the attitudes of some older HIV negative men as well.

Critically, lack of personal experience with HIV means that men have limited reference points from which to develop and shape attitudes. Older HIV negative men demonstrating openly negative attitudes were similar to younger men in that they all claimed to have no personal knowledge of others with HIV. These men indicated that the few interactions they had experienced with HIV positive men, online or face-to-face, had tended to be negative thereby reinforcing other feelings such as fear and increasing associated stigma.

"I know one person with HIV. He's not a very nice person...maybe that influences me, I don't know. I just know that I don't really want to know anyone with HIV."

"I know them on the Internet. They ask for bareback all the time."

Those with some personal experience with HIV, either through a friend or relative, with a partner or by being HIV positive themselves, were the least likely to demonstrate stigma and discrimination towards (other) HIV positive men. While not all were free of stigma and discrimination, particularly in the area of engaging in sexual relation with HIV positive men, positive personal experiences provide another reference point from which to form attitudes.

Further, older men were more likely to have experienced the seriousness of HIV in the '80s, where many had friends that died or became ill. From this, older men are more likely to demonstrate empathy with HIV positive men.

HIV negative men aged 40 and over were also more likely to know sero-discordant couples than younger men (or to have experienced a sero-discordant relationship themselves). Knowledge of this furthered understanding of HIV and tended to assist in lessening any fear of HIV further. This in turn lessens the potential for stigma and discrimination.

Preventative education and social marketing

For many HIV negative men, their primary sources of information and references on HIV are the education and social marketing materials they are exposed to. These are predominantly messages of prevention by the use of condoms. Over the years continuous messages of prevention, and no messages about other elements of HIV, result in men only having the knowledge that HIV is something to avoid at all costs.

Quite simply, unless they have personal experience with someone who is HIV positive their only point of reference is that HIV is something that should be avoided. Further, continued emphasis on avoiding HIV carries a strong message for many that contracting HIV would be extremely bad, which some interpret as meaning that those who contract HIV must be also be 'bad'. For many, the constant reinforcement of prevention messages has resulted in them avoiding any contact with HIV positive men. This was perceived to be the only way to minimise all risk for these men.

A number of HIV positive men also identified that continuous prevention messages and the absence of any 'good news' about PLHIV has been one of the key factors in some attitudes among the gay community changing for the worse. These men felt there was a lack of education about what to 'expect', 'think', 'feel' towards PLHIV, or what the 'experience is' of living with HIV, compared to a continual social marketing focus only on prevention. This marketing reinforces the fear that many men have.

Impact of these factors on younger men

All of the above factors are more prevalent among younger men. Younger gay men are more likely to know little about HIV beyond it being something to prevent, and therefore fear. They are far less likely to know others who have HIV and are likely to be consistently exposed to the preventative education and social marketing materials on HIV that are produced by organisations. It is this social environment in which younger HIV positive men have to live within, resulting in most young HIV positive men choosing to keep their status as private as possible.

Further, most are very aware that their peers are influenced by these factors as they recall feeling similar when they were HIV negative. Many younger HIV positive men are very conscious of the 'stereotype' of someone with HIV that younger men tend to have, as they themselves had it, and choose to guard their privacy closely to avoid being judged in this manner.

"I thought that HIV only happened to a certain type of person...the older guy who fucks around and takes copious amounts of drugs. Its them that get HIV. You never equate young and healthy to being HIV positive"

Other factors contributing to stigma and discrimination in the professional environment

It is difficult to highlight factors outside of those already discussed that were believed to lead to discrimination in the workplace, as there were few instances of workplace discrimination reported by respondents. Fear and lack of knowledge were perceived to be the primary contributors to the few instances of professional discrimination that men claimed to have experienced.

There were few instances of discrimination in the workplace discussed in the group as most HIV positive men did not tell employers about their condition. Legislation and general workplace practices, for example, wearing gloves when coming into contact with blood, meant that most HIV positive men preferred not to tell employers. While this reportedly could cause difficulties when they had to take sick days when the effects of medications caused illness, most felt that non-disclosure was the key way of avoiding what they perceived as the inevitable stigma and discrimination.

The potential issues of discrimination in the workplace was raised more in the interviews with younger HIV positive men, as most of these men were currently working or were actively looking for employment. Two key issues were raised in relation to discrimination. The first involved men who

had decided to disclose their HIV status to potential employers due to their job involving a higher risk of disclosure later, for example, where their employment involved the potential for cutting themselves with sharp implements. A number of these men reported having extreme difficulty in getting jobs and felt that they had been not been successful gaining employment due to being HIV positive. These men were currently re-evaluating their decision of disclosing to potential employers.

The second issue involved men who were in currently employed in particularly challenging and high profile positions. Although most could not identify any reason that they would have to ever disclose their status to employers or colleagues, some of these men feared they would loose credibility in their workplace due to the negativity they perceived their colleagues would have towards PLHIV. Interestingly, those working in medical areas were particularly concerned about the reactions of the colleagues, employers and the general public should their HIV status become known.

"My colleagues are the worst. You would think that they should know better. But they double glove, double gown, double everything."

Other factors contributing to stigma and discrimination in personal relations

A number of HIV positive men identified stigma and discrimination from family members and friends. Being HIV positive was seen to exacerbate already difficult situations with family. Some had difficulty with their families due to cultural and religious factors. Those from certain ethnicities with strict religious upbringings reported having had difficulty with their family members for being gay. This difficulty was exacerbated when they become HIV positive, with some reporting that they no longer spoke to their families.

Although friends would claim to be supportive, few HIV positive men claimed that their friendships with negative men had remained intact after they disclosed they were HIV positive. Most felt that their negative friends were reluctant to be seen with them in public, for fear that others would assume that they were also HIV positive. In a sense, they feared discrimination by association. Although this was only admitted by a number of HIV negative men, others claimed that they did not really go out with the HIV positive men they knew too often. These HIV negative men felt that it was simply because the positive friend's life had changed so much since 'becoming sick'.

The majority of younger HIV positive men interviewed in the second round of research claimed to be careful about the friends they told about their HIV status and those they did not. All identified that telling close friends, straight or gay, was often very difficult. Although none reported losing close friends after disclosing, all clearly remembered the fear they had felt before doing so. A number of younger HIV positive identified that there were certain groups of friends that they would not disclose to due to the potential for adverse reactions. The first of these was the broader circle of gay acquaintances that they may have / had. While they felt that while close gay friends offered

support, the potential for others in their broader circle of gay friends telling others, who would tell others, was too great.

"It's so gossipy. They feel they have to tell other people, whether to warn them off you or just because they want to be seen to be the one with all the knowledge. Once you tell some people, you know they will tell everyone else and you can never take it back"

"Because my straight friends that I went to school with are like motocross riders, tattoos you know at the XXXX Tavern boxing night on Friday nights and they know I'm a poof and they're fine, other gay men is my biggest fear ... rejection and I think it would get around quicker, I think it would be a bigger issue"

Another younger HIV positive man identified that it was his straight heterosexual friends with children that he feared he would lose if he disclosed his status. He felt that while his friends may be able to overcome any fear they would have in relation to themselves, they would not be able to do so in relation to their children.

Other factors contributing to stigma and discrimination in sexual relations

All of the general factors discussed above, fear, lack of knowledge, lack of personal experience, preventative education and social marketing and the changing online environment contribute to stigma and discrimination in sexual relationships. This topic is also discussed in more detail in Section 8.

Other factors contributing to stigma and discrimination with service providers

No specific factors contributing to discrimination in day to day experiences with service providers were identified in this research. This was specifically probed but respondents were predominantly complimentary about the attitudes of services providers. This topic is discussed in more detail in Section 11.

6.5 Specific Experiences of Stigma and Discrimination

Sexual and personal relationships

HIV positive men identified that the stigma and discrimination towards PLHIV / AIDS is considerably worse from other gay men than from heterosexual people. The main area in which HIV positive men felt discriminated against was in sexual and personal relationships. The majority of HIV positive men openly discussed rejection from prospective partners once they disclosed being HIV positive. While for some this was a rare experience, for others it occurred often.

"The moment you say your HIV positive, they run screaming from the room."

"They block you (online). You could have been getting on really well and then suddenly, once you've told them, it's over. You can't even try and explain..."

"They can't run fast enough. They're shit scared that you'll deliberately try and infect them so won't even use condoms."

Some even reported instances of physical and verbal abuse from other gay men. One younger respondent described an instance of being 'roughed up' by the mates of another man he had gone home with. He had told the man he was positive and they had used protection but some gay friends of the HIV negative man had told the HIV positive man to stay away from their friend and called him a 'HIV Fag'. The HIV positive man strongly related this to homophobia that was likely experienced by gay men twenty years ago.

Most HIV positive men also identified that once they disclose in an intimate situation, their HIV status seems to become open knowledge in that it is readily discussed in social circles. Some HIV positive men identified that they are discriminated against in social situations prior to even the possibility of a sexual relationship occurring. For example, going out with friends to a venue, they feel that their HIV status is a source of discussion and warning.

"You can be at venues and people will whisper to other people 'watch out for him he's got HIV.'" (younger HIV positive man)

Given that their status is so openly discussed by others and starts to become an essential part of their identity within social circles, most HIV positive guys believe it is safer not to disclose, even to friends, unless in certain sexual situations where they identify they have a legal obligation to disclose.

'I've learnt not to be open about it...because you get lots of childish bullshit...my straight friends have stood by my side but I lost a lot of gay friends.' (Younger HIV positive man)

"Cause once you tell someone, it's out there. You can't take it back. They talk about it to someone else, who talks about it to someone else, and suddenly everyone knows you as 'Brian⁵, he's got AIDS', not just Brian."

It was readily identified that once it became known socially that someone was HIV positive, they were ostracised from specific social circles so that HIV negative men could avoid the potential for 'guilt by association'. One particular example given of this was that of the 'Pahran Market set':

"(It's)... all about glamour, being cool, driving their BMW and looking great – with their broomstick behind them. They don't want it (HIV) to be there. It goes against their image."

⁵ Names have been changed in all quotations

With such negative social consequences of disclosing their status, most HIV positive men agreed that they lived with a general sense of shame and secretiveness at being HIV positive. Coupled with instances of rejection by potential sexual partners, many HIV positive men admitted to suffering from extremely low self-esteem, and sometimes depression.

"We just want acceptance. We don't want to be ashamed."

Some HIV positive men strongly identified with the fact that rejection and social ostracism are key barriers to disclosing HIV status to potential sexual partners or even to friends and family.

"There are two main reasons why someone wouldn't want to disclose. One is rejection. The other is what happens to that information after you tell someone – you can't un-tell someone. Once you do that, it's all over".

Some specific examples given about the shame experienced by some men, and resulting non-disclosure, included:

- A man found out his flat mate had been diagnosed 18 months earlier and had not wanted to tell anyone because he was feelings ashamed and feared the social rejection he would likely go through once people started to find out.
- An HIV positive man discussed a situation where he was with a man that kept 'slipping it in' unprotected. He told him to stop because he was HIV positive. The other man then claimed that he was also HIV positive but had never told anyone before. *"He said he only told me 'cos I told him and that I couldn't tell anyone. I couldn't believe he was going round slipping it in like it didn't exist. I got the feeling he was really ashamed and didn't want anyone to ever find out."*

A number of older HIV positive men believed that this was in distinct contrast to 20 years ago, when men were originally very open about their HIV status. Those that were HIV positive were more willing, "almost proud" to announce they were HIV positive, as they did not fear social ostracism.

The situation of social ostracism is exacerbated for younger HIV positive men because of the idea of identity. All younger HIV positive men interviewed in the second round of research made a point of stating that HIV is chronic condition, it was not their whole identity. However, as most claimed to have been actively going out and part of a social scene prior to becoming diagnosed with HIV, they were all aware of how others within the scene actively discuss the HIV status of others. They were all highly conscious that once other gay men began to openly discuss their status, it became part of their identity. This is the most critical element of why younger men are more private about their HIV status than older men. They actively try and avoid HIV becoming the focus of their lives and their identities. As most perceive that with current medications they will live long lives, they do not feel that HIV needs to be as much a part of their public identity as what it may have needed to be before modern medications when the mortality rate was higher.

"We no longer need to tell everyone cause we are going to die in the next few years. People just don't need to know like they used to".

"That's one of the reasons that the younger working professionals or younger people that are out on the scene or whatever don't come to groups or events, whatever maybe that's part of it as well because they know themselves and they don't have a huge issue with it within themselves. But they don't want everyone else to know or they don't feel the need to talk about it with other people"

"It's an element of my life, it is not my whole life. Being HIV positive is no the first thing that comes into my mind about me, and it doesn't have to be the first thing that comes into other people's minds when they see me. But it would be if I told them, because people get scared".

Some HIV positive men felt that the word 'disclosure' contributed to the shame experienced by some men. It was seen to imply that HIV status is a secret that men should be ashamed of.

"I don't like the word 'disclosure'. It's as inhibiting as the act of doing it. It sounds like something you do for the tax office."

Stigma and discrimination in the workplace

As stated above, most HIV positive men preferred to not disclose in the workplace for fear of stigma and discrimination. Due to this, there were few actual experiences of this that were discussed in the focus groups. The few examples provided are described below form:

- An HIV positive man was fired from a casual job in a gay bar when he mentioned his status to the boss (twelve years ago). His boss claimed it was because it was 'not safe' to have him working there.
- Another man told one colleague at work about being HIV positive. This 'news' spread around the whole office extremely quickly and was the subject of many whispered conversations among other colleagues. His interactions with colleagues became difficult as many did not feel comfortable with him. The HIV positive man decided it would be best to leave his job.
- Another HIV positive man had not been successful when applying for a series of jobs at 'gay establishments', for which he was qualified and was up-front about his status. As he felt being HIV had contributed to him not getting any of the jobs, he changed his tact of declaring his status. He ended up getting a job that was very similar to those he had applied and been rejected for.
- Another told of a friend who was a nurse was ostracised by other nurses when they found out he was HIV positive.

"You should have seen the nurses scatter when they found out he had HIV."

- Others felt that employers would 'slowly edge' them out or begin cutting their shifts once they found out they were HIV positive.

Stigma and discrimination from family

Most HIV positive men could describe a negative experience with a family member once they had disclosed that they were HIV positive. For some, the negative experience had meant that they lost all support of their family and were no longer involved in their lives. For others, the negative experience had divided the family. Examples are described below:

"...I sero-converted when I was in the States. The family found me in hospital and my brother told the family I was dying of AIDS. I came home about six months later and I was treated like a leper. I was given a room under the house, mattress on the floor, whatever. So if I had my time over again I'd never tell a soul – never – no matter who it is...". This man is no longer in contact with his immediate family members.

"At one stage I was in a situation where I got badly cut, I was with a relative and she was trying to mop me up. I said to just give me the Wettex and back off, there's too much blood here, I had to say I was positive and make her understand. Well, talking about discrimination, that person ultimately lost me my job, rang up and lost me my job and tried to lose Terry (partner) his job. That's discrimination from the straight community, she used that against me". This relative did not attend family functions after this where the couple were present.

- Another HIV man related how his partner's ex-wife was currently trying to use the fact that the partner was HIV positive as a means to secure full custody of their daughter. Currently, the ex-wife does not allow any access for the man to see his daughter.
- Family members unwittingly saying hurtful comments, such as *"We all thought John would be dead by now."* While it was claimed that these were meant as appreciation that the medication had enabled HIV to be a manageable condition, these comments tended to increase any feelings of shame being experienced by the HIV positive man in question.

While not instances of stigma and discrimination, a number of younger HIV positive men identified that their families had actively made their HIV status a 'family' issue. While often the intention was to be supportive, some mothers and sisters, were often overwhelming in their reactions and ongoing response to finding out about the son's or brother's HIV status. Some mothers and sisters were said to quickly tell other members of the family, and some would micro manage ongoing treatment.

"My sister, oh. Before I could get home from the doctor's my mother had told my sister, who had then rung my Dad and my brother and told them, so Dad was ringing me and

telling me that he still loved me while I was still trying to get home. I just felt...I should have been the one to tell people"

"She calls me and reminds me that I have to get my bloods done. She'll even call the clinic and tell them that its time (mother)"

Other instances of Stigma and Discrimination

Discrimination from the 'straight community was obviously an issue for some men with HIV, however, this was potentially the most difficult to deal with when it occurred within the neighbourhood in which they lived. This appeared to be a particular concern for many men in South Australia. Many of these men who were experiencing discrimination, enacted through verbal abuse, lived in state housing making it difficult to readily change home and neighbourhoods. The other main instance of discrimination mentioned aside from those above was of being turned away from other countries when holidaying overseas, such as the USA and some Asian countries, for having HIV or lying about their status to gain entry.

6.6 Positive Experiences of PLHIV

Within the broad topic area of stigma and discrimination, positive experiences were essentially about when stigma and discrimination did not occur where it may have. A number of positive experiences were found in the long lasting sero-discordant relationships of some of the respondents within the research.

Some respondents had been in such a relationship for well over 20 years, with others being with their partner for between 6-15 years. Finding out about these relationships and discussing them with those involved appeared to have a strong impact on both HIV negative and HIV positive men who were within the same discussion groups. Positive men were able to ask about how they dealt with certain issues relating to sex. For some who had openly discussed the depression that comes from continually being rejected due to being HIV positive, finding out about sero-discordant relationship seemed to provide some reassurance about the possibility of finding a relationship. For most HIV negative men, there was often a great deal of surprise that a sero-discordant relationship could occur and that other negative men would consider being part of one.

Some HIV positive men related having been rarely 'rejected' by a sexual partner once disclosing their status.

"I've only had someone 'run screaming from the room' once. It's normally fine."

"That's only ever happened to me once (rejection)."

Within the focus group situation, this tended to prompt a great deal of discussion around whether it was when and / or how someone disclosed that contributed to the reactions of others. This

indicated that some men would appreciate some support and guidance on when and how to disclose, and how to deal and feel about the various reactions that occur. This topic was of particular interest for men who were more recently diagnosed.

Some younger men identified the act of disclosure in itself could be a positive experience in the development of a friendship or intimate relationship. These men saw disclosure as demonstrating a degree of trust in the other person that the majority of people they encountered reacted positively to.

"The one thing about when you tell people is that you actually did tell them and there's an element of trust in telling someone like that ... it's throwing the gauntlet out there and I'm basically exposing a very sensitive part of my life to you and they have respect for me because I'm respecting them. So it can actually turn into a bit of a powerful thing really ..."

Finding a 'peer group' with other PLHIV appeared to be a very positive experience for many. As the organised support groups are not always a positive experience for some men (see Section 9), finding friends and others who were HIV positive who they were comfortable with was often one of the most positive experiences for men since they were diagnosed. These instances demonstrated the value that men gain from support from peers from similar backgrounds, who are in a similar situation and still in mainstream society. It helped to avoid the loneliness that others were clearly experiencing, or that they had initially experienced when other friends began to disappear.

Some younger men had found a 'peer group' in subcultures, such as the 'leather' scene. These subcultures appeared to offer a value to younger men in that the degree of HIV stigma and discrimination did not seem to exist as much as in the mainstream scene, with men were more likely to reveal their HIV status. Younger HIV positive men had found others who were HIV positive to discuss issues with if needed, but at the same time, the focus of the gathering or event was not on HIV. They saw this as a positive experience.

"I want to be able to be open and to talk to others about it, but I don't want the focus of the whole things to be on HIV. I don't want the only thing we've got in common to be HIV"

Some men who were active in specific HIV positive projects claimed to have positive experiences as a result of participating in these. For example, a man who is a spokesperson in a organisation that does community and school 'talks' on HIV claimed that he found a lot of value in educating people about something they clearly lacked knowledge on and were often very fearful of. Similarly, one of the HIV positive men participating in a mixed status group discussion claimed he often found it very good for his self esteem when he had the opportunity to answer questions and educate others. This occurred a great deal within the actual group discussions and was clearly very effective in influencing the attitudes of a number of younger men within the group who had begun the discussion with openly discriminatory attitudes about PLHIV. The process of having an honest

discussion and the ability to ask questions of someone who was HIV positive was often the first time these young men had talked about HIV with their peers, and was the first time that many had met someone with HIV (that they were aware of).

Given the recruitment strategy of the second stage of research, it is not surprising that a number of the younger HIV positive men had participated in initiatives such as the Positive Speaker Bureau whereby they gave talks to others about living with HIV. Some of the younger men who were more recently diagnosed expressed an interest in this. The appeal of this initiative was that it provided an opportunity to talk about their feelings towards HIV to a room of strangers, thereby removing the potential for judgement from someone they may know. Those who had already been involved in this initiative believed that it had provided a degree of freedom from the 'secreteness' of living with HIV, and begun the process of overcoming the feelings of shame they had.

"What you want to do that positive speakers thing. I was only supposed to talk for an hour I ended up talking for nearly 2 ½. It was the most, in terms of my HIV, the single most impacting moment of all of it. I stopped being a repressed child about it and became an adult and acknowledged it and it was the most liberating wonderful thing that I ever did"

6.7 Barriers to Overcoming Factors that Contribute to HIV related Stigma and Discrimination

Some of the key barriers able to be identified are listed here. Other specific issues are discussed throughout the report.

Prevention

The primary public message regarding HIV from the past 20 years has been about prevention of HIV. This repeated message has played an essential role in ensuring rates of transmission in Australia are relatively low to other countries. However, it has also been a key driver in the development of fear about HIV and now of PLHIV. Many men in their 30s strongly recall the Grim Reaper campaign as their first initial contact with messages regarding HIV. For many, while subsequent prevention messages have not been based on fear, they have acted to maintain the fear that this campaign. For younger men, some of whom did not even recall the Grim Reaper campaign, fear of HIV has been driven by the sheer proliferation of prevention messages on HIV. In addition, these are the only messages about HIV they have. Overcoming this fear, while trying to balance preventative messages with other more 'positive' messages on HIV will be a challenge.

Language

Another key barrier to overcoming the factors that contributing to HIV related stigma and discrimination is the established vernacular of HIV that has been built up over the years of prevention messages. References to being 'clean' are made even by those who may not actively discriminate, in regards to everyday matters such as being tested. 'Disclosure' has been

established as the accepted word for openly stating being HIV positive, despite this meaning to many that a secret is being held. Language with violent and criminal connotations such as 'Russian Roulette' and 'gun pointed at my head' have been socially accepted as appropriate signifiers of HIV, after not having been challenged through continuous use over many years. In a sense, they have become normalised.

Self-Stigmatisation

The stigma and discrimination that some HIV positive men will also be a key challenge in overcoming the factors that contribute to stigma and discrimination. Attitudes, behaviours and language are more likely to become acceptable as normal within in a society and culture when there are no voices to challenge their appropriateness. Fear of stigma and discrimination mean that less HIV positive men challenge the prevailing attitudes, and issue become self-perpetuating. As stated by one HIV positive man:

"I'm part of a advocacy group for HIV positive people who speak to groups like school about being HIV positive. Do you know that out of the five of us who speak, only two of us have our pictures on the website?"

"You don't see positive men selling the red ribbon because they just don't want people to see what they are publicly. It's always woman, who probably are just people volunteering out of the kindness of their hearts"

7 REASONS WHY HIV RELATED STIGMA AND DISCRIMINATION APPEARS TO BE INCREASING

The research findings suggest that a confluence of factors is responsible for increases in HIV stigma and discrimination. Change has occurred in a number of inter-related areas, resulting in stronger changes in attitude than may have otherwise occurred. These include:

- broad social factors;
- increased use of online spaces;
- increase in sero-sorting;
- perceived criminalisation of HIV;
- changing impact of HIV; and
- the limited knowledge about HIV of younger men.

7.1 Broad Social Factors

It is well recognised, particularly by men older than 35 years, that the experience of HIV and AIDS in the '80s assisted in creating a sense of a 'gay community'. Most of these men could identify that HIV became synonymous with the activism for legal and social rights in the '80s and was key factor in the gay men banding together in the form of a 'community'. They could identify that the activism that stemmed from the '80s was critical in creating the current social and legal acceptance for homosexuality among the broader community. Older HIV negative men, as well as HIV positive men, were cognisant that HIV was crucial in prompting this activism.

"HIV was like a call sign for the gay community. Something for everyone to band around and be part of."

"It was symbol for the activism of the '80s."

However, now that homosexuality has broadly achieved social and legal acceptance⁶, many do not feel that it is necessary to have a specific 'gay community' any longer. Many men, both older and younger, claimed that they actively dislike the notion of being part of a 'gay community' as this still implied a sense of difference about them. These men preferred to be part of the 'community in general', rather than feel that being 'gay' was an essential part of their identity that they wore like a label.

"I want to be Ross first, not Ross the gay guy. I'm me."

"I've got straight friends, I've got work friends, I've got some gay friends. I belong in lots of different communities, none of them specifically gay."

⁶ It is recognised that there is some inequality in legal rights, however it is believed that this will gradually be overcome.

"We don't need that anymore (activism). My boyfriend and I can be exactly who we are."

Findings from this research indicated that the change in perspective about being a 'gay community' relates to increased HIV stigma and discrimination in two key ways. Firstly, as many men no longer feel a need to be part of a 'gay community', they no longer hold any value of HIV as a binding force for that community. Since this positive feature of HIV, that of being a "*call sign*", is no longer recognised, many men only have negative information and references on which to base their attitudes and opinion.

Secondly, broader social acceptance has meant that the physical spaces, such as clubs and bars, where the 'community' bonded are no longer needed as the only space in which gay men could be themselves. Gay men claim they feel just as comfortable in 'straight' bars and clubs, if not more so, than in 'gay' bars and clubs. Further, many physical spaces that used to be for socialising are now shared with heterosexual people⁷. Purely 'gay spaces' are inevitably those that are related to sexual activities, such as sex on premises venues, saunas or gyms.

Younger gay men in metropolitan areas are more likely to be with 'straight' and gay friends of their age at a club than to be in a physical social space with older gay men. At the same time, older gay men are less likely to feel comfortable at social spaces that were previously for gay men as 'straight' people now frequent these.

"It's all changed. Oxford St is no longer the Oxford Street we knew twenty years ago."

"Younger guys are just a foreign species. The moment you talk to them they think you're trying to crack on so they don't even talk to you".

The change in physical space means that younger and older, HIV positive and HIV negative men are not as exposed socially to each other in the face-to-face environment as they were previously. Some respondents perceived that this was causing a growing divide between younger and older gay men, as well as meaning that younger men grow up with a lack of personal experience with HIV positive people. This, in turn, was seen as perpetuating both generational and HIV stigma and discrimination.

7.2 Increased Use of Online Space

The increased use of the Internet for social networking has contributed to changing social relations for people of all demographics and social groups. For gay men, the online environment has become a key means with which to meet other men, particularly now that physical social spaces have undergone the changes described in the section above.

⁷ This was particularly so of men living in major metropolitan areas. Men in regional areas and smaller metropolitan centres were more likely to still identify specific bars and clubs that were seen as "*more tolerant of gay men than others*".

However, it is highly likely that the increased use of the online environment to meet other gay men could also be a factor contributing to stigma and discrimination against PLHIV. The anonymity offered by online interaction results in users being able to 'voice' opinions in an online environment that they may not do in face-to-face situations.

The majority of HIV negative men who used online dating and chat sites acknowledged that HIV status was one of key factors they used to screen potential dates, and felt that this was a positive feature. Most admitted that they automatically refused to engage with men who actively stated they were HIV positive.

"It's like the high school yard."

"If someone said they were positive online, I'd probably steer away from it. But if you meet them out and interact then it would be totally different – it humanises it."

The online environment gave them the choice of immediately terminating the 'chat' if they were not prepared to pursue a casual relationship with a man who was HIV positive. The anonymity offered by the online environment also made it easier to reject men in a very direct, abrupt manner.

"I just block them. If I think they are trying to pull one over me, I just block them straight away. No discussion."

Some HIV negative men also admitted to terminating online conversations with some unpleasant comments after finding out that some one was HIV positive.

"It's worse when you've started to talk to them for a while and then they tell you. It's like, no way man. How could you waste my time."

"I just sick of old positive men trying to talk me into having bareback sex with them. It's a real problem. I just tell them to fuck off."

Expressing negativity towards others online is easier for people to do than in a face-to-face environment, as there is no need to take responsibility for any hurt that negative comments might provoke. The anonymity of the online environment contributes to the perceived acceptability of rejecting people, sometimes very negatively, based only on their HIV status. In turn, the behaviour, language and means of interaction that have become acceptable in the online environment, can also transfer over to the 'real world'.

Some HIV positive men said they found it easier to disclose online than in face-to-face situations, simply because any rejection did not impact them as much.

"You can't see the looks on their faces. It still hurts but I'd rather be rejected by being blocked online than to my face."

For some, this encouraged them to approach more men online and be open about their status than they might otherwise in a face-to-face situation. In turn, this may contribute to some of the negativity demonstrated in the quotes above as some HIV negative men tend to feel that even being approached online by HIV positive men is inappropriate.

HIV positive men that did not disclose their HIV status online chose not to do so in order to avoid the continued rejection they perceived they would experience. However, this raised the further issue of at what point they should disclose when they met the other man face-to-face. Some men, both HIV positive and HIV negative, felt that disclosing after the relationship had developed from online to the point of sexual relations would likely result in an extremely bad reaction as it undermined any trust that may have developed. HIV positive men that preferred to wait to disclose, while admitting that this was the case in many instances, felt that they had a right to not have to disclose until they were legally bound to.

There was no indication that younger HIV positive men used online sites as a means of meeting others any more or any less than older men. However, a key difference found among younger men who were more recently diagnosed, was that the online environment provided a means of continuing to talk or flirt with others without having to meet them face-to-face. Not meeting face-to-face meant that they did not have to face the possibility of rejection when they disclosed their HIV status. These men claimed to have avoided the potential of meeting others in a face-to-face situation that could evolve to intimacy since they had been diagnosed, simply to avoid having to disclose their HIV status. For some, this had been for a period of 3 months, and for others, this had continued for almost five years.

7.3 Increase in Sero-sorting

As indicated above sero-sorting is widely practiced in the online environment, and there is little doubt that this occurs in most instances in physical spaces. The majority of HIV negative men admitted that they actively avoided sex with men who they 'assumed' or knew to be HIV positive, not only through fear of contracting HIV, but because they would prefer to be able to have unprotected sex should a relationship develop. Most admitted that the issue was rarely directly raised through a direct conversation about HIV, rather assumptions are made based on looks, perceived stereotypes and where they may meet the partner.

That said, most HIV negative men claimed to always practice safe sex in initial sexual encounters and at all sex specific places like venues, beats and saunas. They felt that as people can always lie, it was best to assume that 'everyone is positive'. However, in situations which may lead to a more long term relationship, there was a strong belief that HIV positive men would disclose long before sex occurred. If this did not happen, it was seen as undermining the HIV negative man's right to choose.

Some HIV positive men find it easier to simply choose sexual partners who are also HIV positive. For them, the key motivator was not so they could have unprotected sex, it was to avoid rejection. Other HIV positive men claimed an active sex life with both HIV positive and HIV negative men. They claimed that while the potential for unprotected sex was more likely with other HIV positive men, that this was not a discriminating factor in their choices of sexual partners.

"If he's hot a condom isn't really going to stop me enjoying myself."

As the research suggests that the majority of HIV negative men would avoid interacting with HIV positive men in any circumstances that have the possibility of leading to a sexual relationship, it follows then that sero-sorting contributes to the widening of the sero-divide. The more that HIV negative men make choices to limit their potential relationships only with other HIV negative men, the more they are likely to only engage in social situations with other (assumed) negative men. This means their personal experience with HIV positive men becomes more limited.

7.4 Criminal Prosecutions and Media Coverage

There was very limited spontaneous mention of any criminal prosecutions regarding HIV. Even when prompted there was no direct link to criminal prosecutions and attitudes to PLHIV. However, as shown in the discussions about language in Sections 6.3 and 6.7, there is a prevailing attitude of criminalisation surrounding HIV transmission.

Some HIV positive men believed that HIV positive men reinforced this perception by not being open about their HIV status, and almost 'guiltily' hiding their secret. The legal obligation to disclose their HIV status in certain circumstances was perceived to reinforce the perception of criminalisation among both HIV negative and HIV positive men. This is discussed in more detail in Section 8.3.

A change in how the media discusses HIV was identified as influencing an increase in HIV stigma and discrimination, although this was not seen as directly linked to any media coverage of criminal prosecutions. Instead, comments were made on the language used in the media when discussing HIV and how that contributed to negativity. For example, referring to PLHIV as *"AIDS patients"* or some other label which indicates they're not living a healthy life, was seen to present the worst side of the issue.

At the same time, positive media coverage appears to have diminished in recent years. Some commented that the 'Red Ribbon Day' is not as widely publicised by media as other 'days' and that it seems to have decreased in importance over time.

"You don't see any newscasters wearing the Red Ribbon any more, I don't even think people talk about it. Like it's not a problem any more at all."

7.5 Changing Impact of HIV

Part of the power that HIV had as a binding force for the gay community in the '80s was due to the mortality rate at the time. Given that it is now a manageable condition for most men, to some degree the empathy that was felt from it being a 'killer disease' has been lost. This combines with other factors to increase negative attitudes to HIV positive men.

Younger HIV positive men all use the fact that HIV is a manageable condition, rather than something they are going to die from in the near future, as the primary reason that they do not need to disclose their status to others. This is also the key reason that they avoid the potential for others to learn about their status, such as at a group event organised by a service provider, and then go on to tell others. Whereas younger men are now told upon diagnosis that HIV is not a death sentence and that they can lead relatively 'normal' lives, they are aware that to most HIV negative young men, HIV is something to be feared and avoided. To this end, younger men will avoid the potential for others finding out about their status as much as possible. The negative attitudes they could potentially receive from others would not be continuing to live a 'normal' life.

7.6 The Limited Knowledge of Younger Men

In keeping HIV a private part of their lives, younger men inadvertently perpetuate the perception that HIV is something to be ashamed of and should be kept secret. However, younger HIV positive men feel that to be more open about having HIV risk not only individual rejection for sexual intimacy, but the possibility of social ostracism due to the ignorance of HIV among younger men.

The key difficulty that younger HIV positive men face is a lack of understanding from their own age group. The research found that younger HIV negative men are much more likely to only have the continuous education and marketing materials aimed at prevention from which to draw reference and understand HIV. They are less likely to have personal experience of HIV through friends or family and are more likely to strongly identify HIV with unflattering stereotypes. They were openly more negative and discriminatory about HIV in the group discussions, with many suggesting that it lacks relevance for younger men today (they do not see it as applicable to themselves). Most simply had not really discussed it outside of school sex education classes (some had not even discussed it there).

This lack of education and knowledge among young men makes it extremely difficult for younger men who are HIV positive to disclose within their social environment. Compared to older men, there is a marked difference in education and familiarity with PLHIV among their peer group. What is especially difficult for younger men is that they are often very aware of the knowledge and attitudes of their peers, as invariably they could recall their own knowledge and attitudes toward PLHIV prior to being diagnosed. They recalled that they had little knowledge about HIV, beside some abstract

idea that it existed and they should have protected sex to prevent it. They also recalled that they were more likely to have negative attitudes towards men who had HIV.

"There was no way I would ever have slept with someone who was HIV positive...well clearly I did in the end, but not knowing that he was"

"I remember thinking, Oh my god, he should have told me. What a bastard for not telling me."

"I only ever thought the stereotype, some older guy who fucks around".

Younger HIV positive men were especially critical of the various social marketing campaigns with prevention messages that are continually run by a range of organisations, as they saw these as reinforcing much of the ignorance and negativity. As these are the main source of information on HIV for younger gay men, these campaigns were seen to reinforce negativity and stigma by the choice of message (prevention), the images they used and the lack of any other message about PLHIV.

"...., I found them highly offensive and reinforcing (various campaigns)...But basically the people they had on the photos reinforced that stereotype of this is what someone with HIV looks like and even putting out a campaign that says 'you don't know what somebody looks like' ... yeah that's true but its so simple, it doesn't say anything about the people who have HIV except to stay away from them. They need to promote the fact that there is nothing wrong with us."

The fear of social ostracism had manifest itself into a reality for some younger HIV positive men who had disclosed their HIV status. One young HIV positive respondent claimed to have lost the majority of his friends and was aware that people spoke about his status when out at clubs. He had been subject to physical violence by other gay men who felt he was 'infecting their friend', despite the sex being protected and having fully disclosed to the friend involved. He did not know anyone else his age who was HIV positive. Others had been the subject of negative behaviour in clubs by people they did not know and had associated it with other having disclosed their HIV status.

The threat of social ostracism is especially difficult for those younger men who felt they had only just come to terms with being gay. A number commented that it was only when they felt they had finally learnt to be comfortable with their sexuality and the social world in which they moved, that suddenly they were forced once again to live with a secret.

"Just managed to crawl out of one closet and now I'm back in another, smaller one"

"It's the secrets. I'd just managed to be free from the big secret of being gay and now I've got another. It's the secrecy that I hate".

Interestingly, many younger men recognised that focus of having to keep their secret at all costs meant that they were allowing HIV to be a central point of their lives and identity despite not wanting it to be. These men identified that they needed to deal with the fear of disclosure to friends, family, potential sexual partners, in order to gain some relief from HIV being the focal point of their lives. However, practical application of this knowledge was identified as the difficulty. Others, who felt they had achieved a degree of freedom in that HIV was no longer the focal point of their lives, felt that this could only be gained over time. It was seen to be gained over time by learning how to choose **who** they disclose to, and **why** they choose to disclose.

7.7 Perceptions of a Positive Change in Attitude

It is important to note that the many respondents did not feel that HIV stigma and discrimination was increasing; most HIV negative men and some HIV positive men felt that it had instead decreased. This is despite the attitudes demonstrated by reported behaviours that are described above. These positive changes were seen to be driven by:

- HIV no longer being seen as a death sentence due to the availability of medications, and PLHIV going on to live long lives;

"My best friend has had it since the '80s – he takes a hundred pills, but he's healthy as."

- personal experience of friendship with HIV positive men and continued friendships with HIV negative men (from the perspective of HIV positive men);
- personal experience of sero-discordant relationships, either having friends in such relationships or by being in these relationships personally;
- greater knowledge of safe sex practices (despite not always being implemented);
- introduction of PEP;
- comparisons made to other sexually transmitted infections (STIs) and illnesses through 'positive' marketing materials on HIV;

"You'd be just as likely to die from cancer these days. It's a similar thing – you're a person with a disease that has taken over your body."

- perception that broad social acceptance of the 'gay community' has also assisted in greater acceptance of HIV among the broader community, given that it is believed that the two are intrinsically linked in the view of mainstream Australia; and
- the 'positive' attitude of HIV positive men who are open about their status and continue to actively involve themselves in activities and events.

"Once I got over the fact that I wasn't going to die – I saw the future was bright."

"I was diagnosed when I was 19 and didn't think I'd live to see 40. I'm definitely going to reach 50 now and I think I'll probably see 70."

Typically it was the older HIV positive men who also claimed to have strong support from family and friends and those that appeared more willing to be open about their HIV status, that felt stigma and discrimination had decreased over time. Interestingly, when asked directly about changes in attitudes to HIV, most older HIV negative men would comment that change had been positive over time. However, responses to this question were in sharp contrast to the highly personalised, often implicit discriminatory reaction that they demonstrated when asked about their own behaviours and experiences with HIV positive men in certain situations. Similarly, younger HIV negative men had no relative experience from which to draw so tended to feel that the manner in which they viewed HIV positive men, which at times was openly stigmatising and discriminatory, was typical of how attitudes had always been.

Further, despite claiming knowledge of all the factors that that were perceived to contribute to positive changes in attitudes, all men identified that there was still a stigma attached to being HIV positive. Most just did not identify that the behaviours and attitudes they personally held were discriminatory.

"There is a stigma. Of course there is. There are some people that still think the worst – they see it as a death sentence and they shouldn't".

8 INFLUENCE OF HIV ON ATTITUDES AND BEHAVIOURS TO SEXUAL PARTNERS AND RELATIONSHIPS

8.1 Attitudes of HIV Negative Men

Casual Partners

It was claimed that HIV status had more of an influence on long term partner selection than casual partner selection, regardless of age or status. That said, in terms of attitude and behaviours towards sexual partners, there were three distinct broad groupings among HIV negative men in the research.

Never

The first group were those that claimed they would never have sex with someone they believed could possibly be HIV positive. This group was more likely to consist of younger HIV negative men and older HIV negative men who demonstrated almost militant behaviours towards self-protection from HIV; via total avoidance of social encounters with HIV positive men.

"AIDS is out of bounds. It's not appealing. I don't hold it against them, but I'm petrified of it and it really scares me."

"There is no way I would have sex with some with HIV. Even with six condoms on, it will just never happen."

"It's Russian Roulette. I'm filling all the chambers of the barrel if the condom breaks."

The attitude and behaviours of these men is partly driven by ignorance. They rely strongly on assumptions about stereotypes to determine whether they feel someone may be HIV positive or not, and therefore whether they would have sex with someone or not. The younger ones especially feel strongly that their choice of men are simply 'not the type' to have HIV, so they are putting themselves at risk with the causal encounters they have. There was some indication that the younger men in this attitudinal group did not always have protected sex in casual encounters. It was obvious that some younger men, particularly those in their early 20s, that rather than be an issue of fear and the need to personally protect themselves, they simply did not feel that any of the potential partners they would ever consider could possibly be HIV positive.

Older men within this attitudinal group were more likely to recognise that they may not always be able to tell someone's HIV status by physical appearance. However, these men did still hold some strong stereotypes about HIV positive men, and also tended to believe that they would be unlikely to put themselves in a position where they may encounter them. These men did not discuss situations at venues, beats and saunas as much as others within the group discussion and were more likely to stress only interacting with men who they knew to be, or claimed to be, HIV negative. These men openly claimed that fear had a role in their choice of avoiding HIV positive men, with

many continually reiterating that the fear would result in it being very difficult to enjoy sex with someone they knew to be HIV positive.

"Even if it was casual, you'd be a bit scared if you found out and maybe even turned off having sex with that person."

"Even if you could be guaranteed that the condom wouldn't break or anything like that, I'd be so scared it wouldn't work anyway."

"There's no way you'd enjoy it."

Unknown

Overall, this attitudinal group would not have sex with someone they knew to be HIV positive. They differ from the attitudinal group discussed above, as they place themselves in some 'don't ask, don't know' situations. That is, these men identified that they would readily engage in casual sex encounters in certain situations without any thoughts on asking someone's HIV status, although they claimed they would always use condoms in these instances. In fact, many felt it was a big topic to raise in situations that are likely to be one-off.

"It's a horrible thing to have to do for just a once off – as long as you're safe, why bother with a one nighter?"

The specific situations they were referring to included sex at venues, beats and saunas. While there was some expectation that HIV positive men were legally bound to disclose in all sexual encounters, men in this attitudinal group did not expect disclosure in sexual encounters that occurred at sex specific places. It was assumed that in places such as these, where men are only there for one purpose, people would lie anyway so it was best to always have protected sex. All of these men claimed that they always had protected sex in these situations.

Interestingly, while this attitudinal group claimed that they always played it safe in one off situation, they had different expectations if it was an on-going casual relationship. It may be the greater intimacy of the situation, or that some may see a potential for an ongoing relationship, but there was a distinct difference in attitudes regarding the status of who they were having sex with in these circumstances. The expectation is that they would have been told if the other person was HIV positive prior to any sexual encounter. At which point, these men all admitted they would be likely to walk away from the situation.

"Seriously, if we'd actually ended up at his or mine house together and then they told me, I'd run screaming from the room. He should have told me way before it got to that stage."

"It's different at beats, you'd be mad not to use condoms there. But if you've spent time with the person, you'd expect to know. It's a trust issue".

For these men, any sexual encounter that is ongoing in its nature, regardless of how frequent and/ or monogamous, meant that there should have been some discussion or chance for negotiation, even if they do not initiate it, thereby giving them a chance to say 'no'. In contrast, there is no expectation that negotiation will occur in the on-off nature of sexual relations at a sex specific location, hence the 'don't know, don't ask, always use protection' attitude.

Experienced

There was a significant number of HIV negative men within the group discussions who claimed to be comfortable having sex with HIV positive men. Most of these were older, with only three being aged under 30 years. These men tended to either have previous personal experience of a sero-discordant relationship or to have friends involved in such as relationship. At the very minimum, these men had close friends who were HIV positive.

One of the younger men claimed that it had been the experience of friends in a sero-discordant relationship that had resulted in him overcoming his fears and feeling comfortable in having protected, casual sex with men who are HIV positive. Another felt it was simply because one of his close friends who was his age was HIV positive, and this had meant he had learnt a lot about the inaccuracies of his preconceptions.

"When I was younger I would have stayed clear, due to ignorance. Now I've met people and know about treatments and prevention – I wouldn't go out of my way to find someone but wouldn't have a problem with having a relationship with someone who had HIV."

"I think because of my friend (who as HIV), it would not be a definite No. I'd have to think about it, but it's not something I can say that I'll never do...I've learnt a lot from my friend."

All the HIV negative men with experience of sero-discordant relationships, claimed to have made sure they were fully informed of all the risks prior to engaging in sex with HIV positive men. Many had spoken to their doctors, others to their HIV positive friends, and others with sero-discordant couples. Most stated honest communication during sex as the key to ensuring both a good time and a safe time.

"I have a long term 'play mate' who's positive. It's never been an issue. I appreciate his frankness..."

"I'm surprised it's still being contracted at such a level. There should be enough awareness that you don't share equipment, that you play safe."

Long term partner selection

Only HIV negative men demonstrating 'Experienced' attitudes and behaviours (described above) claimed that HIV status would have no impact on their long term partner selection. Once these men had experience of having enjoyable safe sex, most claimed that they would be happy to engage in

long term relationships with HIV positive men. The only hesitation these men had about the possibility of a long term relationship would be if disclosure had not occurred in the early part of the relationship. For these men, non-disclosure early on was an indication of lack of trust which no relationship could endure successfully.

Some HIV negative men who had experienced sero-discordant relationships identified that the issue of having unprotected sex had been more of a difficulty for their partners than for themselves. For some, it had resulted in the end of relationships.

"He said I was the perfect boyfriend only I wasn't infected, so he couldn't do what he wanted with me."

For HIV negative men that demonstrated either 'Never' and 'Unknown' attitudes, having to always have protected sex was identified as the key reason they would not consider a longer term relationship with a HIV positive man.

"I like it bareback. I'm not going to use condoms for the rest of my life".

"Who wants to use condoms all the time?"

"Sorry, I don't do rubber."

Other common reasons given by HIV negative men as to why they would not want to want to pursue a relationship with positive men, included:

- they would not want someone they love to die on them;
- having to play a role of a carer of their partner when they had 'bad days';
- expectations of a major life adjustment as they would need to take care' in all elements of their lives to avoid infection.

"Casual is a once off but long term – you both have to adjust your lives – for sex, for cutting food, sharing things, you just always have to be aware and I don't want to be infected."

8.2 Attitudes of HIV Positive Men

Casual partners

Very few of the HIV positive respondents within the group discussions claimed to discriminate for causal partner selection based on HIV status. Some did admit that they had reached a point where they specifically targeted other HIV positive men online to minimise the impact of rejection. Where possible they would also seek out other men they knew to be HIV positive at venues, beats and saunas for the same reason. None, within the group situations, claimed they discriminated so they could have unprotected sex, although they were aware of other HIV positive men who deliberately sought out other HIV positive men for this specific reason.

Most of the HIV positive men in the groups felt that it was important to practice safe sex in all casual relationships regardless of status because:

- there are other STIs which could affect their health; and
- they perceive that there is likely to be another STI as serious as HIV that occurs sometime in the future.

There were a variety of attitudes demonstrated in regards to disclosure with casual partners, particularly where the sexual relationship was likely to be a one-off situation where protection was agreed, either by being discussed or by non-verbal cues, as necessary by both partners. Some HIV positive men always disclosed their HIV status immediately with casual partners, whereas others, would not do so if having protected sex. A small minority felt that disclosure in places such as venues was often unnecessary, or was not heeded, so those concerned about transmission had to take responsibility for protected sex.

Long term partner selection

For most positive men, disclosure was necessary in a long term relationship. As was found with HIV negative men, for some the issue of always having to have protected sex in a sero-discordant relationship would be a particular difficulty that they were uncertain they could accommodate. However, none claimed to have ended a burgeoning relationship due to this.

Most HIV positive men felt that they would be unlikely to try to pursue a relationship with someone they felt would be uncomfortable or insensitive about their status. They simply avoided people who demonstrated negative attitudes. One man even indicated he uses it as a 'test':

"I met someone I was suss of, so I put it out there to see what their response would be and their reaction told me I didn't want to know the person anyway."

For men who did not disclose to all sexual partners, there was an inherent difficulty if the relationship evolved from a casual hook up. The issue for these men was the potential loss of trust that HIV negative partners inevitably experienced when they disclosed. For one man in particular this appeared to have resulted in the termination of a number of relationships.

The topic of long term relationships was one of the more difficult areas for some younger HIV positive men to discuss. While some of the younger HIV positive men had partners, the majority of whom were HIV negative, those who were single tended to feel that their potential for a long term partner had diminished significantly. At a maximum, they felt they were limited to only having a partner who was also HIV positive. This was especially the case for those who had yet to begin dating again after being diagnosed.

"I don't want to feel like I'm constricted to dating within my species...but my biggest thing is the disclosure. I don't want to disclose and I don't want to develop feelings for someone and not have told them"

8.3 'Responsibility' for Transmission (Disclosure)

All respondents were aware that HIV positive men were under some legal obligation to disclose their HIV status if engaging in situations which may put others at risk. However, it was very clear that different men had very different understandings of when this legal obligation was to occur.

HIV negative men

The overwhelming majority of the HIV negative men felt that it should be the responsibility of HIV positive men to disclose their HIV status, thereby taking responsibility regarding transmission. Most expected that this should occur as soon as it was understood that sex would likely occur, regardless of whether sex would be protected or not. In particular, younger HIV negative men identified that they would be highly unlikely to even consider that the partner they had chosen, for a casual or long term relationship, would be HIV positive due to the perceived stereotypes they have. They would be highly unlikely to ask, therefore, as these younger men believed that it is definitely the responsibility of HIV positive men to disclose their HIV status and assume responsibility to prevent transmission.

"Anyone with the ability to give something to someone should disclose, whether it's a one night stand or a relationship."

"If they don't tell you that's real slack. A real low blow."

"Of course they should disclose. That's the only way you have choice about the matter, regardless of condoms."

While some older HIV negative men identified that they too had responsibility regarding HIV transmission, by making the choice to use condoms (at the least) or to have a conversation with their prospective partner, many did not assume this responsibility unless at a sex specific location such as a venue, beat or sauna. In these instances, they claimed to always use condoms thereby taking responsibility. However, most admitted that very rarely, if ever, would they discuss the issue. Many men felt that due to stigma they associated with HIV, it was 'rude' to ask and would likely embarrass the other person, particularly if they were HIV negative. At a minimum, most felt it would 'ruin the moment'.

"It would be offensive to ask."

"If you ask and they are not, they either think you are or you offend them because you are saying that they are like someone who is."

"It's a real mood killer".

Most HIV negative men would also expect HIV positive men to disclose their status even if it was obvious that sex was going to be protected. Although they were aware that this may not always occur at venues, beats and saunas, most still believed that even protected sex carried sufficient risk of transmission to fulfil the legal obligation of disclosure that HIV men have.

HIV positive men

HIV positive men all perceived that they were unfairly burdened with responsibility regarding HIV transmission. Very few had experienced others that ask, meaning that it was up to them to start the discussion and, usually, disclose. They felt that HIV negative men take little responsibility for this, interpreting the legal obligation that HIV positive men have in regards disclosing if other people are at risk, as meaning they must disclose their HIV status the moment a conversation that may lead to sex is initiated.

Some HIV positive men identified that it was partly a matter of inexperience for HIV negative men, with many not having the vocabulary or maturity to raise the discussion in a manner they are comfortable with.

"It's not in their world, they don't want to know about it."

"Many don't have the skills to say what they want to say. A lot of people struggle to verbalise or talk about it."

"We have a bit more practice in bringing it up than others do."

Some positive men felt that the legal obligation to disclose HIV status, should others be at risk, had a dual impact of:

- firstly, taking away the responsibility of HIV negative men protecting their own health; and
- secondly, criminalising HIV in the eyes of both HIV positive and HIV negative men.

Both of these issues were seen to contribute not only to the stigma and discrimination practiced by HIV negative men, but to the shame, secretiveness and self discrimination that HIV positive men practice against themselves.

"Perhaps some of this perceived separation is actually coming from the positive person who now has the onus to tell, whereas before it was advertised in an educational manner the same as all safe sex practices are, that the positive person has to disclose to the other person otherwise you're a criminal..."

"It comes back to the old argument about why can't the person be responsible for their own health and wellbeing and personally instigate safe sex practice and not expect the other person to. That comes back to the amount of education out there – and James (Younger respondents in a mixed age group) said all the 18 year olds are aware of it, people have

had enough of being told about it. So that's the predicament I've found myself in when it comes to disclosure or whether you have safe sex or not with another person, and if you're in a sex venue, etc. If you're in a sex venue the other person has gone to that venue to have sex, there are posters up all about it – if someone doesn't want to have safe sex with you and doesn't disclose or say anything – well, who's the ignorant person? Who of the two of you is making the wrong assumption and why should that responsibility be put on you because you're positive? Is that where some of this supposed underlying separation is occurring – that the positive group are feeling pushed away from mainstream because we're the ones with the problem, we're the ones who have to put our hand up, we're the ones that face rejection, again, which is what has been ongoing all the time..."

Finally, HIV positive men all spontaneously discussed the issue of disclosure within the group environment, covering questions such as:

- when is the time to tell someone they really like that they are positive?;
- how to tell someone?; and
- how to work out what the consequences will be, that is, will the door be slammed in their face or not?

Some found it incredibly difficult to navigate their way through when/how to disclose due to fear of others' reactions. Many felt their responsibility to prevent transmission was fulfilled by the use of condoms and would not disclose their status unless specifically asked for unprotected sex. Whereas others tended to be upfront as soon as possible, feeling that if the other man reacted negatively, it was better this occurred before things really got started.

Despite individual differences, all of the HIV positive men felt that until they had learned a way of disclosure that minimised rejection for themselves, all potential social and sexual interactions were usually uncomfortable. Often they felt that disclosing to someone due to a sexual interaction would result in more people knowing in the broader social environment, thereby 'outing' them to everyone else. This was particularly the perception in regional areas and smaller metropolitan centres where social anonymity was difficult to achieve.

"A thing about disclosure is you can't un-tell someone. So that plays on peoples minds...you have to pick who you tell as you don't know what someone will do with that information."

"Once it's out, it's out. You can't take it back. Everyone knows."

The second round of research also found that this was one of the primary fears of many younger HIV positive men. Even in the larger metropolitan centres, it was generally believed that social anonymity was difficult to achieve if one was going out on relatively regular basis.

"Its not six degrees of separation in the gay world. Its three"

The possibility for disclosure in a potential sexual encounter resulting in others in the broader social environment finding out about their HIV status, was a primary reason that some younger men chose to not place themselves in a position where they may have to disclose their HIV status. The possibility of social ostracism and others passing judgement, should it become common knowledge in the social group or *"in the scene"*, held as much to fear as the possibility of rejection by the individual they were disclosing to.

Dealing with the matter of disclosure was identified as one of the key areas in which HIV positive men could benefit from assistance. This could be an area for future strategies for organisations.

8.4 Sero discordant Relationships

Perceptions of sero-discordant relationships

Respondents currently involved in, or with past experience of, sero-discordant relationships were involved in the research to assist in identifying methods that may assist HIV negative men overcome their fears in regards to relationships with HIV positive men. There were a number of men who had been involved in sero-discordant relationships for twenty years or over. In all of these 'older' relationships, the HIV positive partner had been diagnosed prior to the relationship beginning. Other couples had more recently got together.

One of the key learnings from the research was how respondents thought others perceived sero-discordant relationships in the 1980s compared to now. All the older couples did not report any negativity from others within the gay community when they first got together. All negativity had stemmed from heterosexuals who were aware of their sero-discordant status. Comparatively, now many found that it was gay men were more likely to be critical of their relationship than the heterosexual people they knew. Often there was blame levelled at the HIV positive partner, with *perceptions* that they were selfish by keeping their partner in a relationship that:

- was limited sexually;
- placed the HIV negative partner constantly at risk;
- placed on onus on the HIV negative partner to provide health care for the HIV positive partner; and
- would result in the HIV negative partner having to deal with an early death.

"(Gay friends have said) "How could you do that? How could you stay with him. You're selfish. And that was someone we'd been friends with for 25 years. He was a real bitch."

"We've lost a few friends because of it. They don't understand how we can be happy."

"(People talk negatively behind their backs) and say 'How can they be together? He could pass it on to him?'"

The negativity that some people in sero-discordant relationship experience was typified in the local gay community's reaction to the sero-conversion of a previously HIV negative partner of a 7 years sero-discordant relationship. Although the decision had been a much argued for, and deliberated choice, of the previously HIV negative partner, the positive partner had been vilified by other gay men.

"They treat me as a monster. Some just simply don't speak to me anymore or they openly insult me."

"They're bitches. I just don't talk to most of them anymore. They don't understand I made the decision."

Differences in perceptions of sero-discordant relationships over time are attributed to education about HIV, which was once again, related to age. It was believed that older men were more educated about HIV, and this meant they were both more accepting of sero-discordant relationships for themselves and in regards to friends.

"We didn't think anything of it. We all knew how HIV was caused, and how prevalent it was. I was never raised to discriminate against anyone, so it didn't even cross my mind that HIV was a reason for us to not be together...my parents were really supportive. They didn't see a problem with it either."

Many of the younger HIV positive men involved in the research who were in relationships were in sero-discordant relationships. Being educated about HIV and / or having an established friendship or relationship were given as the key reasons as to the success of these sero-discordant relationships among younger men. Some respondents claimed that their relationship had worked as the HIV negative partner was already well educated about HIV, and had known other HIV positive men prior to entering the relationship. Others felt that their relationship was successful as they had already established themselves as friends before becoming intimate.

"We worked together...He'd got to know me, so he already knew me and liked me before I told him."

"Its different when they get to know you first."

More recently diagnosed younger men found it difficult to imagine that they could be in a sero-discordant relationship in the future. Many felt that they were limited to only having a relationship with someone who was already HIV positive. This perception was due to:

- feeling that only someone who had shared their experience of HIV could understand them;

- not wanting to face the possibility of rejection and judgement by disclosing to someone;
- not wanting to feel responsible for passing on HIV to someone else, thereby not even confronting that possibility; and
- feeling like no one who is HIV negative would want to be intimate with them.

Many of the younger men easily recall their own attitudes when they were HIV negative, and use these as the primary reference for what is likely to be their experience in the future. Because they had previously chosen to not sleep with men who had disclosed as being HIV positive, nor had even contemplated a long term relationship with a HIV positive man, they assume this will be the views of all HIV negative men.

"I used to say no if someone told me they were HIV positive. There's no way I was going to risk it even if ti was protected"

"I didn't run from the room, but I got out of there pretty fast"

"When I was negative, there is no way I would have had sex with someone who was positive. No way"

One of the key areas of education for most HIV negative men in regards to sero-discordant relationships is about sex. Most are curious as to how long relationships, in particular, manage to maintain having protected sex over a long period.

"Can I ask is there any temptation to play unsafe within yourselves?"

"Speaking as the one with the bug, there have been times, you're right, I think oh, it would be so nice. When I think about it in terms of maybe a cure, I look at that just so I could throw the condom away. I'd just love to do that, not have to wear that, not have to observe certain things, not have to be careful about going certain places and doing certain things that are classed as unsafe. To be free of that would be just great...but really our relationship and our health is worth more than that"

This quote above highlights the one issue that sero-discordant couples all felt needed to be communicated in regards to sero-discordant relationships. That is, *"ultimately, a relationship, is not always just about sex. It's a part of it; but if it is about sex, the relationship is probably doomed anyway"*. However they recognise that communicating this to young men in particular is difficult to achieve, as for many, it is all about sex.

Personal experience

As has been previously identified, being in or knowing others in a sero-discordant relationship is one of the key educative experiences for HIV negative men in terms of stigma and discrimination

about HIV. This was illustrated in two of the mixed groups where younger men used the group discussion to ask questions and learn about the sero-discordant couple within the group. Many of the young men claimed to have not even been aware of knowing anyway who was HIV positive prior to the discussion, and could certainly not imagine that people could be in a relationship if they were not of the same HIV status. Exposure in the group discussion both provided knowledge and overcame some negative assumptions that these young men had.

Learnings

Specific findings from the discussions with sero-discordant couples that may assist in moving forward with communication strategies target HIV stigma and discrimination include:

- knowing sero- discordant couples is one of the key educative experiences for young men to overcome some negative assumptions they have towards HIV;
- sex is not everything in a relationship, however sero-discordant couples can have fulfilling sex lives by continuously keeping up with new information about HIV and transmission that has it comes to light;
- there are more sero-discordant relationships around than people realise;
- men are probably having sex with more people of different sero-status at other times; a relationships is merely an extension of these types of experiences; and
- there are support organisations that can help those who may need help overcoming fears/ worries about being in a sero-discordant relationship.

Issues that occur in sero-discordant relationships

Some specific difficulties were identified as caused by individual partners in sero-discordant relationships. While this may not be useful in contributing directly to the development of a social marketing campaign aimed at combating HIV stigma and discrimination, it may be of interest for other activities. Some of the issue particular to sero-discordant relationships that were raised included:

- partners using HIV as an excuse or a means to their own ends;
"He would tell friends that we wouldn't be going out because 'Tom is having one of his bad days', when in fact he just couldn't be bothered to go."
- the perception that the HIV negative partner held the attitude that he was doing the other 'a favour', which impacted a great deal on the HIV positive man's self esteem;
"He was supportive but it was always forced."

- non-disclosure over a long relationship. For example, one respondent had been in a relationship with a man who was HIV positive for six years, but did not disclose until it developed to AIDS. This respondents did not discuss his experience in any great detail;
- some complained of having a 'boring sex life';
- positive partners subjecting themselves to stigma and discrimination;

"The only one who had a problem with our relationship was me. I was always worried. If I'd been to the dentist or doing the gardening or had any wounds or cuts, I wouldn't even let him kiss me. It was stressful being on guard all the time."

- difficulty in overcoming fears and developing confidence in protecting oneself; and

"It was always on your mind, just little niggly things"

- uncertainty about the support services that exist for sero-discordant relationships, particularly for negative partners.

"It takes a little while to understand that there are others out there as well. When I finally found Andrew (friend who was also in a sero-discordant relationship), at least we both had someone to talk to."

9 SUPPORT STRATEGIES

9.1 Current Involvement

HIV positive men strongly endorse the use of professional advice and social networks as a means of support in living with HIV. In terms of current support strategies, the services most HIV positive men identified were the individual counselling and specific 'assistance' based organisations that helped with ensuring HIV positive men had adequate food, shelter and healthcare. Most had experience of individual counselling available to assist them in coming to terms with their conditions and support for when they were undergoing mental duress. For some, this individual counselling had also provided guidance as to how to access assistance from various agencies and government services, when men found it difficult to hold full time jobs.

"(they) were great. Told 'em where to go to get my medications, what benefits I was entitled to when I couldn't work, what my legal right were, how to get help with housing".

However, few men identified specific support that was aimed at building resilience to discrimination. It was suggested that agencies tended to focus on ensuring all basic physical and mental needs were met (and had to due to limited funding), rather than on providing 'tools' to enable men to live more confidently in the community. Some HIV positive men felt that there was large gap in the ability of men to deal with certain basics of living with HIV, and that overcoming these may help in building resilience to discrimination. Some examples were:

- helping men to deal with the issue of disclosure given sexual rejection is the key issue on which HIV positive men feel stigma and discrimination. For example, some basic ideas on how, when and where to disclose to help to minimise the rejection;
- providing some ideas on how HIV positive men can live off limited funds and still be involved in 'normal' social situations if they need to limit their work life and their finances are constrained. Men who live on a disability pension do not have that financial means to socialise in 'normal' social circles and spaces, especially if these involve drinking and drugs; and
- the building of social support systems with other HIV positive men with whom experiences can be shared.

This last point was strongly endorsed by many older HIV positive men. Some very strongly felt that there was a real need to a 'positive identity for positive people' through the development of social networks, rather than other occasions with HIV positive men which focus on assistance services. However, while HIV positive men could all identify with the 'theory' behind the idea of building social networks through support agencies, for some, this had been tried with little success. In some instances, events aimed at building networks had instead reinforced feelings of isolation and shame. Some examples given are described below:

- There is a reluctance for some men to attend specific events for HIV positive men in regional areas (and smaller metropolitan centres) due to a fear of others among the mainstream community finding out about their being HIV positive. As a result, events end up with low attendance which can serve to perpetuate the sense of isolation and 'difference' among those that do attend.

"I don't like going to those things. It just screams being positive. Once you go, you're being open and it's out there, you can't take it back."

"I've been at the Workers Club for an evening for friends and family, and we've had full buffet dinner for a hundred, bottles of wine on the tables and five people have turned up. That just makes you feel fantastic. We can't even support ourselves."

- The same men seem to attend all the events, with few new people turning up; and

"It's the same old faces all the time. We run out of things to talk about, don't we Gareth?"

"This was great (group discussion). I expected the same bunch of old fags talking about the same old things....then all these younger ones (negative guys in a mixed group) walk in."

- Limited frequency with little association outside of specific events, at times due to stigma and discrimination, means positive inroads made in developing social networks is limited.

"It was great the 'Positive Picnic' I went to. It's only on every 6 months or so through."

"The issue is that people don't mind being together when it's just them away on some organised event, but they don't want to go out with them socially....especially with the guys who look sick".

The examples given above illustrate the difficulty of trying to build resilience to discrimination, when HIV positive men suffer from self-discrimination, and / or discriminate against other HIV positive men due to fear of stigma via association. The cycle is self-perpetuating. This does not mean that the support strategy of building social networks is not valuable. Section 9.3 below highlights that support networks are vital in building confidence and resilience. Instead, the experiences related above just highlight the need for efforts to combat discrimination to be multi-pronged and aimed at addressing the source of stigma and discrimination among the HIV negative community as well as helping to provide support for those who experience it.

9.2 Experiences of Younger HIV Positive Men with Support Services

The following section is based on both rounds of research. Many of the observations made from the small sample of HIV positive respondents under the age of 35 years in the first round of research were confirmed in the second round.

Positive Experiences of Support Services

Overall, respondents were very positive about the experiences of the support services they were familiar with. Younger HIV positive men had all received invaluable assistance from support services in the area of education about HIV, and with initial and ongoing questions on about the health implications and management of the HIV. For some, the support organisations had supplied a vital service in providing information and education about HIV to family and friends, thereby eliminating the need for the newly diagnosed man to become the educator to those from whom he needed support.

"It was great. I told Mum not to freak out. Told her (about having HIV). Took her down to XXXXX. She listened, she learnt, and then came back and gave me all the support I needed. I didn't have to try and help her through her fear while trying to deal with mine."

Despite the positive feedback on individual services offered by support organisations, most of the younger HIV positive men identified with a reluctance to engage in group or organised activities with these organisations. They recognised that they did not readily engage in activities where they may be part of a 'positive group' or 'positive community', which could offer some emotional support. A number of drivers for this were able to be identified, each of which are discussed below.

Issues of Identity

One of the key difference found with young HIV positive men is that the concept of building a positive identity for positive people is not as appealing as it is for older men. Younger men did not want HIV to be a critical part of their identity. They were currently struggling to maintain a sense of self that was not dictated by the health and social elements of living with HIV, and would prefer to treat it as a manageable chronic condition that did not determine multiple areas of their lives.

This is one of the key issues that makes it difficult to provide group support services for younger men. There is no doubt that younger HIV positive men are very interested in gaining a peer group of other younger HIV positive men that they can use for emotional and mental support. However, as the focus of the event is invariably on HIV, this can signify to the younger man that HIV is becoming an increasing part of their life and identity, rather than being a chronic condition that they have to manage.

"I want to know other guys my age who are HIV positive, but I don't want to have to be friends with them just because of that. Like that's the only thing we have in common, that we're positive..."

Threat of gossip

Another key issue in encouraging young men to attend events organised by support services is the possibility of others at the event telling their broader social circle who attended the event. In effect, others disclosing their status after seeing them at an event for HIV positive people. This was seen as likely to lead to those people telling others, who would tell others, and possible social ostracism.

"I know my flatmate – he is a shocker. He's negative, but I know that if I told him a name he'd happily chat away to others about that person. He wouldn't mean to be nasty, but he's used to me being so open...he just doesn't think that others might not want everyone to know"

"Even though we're all told that everything and everyone is confidential, you know that people will go home and tell their partner, or flatmate who was there and then they tell someone else, and then they tell someone else and before you know it, your in a club and people are whispering about you behind your back and warning everyone off you. "

Perceptions of older HIV positive men

The majority of younger respondents commented on the difficulty of finding support services specifically for younger men also, particularly events which were not specifically focused only on HIV. That is, events that had a social element such as entertainment rather than being an information session. While almost all were aware of the more social events such as 'Planet Positive', experiences of these events were invariably negative for younger men.

In the experience of the younger HIV positive men, these events tended to attract older HIV positive men who appeared ill, who may have had HIV for some time, who they perceive are possibly struggling with unemployment and loneliness. While it is identified that many of the services offered by organisations have an important role in providing both social and services support, they were often highly *"uninspiring"* for younger men trying to come to terms with having HIV. Rather than find 'positive' support from people living active and happy lives with HIV, they perceive that they are usually confronted with the stereotypical "AIDS victim". This has resulted in the perception of two different 'cultures' that exist among gay men living with HIV:

- those who have lived with HIV for an number of years, who were more likely to have initially believed their condition would result in death; and
- those who have been relatively recently diagnosed and have been told that HIV is now a manageable chronic condition, rather than resulting in death.

Organised social events are seen to highlight the stark differences between these two groups. Younger HIV positive men felt that these attracted a 'certain type' of person with HIV. That fact that these events were 'free' was thought to increase the chance that the events would attract men who were older, and with low incomes because they were no longer working, rather than others like themselves who were young and working.

"I have met some younger guys around my age group kind of thing at Planet Positives, few and far between but I have met them. This type of thing tends to attract all the older guys that have the victim mentality. It's one of those BBQ things, there again that would be held during the daytime on a weekday when a person that is working like you can't get to it. So that's why you attract that semi-retired, retired victim mentality of people who have been positive for ages who have nothing better to do other than rock up to a BBQ and get a free feed kind of thing.

"This guy talking to us just reinforced all my negativity towards HIV. That stereotype, where it's all about self gratification, really queeny, really gay, really whiney...relishing in the gruesome details of how he got it and how it is as an illness...All the things I didn't want to be associated with"

"Because the older people have that victim mentality and the younger guys don't want to hang around with the older guys who have this victim mentality"

"Well to me there is a very clear delineation between those who were diagnosed in the 80's when there was no hope, where people died and then newly diagnosed now, who have been diagnosed in the period where there is hope for an extended life. So my view is I see very much the clash of those two cultures, those who are now 20, 25 years later going 'Oh my God I survived, I'm still here, what went wrong' to people like ourselves who can look forward to at least 25 years of life. To me there is quite a clash between the two because with the old school there is a certain amount of entitlement – 'We should be provided for, we are victims, everything should be handed to us on a silver platter ... whereas you get people within our age who are busy working and getting on with life"

"I had 3 different people come up to me going, 'Yeah, waiting for housing commission', 'I'm on the pension', 'I deserve the pension' and I was like going 'Well you're not a fucking victim because I have got what you've got and I work 50 hours a week and I pay my car payment and I'm not a victim, how dare you say I'm a victim or I have an illness because I'm not ill'

Rather than assist with self-esteem, these events can have a negative impact as the perception they have of the people they see reinforces the negativity they know others have for HIV positive men. It also reinforces the fear they have of what the impact of HIV will be on their lives. The net

result is that younger men tend to avoid organisations such as ACON, BGF and Positive Life, and do not receive the support from others that they could.

Most older HIV positive men confirmed that when they attended events, they saw the same people, most of whom were older and long term survivors.

"It's only the ones who remember having to fight for respect that go to events now. All the activists are almost gone, and the ones that are left are the only ones that show up at things trying to promote a positive image. The younger ones don't care...."

"The younger ones are too scared to....The poor young blokes don't turn up, they're too frightened about all the old farts trying to hit on them".

Time

Most younger HIV positive men were actively working and/ or studying during the day, so were only available in the evening to attend events. Given the limited free time available to those working, events organised by HIV support services competed for attendance other leisure, recreation, family and social commitments. Simply, sometimes younger HIV positive men did not have the time and / or chose to prioritise non-HIV related activities. It is the non-HIV related activities that are the most conducive to maintaining a 'normal' life.

9.3 Confidence and Resilience

There were stark differences between HIV positive men in terms of having confidence and resilience in dealing with stigma and discrimination. Quite simply, this confidence and resilience appeared to be strongly linked to the support networks of family and friends that men had around them. Those with long term partners, either HIV positive or HIV negative, demonstrated the most confidence and resilience in regards to stigma and discrimination. Similarly, those who claimed to be very active in various gay or HIV specific organisations demonstrated strong levels of confidence. These men all claimed to openly declare being HIV positive in the majority of situations they find themselves in, from family dinners to speaking as an HIV Positive person on an information night, to casual sexual relations.

"I've stood up in front of high schools all through regional (state) telling them I'm HIV positive. The comments, the questions have never bothered me. It's only a secret (and something to be ashamed of) until we talk about it".

"I tell straightaway that I'm positive. If they don't like it, they miss out. I'm a good root."

In contrast, the men that lived alone and claimed to have little or no support and acceptance from family and friends seemed to feel the impact of stigma and discrimination from others within the gay community to a far greater extent. Some reported being ostracised by family due to ignorance, culture, and stereotyping. To then also incur this from the gay community undermined the ability of

most to develop resilience against discrimination. These men begin to stigmatise and discriminate against themselves and other HIV positive men, perpetuating the cycle of lack of support.

9.4 Strategies to Cope with Stigma and Discrimination

It was difficult for HIV positive men to identify how they specifically dealt with issues of stigma and discrimination when asked directly. Most felt that they simply settle in a way of being able to minimise the impact of stigma and discrimination, through making active choices in regards to when and where they needed to disclose their HIV status. For some, certain strategies worked well in certain areas of their lives, but not in others. For example someone living in a large metropolitan city who is actively employed may be out and proud in his sexual life, but practice non-disclosure in the workplace and in mixed social situations. Four different approaches to how HIV positive men deal with stigma and discrimination were found in the research. These are described below.

Out and proud

There was a great deal of difference among HIV positive men in terms of how they attempt to combat stigma and discrimination when they encounter it. Some men advocated that openly disclosing their HIV status whenever relevant was the best approach as it removed the element of self discrimination which they feel is an important part of the battle. For these men, education was key to overcoming HIV stigma and discrimination. The more they could demonstrate that PLHIV are similar to others, and more importantly, were not ashamed of their condition, the better.

While this may not stop stigma and discrimination, it appeared to be a useful method of minimising the impact of it on these men as:

- they did not treat being HIV positive as a secret to be ashamed of: and
- felt that any stigma and discrimination was clearly a negative reflection on those exhibiting it rather than themselves.

These men were all confident in the group discussions. Most claimed to either have a long term partner or a strong peer group surrounding them which provided a great deal of support.

Non-disclosure

Other HIV positive men dealt with potential discrimination were more likely to prefer to not to disclose unless absolutely necessary required by the law. While some claimed to have been more open about their HIV status initially, negative responses from friends and experiences of stigma had led them to now avoid any potential for discrimination. This seemed to be particularly the case for younger men, and those who were still maintaining full time employment.

"Most of my friends don't disclose. It's their policy not to."

"I don't disclose if I'm only sucking dick."

Only being with other positive people

Other men dealt with potential stigma and discrimination by only mixing with other HIV positive people. Some actively sought other positive men for sexual relationships feeling that the potential for rejection was less. Others had made a conscious choice over time to confine their social circles to other positive people to avoid the potential for stigmatising and discriminatory remarks to be made in their presence by 'friends' who did not know they were HIV positive. Some of the older men who had lived with HIV for a long time claimed that over the years they had become familiar with other HIV positive men through running into them at various support services.

"It seems easier to negotiate with other people with HIV."

"I just prefer to not be around them now. There's always some little bitchy comment about AIDS freaks or something, so it's just easier to not be around them rather than bite my tongue. At least with my positive friends we don't have to watch what we say so much."

"Oh, we've known each other for years. We've both had this thing for over twenty years, you get to know each other pretty well."

Part of this, however, was that it was difficult to maintain the same social lives as HIV negative friends if their employment had suffered due to health impacts. Once it became difficult to work full time, HIV positive men did not have the same financial capability for socialising as their HIV negative (working) friends, nor was their health as resilient to the influence of alcohol, drugs and late nights. Some felt that it was only natural that they then chose to socialise with other HIV positive men with similar financial and health limitations.

Reclusiveness

Other HIV positive men deal with potential stigma and discrimination by avoiding any potential situation where they may encounter it. Typically, this meant avoiding sexual encounters as this was the one area which HIV positive men would be forced to disclose and held the greatest potential for rejection. Some older men say that it is natural and typical *"to go off sex for a while when you find out your positive"* in order to avoid this situation.

Most older HIV positive men claimed that after self-imposed reclusiveness for awhile, they realised that they just had to find a way to deal with the situation. For most, this meant either looking for other HIV positive men or finding others who were more accepting of it.

"People take themselves off the scene for a period...it's really sad...it's unhealthy not to have sex!"

However, a small number of HIV positive men reported that they had 'removed themselves from the scene' for a long period of time and had now reached the stage where they felt that a relationship would be too difficult to attempt emotionally. These men claimed to avoid any situations that could involve potential for relationships, either casual or long term, and tended to use venues or beats as a means of fulfilling sexual needs.

"It's been hard because I've been on my own the whole time, no family, no support, a few friends that know. When I came back to Australia, people who were my friends and had been my friends for a long time, when I disclosed to them they were my friends for about three months after that and I've never seen or heard from any of them since. So experiencing that and rejections and so forth, therefore I don't want to put myself back in that firing line of rejection again...you have big barriers..."

"It's not a picket fence, it's a brick wall".

"And a moat on the outside with no drawbridge!"

9.5 Social Networks for Younger Men

As support of social networks is a key to developing confidence and resilience, key questions for the research focused on what social networks younger HIV positive men have and what support services can be offered in this area to assist younger men.

The existing social networks of younger men varied to a large extent on the length of time since diagnoses. Those who were newly diagnosed are much more likely to be in stage where they had withdrawn from the friends and social circles that they had been involved with, especially when these social circles involved being part of the 'scene'.

"I've just dropped out of the scene now. It's not worth it. None of them would be my friends if they knew"

While one of the key reasons for avoiding their previous circle of friends is the potential shame of others finding out, many also spoke about how it offered a chance to re-evaluate whether the social life they had been living was satisfying them or not. Most spoke about experiencing a change in life socially, physically and emotionally, and feeling that it was needed, but in some cases being unsure of where to turn next.

Younger men that had been diagnosed for a longer time all recalled the experiences of the newly diagnosed in their initial withdrawal from the 'scene' and the uncertainty they felt about where to turn next. These men felt that it was a normal stage to go through, and gradually men began to re-establish their social networks.

The majority of younger HIV positive men that had overcome the initial need to withdraw socially, all claimed to have a mix of HIV positive and HIV negative gay friends. These men did not tend to feel that it was necessary to disclose their HIV status to all their friends, with many questioning why it should be seen to be a consideration. Although it was clearly identified that having friends who were also HIV positive meant that they had others around them who could sympathise with certain issues when they arose, this was not seen as a necessity for many younger men who had been diagnosed for some time. More important was the type of support offered by friends if they chose to disclose to them.

A number of men also identified that the more accepting attitudes towards homosexuality and HIV from the broader community mean that many younger gay men often have a diversity of social networks, both gay and straight. This means that some of the critical support is found through both family and heterosexual friends, with the 'gay community' no longer core to their social environments. It was believed that whereas 20 years ago, HIV positive men found greater understanding and support from their peers within the gay community than others, this was no longer the case. This was especially so for younger men who have peers that have a limited understanding of HIV. At the same time, family and close friends, straight or gay, have become more accepting.

Many of the younger HIV positive men questioned what else the service providers could possibly do to help young men expand their social networks. They felt that for many younger men who become HIV positive, the fact that it is a manageable condition, means that they deal with their initial emotions and then "just get on with life". These men may contact service provider to get initial assistance and direction, and then seek emotional support through existing family and friends if they need it. Although they have a need to seek out others 'like themselves' especially when they are newly diagnosed, there is a need to balance the extent to which any social situations focus on HIV. Too greater emphasis on HIV would challenge the perception of younger men that HIV does not have to be an integral part of their identity.

The focus of the services offered is the one of the key challenges to overcome if younger men are to be supported by service providers in developing social networks. As discussed above, although younger HIV positive men would like to be able to access peer support through HIV service providers, they will not do so if the event focuses on HIV. Nor do they want to be in a situation where they feel they are with people only because they all have HIV, and no other common interests. This would be making HIV a focal point of their identity, something they wish to avoid.

"I'm just interested in meeting younger positive people, without the only thing there having to be like, we must be friends or we're in the same club or something. I don't want that"

"It's unsaid understanding that you want. Especially if you're newly diagnosed you go through that roller coaster thing. One day your emotions could be really great and the next

day you could be really low, so how do you explain that to someone? But if someone's been through that you are like I understand I've been through that myself and I kind of know what you're going through. It helps just knowing you've got peer support even if you don't speak about it"

Offering services and /or working through other organisations where the focus is on a different interest or activity may be useful in offering younger men a way to involve and engage with others. In a sense where the focus of the 'club' is on something else besides HIV, but a lot of the people there have HIV so support is there if needed. Some of the younger positive men had already achieved this through their interests in 'leather' and other subcultures.

"That's why I think its important to be in an environment where its separate but its not the point of why you are there. You are there because of an interest you have which makes you feel good rather than be there because of something you probably hate yourself for having"

10 SHARING OF SPACES

10.1 Online Space

Sharing, or lack thereof, of online space has been discussed in great detail in Sections 6.4 and 7.2. In summary, screening potential partners online according to HIV status is not typically perceived as discriminatory by HIV negative men. Being HIV negative is just another attribute on the list of preferences for their ideal partner, albeit, most admitted that being HIV positive would cause many men to be automatically dismissed. Online sero-sorting occurs frequently with many negative men are more confident in the online space in terms of asking about others' HIV status, although there is general agreement that men are more abrupt and rude online. It's easier to ask, and also easier to reject.

Once men become accustomed to rejecting others online based purely on their HIV status, this is easily transferred into the face-to-face environment. Further, there is general agreement that people are more abrupt and rude online than face-to-face. That said, many HIV positive men would prefer to use the online medium to disclose to potential partners as it is easier to face rejection online than in person. There is also evidence to suggest that HIV positive men 'discriminate' against negative men online. They actively target other HIV positive men to limit the potential for rejection.

One of the key learnings about the sharing of online space, is the issue of different interpretations for selection criteria across the groups. There did not appear to be a consistent interpretation of a number of the descriptors that men used. For example, when describing themselves as 'bare backers', some felt that this indicated that these men were obviously HIV positive, and were seeking other positive men. Others felt that these men were obviously positive and were trying to encourage negative men to have unprotected sex with them. While still others, felt that this was obviously HIV negative men looking for other HIV negative men with whom they could have 'safe' unprotected sex with. Age or HIV status did not seem to influence how men interpreted the phrase.

Similarly, HIV negative men interpreted the preference for safe sex that is used as part of a profile – 'Always', 'Never', 'Needs discussion' – in a variety of different ways. However, their interpretation of this part of someone's profile was a critical factor in whether they saw this as meaning someone was HIV positive or not. For example, one man always rejected someone who stated 'Always' as this implied to them that the person must be HIV positive. While for other negative men this was seen as implying the person was HIV negative, and 'Needs discussion' was seen as indicating someone was HIV positive.

The concern with the different interpretations of descriptors lies in whether a conversation regarding HIV then occurs either online or when meeting face-to-face. Learning that someone is HIV positive

after interpreting the different descriptors as them implying they were HIV negative, can reinforce negative perceptions that HIV negative men hold towards HIV positive men.

10.2 Physical Spaces

A general discussion about the lack of, and need for, 'gay' physical spaces compared to previous decades, and the subsequent impact this has had on a sense of 'gay community' has been provided in Section 5.3.

Perceptions of who shared their physical spaces differed across aged groups. As younger men tended to relate being HIV positive to a particular stereotype that they could visually identify, they did not believe that men with HIV were likely to be at the same places that they frequented. Most older HIV negative men were more likely to be aware that they shared physical spaces with HIV positive men. These men admitted that the conversation about HIV status was more difficult to have in physical spaces than online. Most of the time, the issue of HIV was not verbalised, rather assumptions were made or men simply 'played it safe'. It was recognised that in physical spaces the use of drugs and alcohol influences assumptions that are made about HIV and often results in the conversations not occurring.

"When I was in Sydney last, I did ice. It makes you so horny, ohhhh.....I didn't care and it was only afterwards that I thought to ask if he had anything that I should care about. He said that he had HIV and I thought, 'well, thanks for telling me'. Anyway, I went and got PEP the next day. That wasn't very nice either".

While no respondents in Sydney and Melbourne felt that the various clubs and venues had developed so far to be *only* HIV positive or HIV negative spaces as yet, some HIV positive men identified that there were definitely certain physical spaces in which they were more comfortable.

Some positive men in Sydney identified 'Planet Positive', which happens in a pub every three months, as a good space where they were free of the potential judgement that occurs with HIV negative men. This differed to 'events' put on by organisations as the purpose was for a night out. Most men found the atmosphere positive. Some likened it to when men would attend gay bars in the '70s and '80s so they could feel free of hiding their secret homosexuality against a hostel heterosexual society.

"It's like going back to the '70s. Everyone's secret is out and it's open and everyone's having a good time."

It was identified however, that it is not held in prominent location. Some felt it was "off the beaten path" by being nowhere near Oxford Street. This was seen to imply that, to some extent, everyone was still in hiding.

Another respondent in Sydney identified that they preferred to attend 'fetish' venues such as Manacle and Clearance, as the people here were more 'open-minded' than in the mainstream clubs and venues. These respondents felt that they encountered less rejection in these venues from casual partners.

10.3 Knowledge and Perceived Efficacy of Condom Use

No respondents were going to openly admit that they lacked knowledge and confidence in condom use and protecting themselves. However, all HIV negative men who claimed they would never have sex with a man they knew to be HIV positive, claimed it was because 'accidents' with condoms can happen. Therefore, the only way to remove all risk was to avoid HIV positive men.

"But the condoms can break. What happens then?"

"Because they don't believe that protected sex is going to be safe enough, that's their level, that's all...(negative man who is happy to be involved with a HIV positive man, talking about others in the group)"

"No, it's not 100 percent, even with a condom..."

"Not 100 percent protection, no. Abstinence is 100 percent protection I guess..."

"If you know someone is HIV then you risk it even if you are using a condom."

"I know I would wear a mask if I was going to work with the asbestos in the roof but that's not enough for me to climb up into the roof."

Notably, younger HIV negative men and older men who were adamant that they would never have sex with someone who was HIV positive, did not extend the conversation on methods of protection beyond using condoms. In contrast, the older HIV negative men who were more open to having sex with someone who was HIV positive, and HIV positive men also, also discussed other means of protection, such as:

- lube;
- not to have oral sex after brushing teeth;
- be aware of cuts, open wounds, in mouths;
- use protection for oral after visiting the dentist; and
- having the discussion so both parties are aware of what is safe and what is not.

The difference in knowledge levels demonstrated by different groups of men suggests that many men have a lack of knowledge about how to most effectively protect themselves during sex with HIV positive men.

HIV negative men, especially younger men, were also more likely to admit to 'slip ups' in regards to condom use, particularly while under the influence of alcohol and drugs. Most believed that this was another reason to ensure that they avoided the possibility of having sex with men who may be HIV positive, rather than identify it was a reason to ensure that they always used condoms or raised the topic of HIV with new partners.

10.4 Overcoming Fears of Positive Partners

Critically, the first step in overcoming fear of positive partners for many men is to start talking about HIV. It does not seem to be a topic that is discussed among gay men much anymore, except by social marketing campaigns that advocate prevention. Men usually begin to talk about HIV when they begin to know others, particularly a friend, who is HIV positive. Quite simply, overcoming fears of positive partners starts with knowing HIV positive men. All HIV negative men with a friend who was HIV positive, particularly a friend who was still active in employment and in their social circle, were by far less fearful of HIV as a condition. They were also less likely to believe in a stereotype or to make explicit or implicit discriminatory remarks about HIV positive people in the group situation. Knowing someone with HIV 'humanises' the condition. It also begins the educative process on other sides to HIV and PLHIV rather than only the need to prevent transmission.

Knowing other people in sero-discordant relationships is also an important factor in overcoming fear in engaging with positive partners. HIV negative men who had known sero-discordant couples identified that witnessing the relationship had been one of the key factors in understanding that they too could have HIV positive partners. Experience of sero-discordant couples, especially long terms couples, not only addresses the fear of whether protected sex is enough, it also addresses fears associated with partners being ill and dying.

"They change your perceptions in a good way. They get on with life, they're happy, they have a normal, lovely, healthy life together."

"It's inspiring, it cuts down the stigma – it's not the end of the world."

The final step in overcoming fears of having HIV positive sexual partners, was for HIV negative men to educate themselves on all the risks associated with sex. This was often achieved via a discussion of risks with an understanding health professional such as a GP as well as reading the latest information and research. While for some men, this final step in education had occurred due to finding a HIV positive man that they wished to be involved with, for others, it had simply been a means of ensuring responsibility for their own health.

"When I finally came out (four years ago), I felt I should know all the risks. So I went to my GP and I asked. About everything, including the risks with sex with HIV positive men."

While not discussed in great detail, HIV negative men who had experienced HIV positive partners also challenged others within the group who stated that sex with condoms would never be as good as bareback sex. The implication was that these other men needed to possibly be more imaginative. Some HIV positive men also agreed that negative men could be somewhat limited in how they equated good sex with bareback and bad sex with protected sex. Although it should be recognised as an 'excuse' covering fear of sex with HIV positive men, challenging the assumption of only 'bareback is good sex' was quite provocative to those HIV negative men that claimed this.

10.5 Strategies and Partner Selection

HIV negative men who are comfortable having sex with HIV positive men, did not identify any particular strategies they use in partner selection. While these men did not actively seek out HIV positive partners there were two key differences that seemed to exist between these men and other HIV negative men. Firstly, HIV was not a discriminatory variable in whether they would engage sexually or socially with men as it was for other men. Secondly, they were more likely to openly discuss HIV with all prospective partners, including use of condoms. When with an HIV positive partner, they felt it was necessary to have honest communication about boundaries in sex, particularly what sexual acts they were comfortably with as being protected or not.

11 SERVICE ORGANISATIONS

11.1 Issues of Discrimination with HIV Service Providers

Discrimination to HIV Positive Men

HIV positive men indicated there is an incredible amount of support for PLHIV. They recognised that PLHIV had access to more services than people living with many other chronic diseases. The key issue that HIV positive men identified in relation to service providers was with the focus of support rather than it being an issue of discrimination.

All acknowledged that there was a great deal of support available through organisations such as Positive Life, BGF, ACON, AHAG, Australian Arrows, Vic AIDS Council, ACON, Country Awareness Network (CAN – previously Country AIDS Network), VIV AIDS, as well as through various community health centres. However, this support was perceived to be more for men who were very ill such as those in the advanced stages of AIDS, or for those who had been HIV positive for some time with limited support networks around them, therefore they were very lonely. This perceived focus of service providers meant that the support options were not appealing to men who had been diagnosed more recently, younger men, and men who were still maintaining employment and so on.

“I hate going to the PLC. It’s really confronting and not inspiring.”

“Lots of people find people with HIV weird and unpleasant And that’s from someone with HIV.”

Similarly, some HIV positive men felt that the focus of service providers to date has all been on the illness itself, by:

- preventing the illness through social marketing aimed at this; and/ or
- aiming all services at people who are obviously very ill and need support for basic food and shelter.

While it was recognised that these organisations relied on funding, many simply felt that the focus of where funds were being directed needed to change now that medications were changing how people are able to live with HIV. For example, some felt that there was a large gap in support for people that are still working, paying taxes, trying to be healthy and get on with life. These men would like to see some funding being directed towards promoting positive and healthy life experiences for HIV positive people.

“Twenty years ago, those people wouldn’t have been well and working. They should try a bit more to keep those people healthy. They’re better off being in the system.”

Many HIV positive men indicated that they had begun to limit their contact with organisations as much as possible, as they felt that the focus on illness was not positive.

"I spent all my time being comforted and talking about my illness rather than focusing on my health. So I changed my focus. I realised there's a life to live so I'd better do it."

One HIV positive respondent was also now in the process of raising money to build a retreat for PLHIV. The retreat was being aimed at providing PLHIV people with a place where they can take time out, rejuvenate and focus on health and wellbeing. He was undertaking the project because he felt that nothing similar was available through existing organisations.

System dependency

HIV positive men raised the issue of potential 'abuse' of the system, institutionalisation and dependency. As also discussed in Section 9, some younger men feel that there was potential for the focus on illness and services had some strong negative implications, such as:

- creation of a 'welfare dependency' among a group of people; and

"HIV is their life. They have been 'professionally dying' for 10-15 years and milking the system for all it is worth."

- the perception that some men try to get HIV so they can go on the pension and get all the benefits/assistance that comes with it.

"Professional welfare recipients that sit back and take hand outs."

One respondent identified that he had once asked a group of HIV positive people if they would take a miracle cure if it was available tomorrow. He said that three had said no because it would "affect my lifestyle".

Whether these perceptions have an element of truth or not, they indicate the frustration that some HIV positive men feel towards the support systems being offered. It is not that they want funding directed away from providing essential services to the very ill, but they believed that the lack of focus on providing positive support and a focus on health and well-being contributed to negativity towards PLHIV among gay men and the broader community.

"People never see those who are living healthy lives. They only see the really sick being helped out by others. We need to focus on the positives of being positive."

Discrimination towards HIV negative men

None of the HIV negative men involved in the group discussions criticised the availability of and access to service providers. Most were aware that specific organisations existed to assist PLHIV, however few could name any. BGF, Positive Life and the various state AIDS Council were perhaps the most well known among HIV negative men.

The majority of HIV negative men were aware that organisations such as ACON, Vic AIDS Council, and QAHC were as much aimed at the entire gay community rather than only HIV positive men. This was demonstrated through various social marketing campaigns aimed at prevention consistently put out by these organisations. Some had accessed the services of these organisations for various support services that are offered to gay men in general. For example, counselling services for young gay men just coming out to friends and family. Others volunteered at ACON and other organisations in order to make contact with and feel part of the community.

"I used it as a way to get to know people when I first moved here."

Aside from this HIV negative men had limited contact, knowledge or experience with these organisations. That said, they did not feel discriminated against.

"If I needed some 'gay specific advice, I'm sure I could go there. But I don't really know what I could need off somewhere like ACON that I couldn't get from...like...my doctor or somewhere."

"I know they exist, but I don't have any reason to go there."

11.2 Attitudes of Service Providers

Overall HIV positive men felt that HIV service providers try hard and make the best from limited funding. However, there was the inevitable criticism that there is not enough involvement from gay men in the support organisations.

"They're run by lesbians. Gay men put their head in the sand."

"I don't understand why we can't have more male counsellors. They're all women"

"All the CEOs and heads of the organisations are straight men. What would they know about how it is to be a gay, positive man."

Some HIV positive men identified that funding issues could often result in loss of staff. This could result in a number of difficulties:

- perceived loss of support for the HIV positive man if they had developed a relationship with the staff member over time; and
- existing staff members having to fit more into their schedules.

Both these could contribute to HIV positive men feeling that they were treated negatively by staff of service providers.

One of the key issues identified by HIV positive men was the treatment they often received by general medical professionals such as hospital staff when they were required to be in hospital. They felt that staff felt free to announce loudly to others about them being HIV positive. While they recognised that this was essential information for treating staff to have, it had been the experience of some that hospital staff were callous in how communicated this information. They felt it is was often very public and very pointed.

"Just over two years ago I was severely bashed in a park and I was rushed to the Gold Coast hospital absolutely covered in blood. The triage nurse wanted to know details and get me treated, and I said I needed to let her know I was HIV-positive and she screamed it out and everyone in the waiting room heard – it was like ... god, anyone could have been there..."

"I was in hospital for treatment about something else entirely last year. Every change of shift the head nurse would personally bring in the nurse on shift and say in front of me 'Now, Greg is HIV positive'. You know what that means, don't you?'. And not just in front of me, but loud enough so the whole ward could hear. They never acknowledged me the entire time...would just bring in the nurse and say that and they would leave."

Some reported also having similar situations occur at GPs and pharmacists until they were able to find ones they were satisfied with.

12 DEVELOPING COMMUNICATIONS

12.1 Informing a Strategy

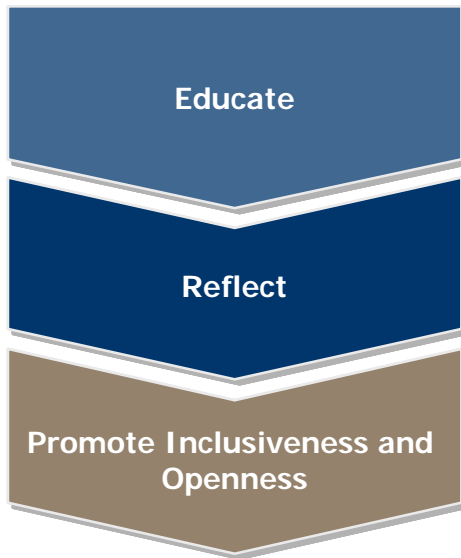
It needs to be accepted that some HIV negative men will never overcome their fear of HIV and PLHIV. Just as the broader heterosexual community will always contain people that stigmatise and discriminate against gay men, so will some gay men still stigmatise and discriminate against HIV positive gay men. In this sense, social marketing strategies may provide the best value if they aim to achieve change with those for whom change is possible, and make negative attitudes to HIV the exception, rather than the rule.

However, the research has identified a number of areas in which sustained social marketing strategies can have an impact and reverse the trend of some of the factors that are causing increasing stigma and discrimination. The approach to achieve this that is outlined below is put forward as a starting point for the development group to consider as they use their skills and broader knowledge to move forward in developing an appropriate social marketing campaign.

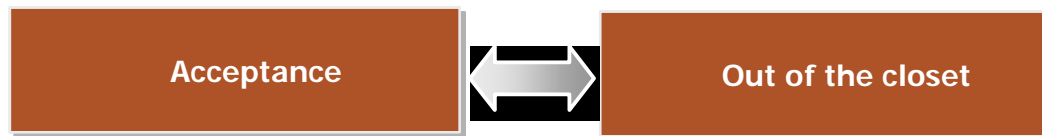
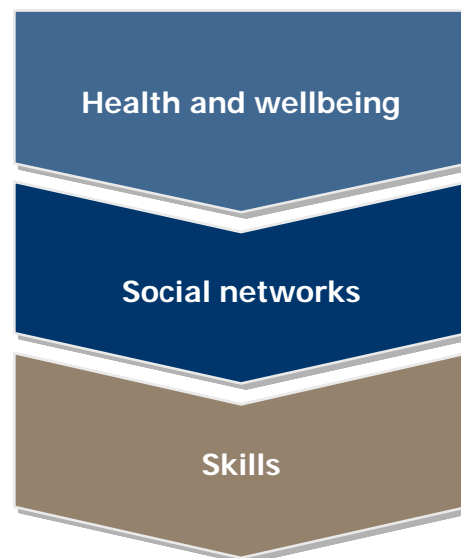
The research suggests that two broad strategies should be considered in moving forward. One strategy should aim at changing the prevailing attitude among HIV negative men via communications. It is likely that this will need to be a phased process delivering a series of messages over time as even after two hours of discussion, many HIV negative men could not move beyond the prevention message, when asked to provide suggestions for messages for a campaign on HIV discrimination. This highlights the challenge in getting different messages across. They see 'HIV' and read 'prevention', whatever else the message may be.

While a broad communications approach aimed at HIV negative men would also reach HIV positive men, a specific service delivery strategy aimed at HIV positive men should also be considered. This would aim at building the confidence and resilience of more men to be 'out and proud' about their HIV status at appropriate times, rather than use other methods to deal with stigma and discrimination. If these services are already available, then a communications campaign to promote these will be necessary, especially for younger HIV positive men. The figure below illustrates these two different strategic approaches.

Phased Communication Strategy aimed at Negative Men



Specific Service Delivery Strategy aimed at HIV Positive Men



Please note, the intention is not for the approach for HIV positive men to work in isolation. Given the negative issues that can arise for HIV positive men when they disclose their status, it is untenable to assume that approaches aimed at HIV positive men to be open about disclosure would be successful without the aim of ‘acceptance’ also being achieved among HIV negative men. The goal is for the approaches to work in conjunction with each other and to be achieved over a period of time.

12.2 Communications Strategy for HIV Negative Men

Stage One: Educate

The lack of knowledge regarding HIV and the simple absence of any messages aside from prevention suggests that the first stage of any marketing strategy aimed at HIV negative men should be to educate people about what HIV is and who it affects. Breaking down the stereotype and addressing the labelling that has developed to become part of the everyday language of some gay men, especially younger ones, will be an important part of this.

Further, given that one of the key barriers to overcoming the fear and ignorance of HIV that cause stigma and discrimination is avoiding minimisation of the prevention message, this stage of the strategy will need to aim at achieving a balance. A message that aims to ‘break down the stereotype’, by showing that there is no ‘typical’ HIV positive person can be coupled with a condom

prevention message. For example, 'If HIV affects men of all ages, shapes and sizes, then it is relevant to you. Learn to use condoms'.

When breaking down stereotypes it will be important to explicitly tell people that 'you cannot tell if someone has HIV by what they look like', 'people with HIV are doing all kinds of jobs, going to all kinds of clubs and bars', 'many people with HIV are in relationships' and most importantly, 'you probably know people with HIV, they just haven't told you'. When delivering these messages it will be important to avoid using stereotypes like Madonna or Kylie fans, drag queens, guys who look like they've walked out of a gym. It will also be important to ensure that this message does not stimulate more fear of HIV and PLHIV, via the adoption of an appropriate tone.

"If you don't show the diversity of the gay community then it looks like you don't understand it. Also, we need to see that it's all people."

*"(Dave) But I don't know anyone with AIDS...(Friend in the same group) Yes, you do Dave. I know that you know people who have AIDS...(Dave) who? No-one looks like they do. You two don't look like you do (to others who had disclosed they were HIV positive)."*⁸

Stage one should also aim to address the basic facts about HIV. Younger men, in particular, do not know simple facts, such as:

- most people have HIV, not AIDS;
- it is a manageable condition, albeit chronic, and people live long, mostly 'normal' lives;
- it will still impact on your life, there will be certain things you can no longer do, but it is not necessarily a 'death sentence'; and
- It's a chronic condition, not the person themselves– 'I am living with HIV, I'm not HIV'

All stages of the approach could use the idea of sero-discordant relationships as it is personal experience with one of these that seems to have the greatest impact on allowing men to overcome negative perceptions of HIV. However, what is shown about these relationships should fit with each stage. For example, in Stage One the focus should be on ensuring that the sero-discordant couple contribute to breaking down the stereotype, and should be of relatively long term so the idea of prevention is reinforced as well.

Stage Two: Reflect

It was very apparent within groups, in particular with older men, that many were simply not aware of their discriminatory behaviour towards PLHIV. When the group discussion highlighted the language

⁸ Note: in this quote, 'AIDS' should be read as meaning 'HIV'.

they commonly used to describe PLHIV and the discriminatory behaviours they exhibited, some men were actually startled at their behaviours.

Stage Two could focus on holding a mirror up to men and showing them their behaviour. While there will be some groups that will be unlikely to change their attitudes for any reason, reflecting the unattractiveness of discriminatory attitudes and behaviours will likely be effective for many men. This could involve likening HIV stigma and discrimination with other socially unacceptable forms of discrimination such as, ageism, racism and, even homophobia. How blatant this concept of reflecting behaviours back to the perpetrators will need to be looked at further, as going too far may impact on credibility. The key element of this will be to start men on the process of thinking about their behaviour as an undesirable characteristic.

At a minimum, this stage should aim to focus on the person, both those with HIV and those who discriminate, and how they feel rather than about HIV the condition.

"You don't hear much about people with HIV and their feelings, that they're human" (Neg U30)

"How it affects their social life, you would feel rejected, alone, let down...so people can understand and sympathise"

"I've never really thought that they might be less likely to tell you because of that (discrimination)"

Some respondents suggested that t gay men who are HIV-phobic could be parodied, in the manner of the RTA's 'Little Pinky' campaign, which makes young men who speed 'look silly.' Some examples of other types of messages that focus on the 'person' may include:

- HIV doesn't discriminate, do you?
- You have a choice to not have sex with someone who is HIV positive, but you've also got a choice in how you say no
- Did you know that gay men are now the bullies?
- Do you know that your more homophobic than the straight community?
- People with HIV have learned to live with it. Why can't you?

These ideas are based on comments made by respondents as well as researcher interpretation. They should be used as a base for others with more creative training to develop, not be taken literally as creative suggestions. Further, it would be useful to undertake future research in terms of the creative approach, particularly for this element of the strategy, as is it basically a confronting message. Making it relevant while maintaining credibility will be important to ensure that the

message is provocative but not easily deflected. Will this be best achieved by humour, shock or somehow else is difficult to determine from this research.

Again, the use of sero-discordant couples could heavily involved within this stage of the strategy, with the focus on demonstrating a lack of discrimination in choosing a partner. As an example, sero-discordance could be compared with couples of different ethnicity, different age, different religion.

Stage Three: Promote Inclusiveness and Openness

The final stage of the strategy will be to encourage gay men to stop excluding HIV positive men in sexual and social situations. Gay men need to appreciate that HIV is not something that has gone away and it can no longer be something that should be ignored and kept 'in the closet'. Ideally HIV would become a topic that is discussed among gay men and would become aware of the inequality within their own sub-culture. Ultimately, the aim would be for the majority of gay men to believe:

- it's OK to be with someone who is positive;
- it's OK to disclose;
- it's OK to talk about it and you should talk about it; and
- it's not OK to treat PLHIV badly.

While this is obviously the goal of the whole campaign in terms of overcoming HIV stigma and discrimination, it will only be possible to reach this stage after taking men through the first two phases. To go straight to this type of message will likely result in perceived lack of credibility and would be unlikely to be as effective.

"Look after you mates, look out for each other...a sense of community, and inclusive community. We should all be caring for each other." (U30 Neg)

"It's not 'us' and 'them'. The issue belongs to everyone."

"It's still under the carpet. It needs and identity."

12.3 Service Delivery Strategy for HIV Positive Men

As the Development Group involves representatives of various service providers, it is appreciated that the suggestions for a strategy with positive men may already be being implemented within different organisations. If the perceptions on what is offered by organisations, that have led to the suggestions for a strategy made below, are different than what is offered, then the real issue may be one of simply communicating what is already available.

Stage One: Health and Wellbeing

HIV positive men would appreciate a change in focus of services offered by some organisations. Rather than focus on managing the 'illness' of HIV and the provision of basic services for the very ill, HIV positive men identified they would welcome support services to direct some funds towards promoting positive and healthy life experiences for HIV positive people.

Aside from the mental and physical benefits that this would achieve, a change in focus was seen as particularly necessary for younger men, and those who are still working, and being active socially. A focus on 'health' as opposed to 'illness' may create a different environment at organisational events, and mean that younger men and those who are recently diagnosed may be more likely to continue to attend events, rather than find them 'uninspiring' and something they try to avoid.

Stage Two: Social Networks

As the research findings suggest that the more confident and resilient HIV positive men drew a great deal of support from their the social networks and / or family, it flows that one strategy of building confidence and resilience for men would be to assist in the development and maintenance of social networks. Some identified this as the main way to begin the development of a 'positive community' or 'positive identity'. Such an idea of a 'positive identity' was welcomed by older men in particular, who felt that HIV now needed what 'gay' needed 25 years ago. That is, the development of a community that could stand together.

"There are 10,000 people with HIV in NSW. Of that 60-70 % live within 10km of Taylor Square but there is no Positive community."

"It's like the deaf community coming together"

"I'd prefer to have our own identity than be given one."

However, younger HIV positive men and some HIV negative men who were more open to relationships with HIV positive men, felt that this type of 'activism' would only increase the 'divide' and the 'us and them' experience that exists. They felt that HIV positive men needed to be part of a broader community, not a separate community.

Regardless, the development and maintenance of social networks for HIV positive men has an important role in confidence and resilience. The question is whether a changed focus in the different events that are organised, to one of positive living and wellbeing, would assist this to occur more so than it does now? Maintaining participation of more men in events offered by service providers by a changed focus may assist in maximising the opportunity to develop social networks among other HIV positive gay men.

The experience of the younger HIV positive man in finding a 'helper' at ANKALI provides an example of how important it is for younger men, and those who are recently diagnosed, to find others to identify with in terms of age and social experience. After trying to find social support within a range of other HIV organisations, and only finding that attendance at certain events increased his feelings of anxiety and isolation, the younger HIV positive man went to ANKALI. The model that ANKALI adopts is reportedly one of trying very hard to match support people by personality, and other characteristics, in order to ensure the appropriate emotional and social support is given. The younger man was matched with a female 'helper' of the same age, and who shared very similar social interests. Although not a HIV positive gay man, this 'helper' plays a vital role in the younger man maintaining social networks and providing support, thereby helping him to maintain confidence in himself.

It should be noted that encouraging more active participation in events focused on the social would not be occurring in isolation. The broader strategy aimed at HIV negative men would hopefully be assisting to make HIV positive men less reticent about being seen at 'positive' events, or with 'positive' friends.

Stage Three: Skills

Throughout the group discussions, HIV positive men all discussed and argued consistently about the issue of disclosure, particularly when and how it should be done. This topic could have filled a full two hour discussion group alone. Everyone had their own views on what they felt worked best for them according to satisfying their sexual needs, however, it was clear that some strategies used resulted in stigma and discrimination being more of a problem for certain men. In a sense, some had learned the skills of how to approach disclosure in a manner that allowed them to protect themselves from the more hurtful side of rejection, while others had not. Providing some basic ideas on how disclosure could be handled, in a variety of situations, may assist some men. Particularly when men are first diagnosed and are unsure on how to approach discussions. Similarly, skills on handling rejection were thought to be beneficial.

In addition, learning skills on other impacts of HIV would be useful for some men. For example, caring for health while maintaining a 'normal' social life, how to maintain a strong social life when finances become tight (for me no longer working) and how to deal with medical professionals when they act inappropriately. Inherent in most of these examples is a focus on maintaining an active and 'normal' life.

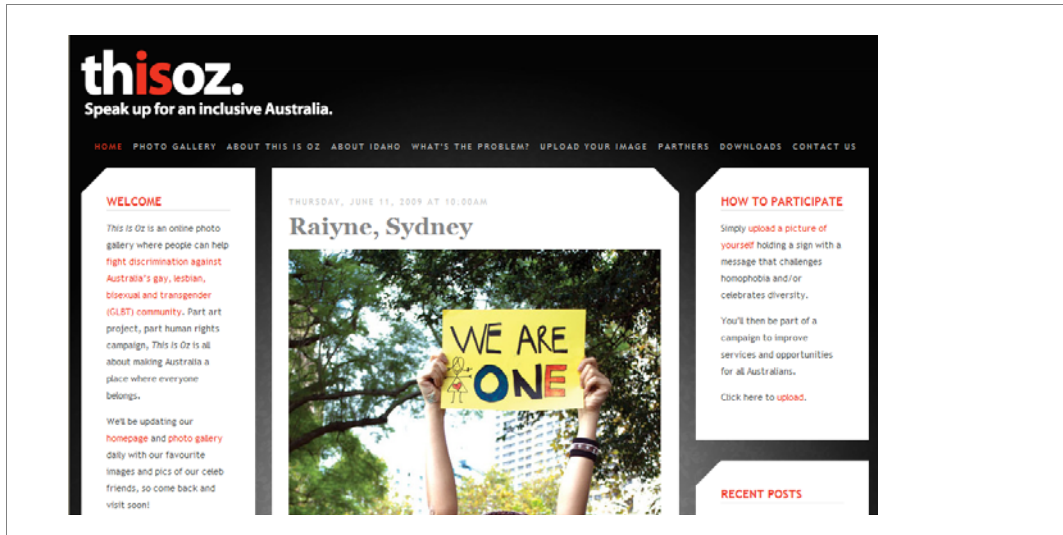
12.4 Learnings from Other Communications Materials

A range of different communication materials about HIV and gay discrimination were included within the research. These were shown to identify messages, style, language, tone and media that men responded more positively or negatively to. Some of the learnings in regards to messages

from these elements have been incorporated in the discussion on a strategic approach above. The intention of this section is to provide some guidance as to a possible creative direction and executional elements for any marketing materials that may be developed in the future. As such the strengths and weaknesses of each, as identified by the target audience, have been reported. Due to time limitation, not all were shown in all groups.

This is Oz - www.thisisoz.com.au/

This Is Oz is an online photo gallery where people can help fight discrimination against Australia's gay, lesbian, bisexual and transgender (GLBT) community.' It claims to be 'part art project, part human rights campaign' and is aimed at 'making Australia a place where everyone belongs'.



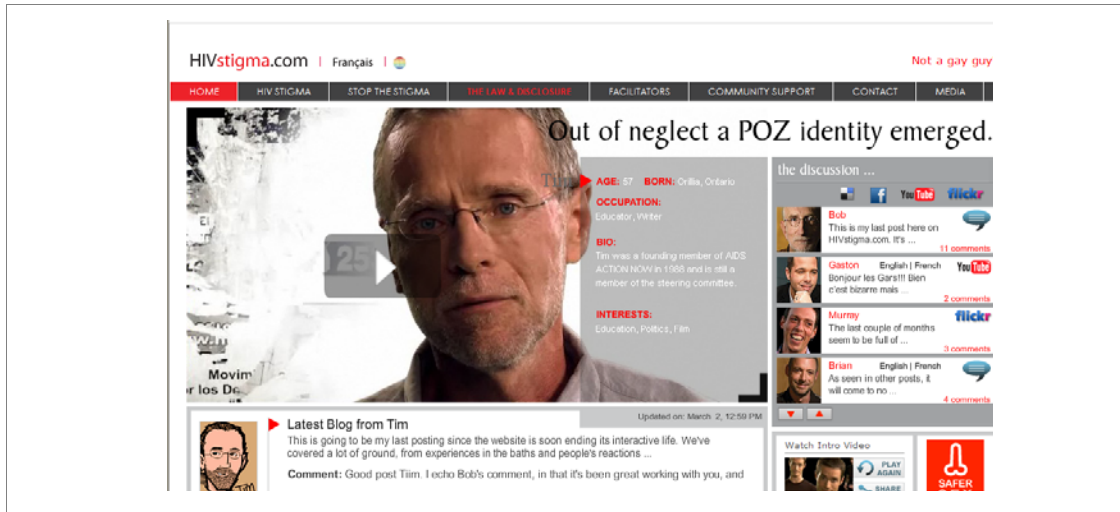
Strengths	Weaknesses
<p>Very strong creative idea:</p> <ul style="list-style-type: none"> personalised with 'real people', who are not stylised or stereotyped ; updated daily with something 'new' to look at so very appealing to younger target groups. <p>Upbeat approach with colours and design of site</p> <p>Message resonates strongly with younger gay men who may still feel discriminated against from the broader community to some extent.</p>	<p>Some rejected the approach as 'moralising' and trying to convince.</p> <ul style="list-style-type: none"> felt it would be more effective if done in a manner that allowed them to see discrimination as negative themselves rather than being 'told' that it is. <p>The idea is strong once engaged with the site, however the question is what motivates people to become engaged with it in the first place?</p>

HIV stigma - www.hivstigma.com

This Canadian website uses videos, discussion boards and blogs to discuss HIV stigma and discrimination. Two video from this site were used in the research:

- 'Out of neglect a poz identify emerged'; and
- the 'Introduction video'.

Poz Identity



Strengths	Weaknesses
<p>Older HIV positive men welcomed the message:</p> <ul style="list-style-type: none"> idea of a 'positive' community; likened strongly to the history of activism. <p>All welcomed the idea of discussion about HIV that is not just about just about prevention:</p> <ul style="list-style-type: none"> a new perspective that is fresh and interesting. <p>Visual delivery and idea of blogs discussing the topic was an appropriate method of communication.</p>	<p>Younger HIV positive men and HIV negative men did not find it relevant:</p> <ul style="list-style-type: none"> limited knowledge of what was being said; perceive 'activism to be 'outdated'. <p><i>"I didn't really follow it...I don't know about HIV history and about the people who died and the reasons."</i></p> <p>Seen as promoting a 'divide' and an 'us and them' mentality'</p> <p>Being labelled feels discriminatory anyway:</p> <ul style="list-style-type: none"> singled out for special attention <p>Not all HIV positive men have heard the term 'pos'/'poz' being used, and some felt it had negative connotations.</p> <p>Style was perceived as very 'didactic'</p>

Intro Video



Strengths	Weaknesses
<p>the messages were appreciated 'struck a chord' with both HIV positive and HIV negative men:</p> <ul style="list-style-type: none"> • that it's not the sole responsibility of positive guys to initiate the discussion; • that stigma means people don't disclose; • drawing on the 'gay community' for support (more with 'positive' men). <p>Although many did not understand 'Clean UB2' terminology, but for those who did or when explained recognised this is a good example of stigma:</p> <ul style="list-style-type: none"> • implies those with HIV are 'dirty'. <p>When pointed out it 'struck a chord' as to own behaviour.</p>	<p>Although it was greed the talent used was 'hot', many found the stereotyping of gay men irritating:</p> <ul style="list-style-type: none"> • especially the mention of the Madonna concert. <p>Others felt he lacked credibility because he was so stylised.</p> <p>Key weakness was that there were too many messages trying to be covered::</p> <ul style="list-style-type: none"> • talks about fear and why people don't tell anyone • but also what people with HIV's obligations are under the law • and the statistics are 'scary' and hence seen as a prevention tool <p>This suggests that a focus on one message at once is better.</p>

QAHC television ad

An television ad developed by QAHC which aims to convey the message that homophobia is “backwards thinking”. This ad was only shown to three groups – two younger HIV negative groups and one older HIV negative group.



Strengths

Value in the strategic idea of holding a mirror up to people who are homophobic:

- illustrates their behaviour in a manner that doesn't lecture or patronise;
- reactions to homophobia are seen as credible.

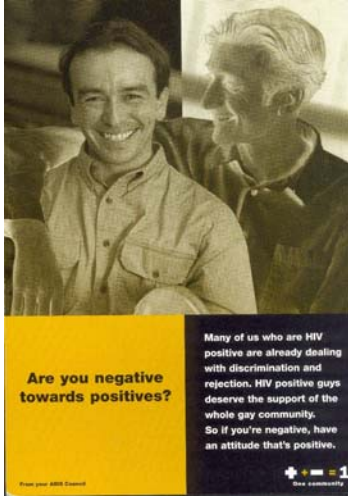
Likened to the 'little pinkie' RTA speeding ad.

Weaknesses

Some difficulty in working out 'what the ad is trying to do':

- message is somewhat convoluted.

'Negative toward positive' poster

	
Strengths	Weaknesses
<p>A strong statement that forces one to confront their own attitudes.</p> <p>Especially well received by those who still feel some desire/ sense of gay community:</p> <p>Accepting of saying gay men 'need to look after our own'</p> <p>'Negative towards positives' is seen as a good play on words.</p>	<p>Creative idea is unlikely to engage:</p> <ul style="list-style-type: none"> • dull execution / no humour; • not memorable / no impact. <p>Ghostly image and age of talent reinforced stereotype.</p> <p>Some felt the linguistic separation of negatives and positives increased the 'divide'.</p>

Cup and sneeze posters



Strengths

Execution was straightforward and simplistic.
 Message take out was immediate.

Some drew a parallel between the need for such a simple message to be openly stated and discriminatory behaviours towards HIV positive men:

- albeit only those more open minded and sophisticated in their attitudes.

Some identified they would appreciate a message on 'how you can't get HIV' rather than only a message that states 'prevention'.

Weaknesses

Many just dismissed the posters as providing a known simplistic message:

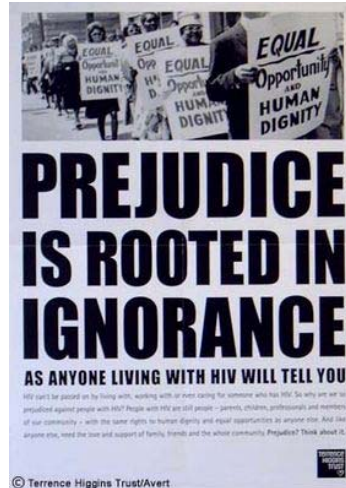
Most had to be prompted in how the ideas could be used in relation to HIV discrimination.

Communicating messages on 'how you can't get HIV' in relation to sexual relations (while seen as a strength overall) was perceived as difficult to achieve 'safely':

- eg. its hard to communicate that oral sex is safe if no cuts or wounds are present;
- convoluted messages that could get confused.

"It will give people an excuse to have risky sex, which shouldn't be sanctioned."

Ignorance poster



Strengths	Weaknesses
<p>Message was endorsed by HIV positive men and some older HIV negative men:</p> <ul style="list-style-type: none"> • confronts the core problem – that of ignorance; • holds the sense of activism that many recall as being so effective in the 80s. <p>Compares discrimination towards PLHIV with other minorities.</p> <p>'Rooted' is a good word to use – opportunities for humour!</p>	<p>Others felt it was a negative message and would not engage with it:</p> <ul style="list-style-type: none"> • is only 'one way' • activism is seen as archaic/ irrelevant. <p>A belief that the message should encourage dialogue and open communication on the topic which this does not do.</p>

'Horny as...' Share this space



Strengths	Weaknesses
<p>Message of both people being with the same space and horny resonates as relevant and credible.</p> <p>Some perceive it as a positive message that is about inclusiveness.</p>	<p>But the message polarised:</p> <p>Others saw it as separating two types of people, thereby reinforcing the 'us' and 'them' mentality.</p> <p>Would be unlikely to engage except for the 'horny as hell':</p> <ul style="list-style-type: none"> • creatively not a strong idea, • dull.

12.5 Style and Tone

Messages that personalised worked well, as they confronted people about their potential ability to discriminate. One respondent gave an example of a campaign involving a full length mirror in gay clubs which read at the top "this is what a person with HIV looks like" as something that involved people at a highly personalised and individual level. The approach of 'This is Oz' was also seen as relatively personalised as 'real people' were involved.

'Real people' and 'real life stories are also important, particularly for younger audiences. Many are very critical of the use of stereotypical models as talent.

Similarly, for younger people it will be important to keep messages simple. Take out of the message needs to be immediate, otherwise the effort spent to engage them is lost.

Many of the messages will be somewhat confronting. Care will need to be exercised in the creative idea in delivering these messages, as many creative styles and tone can be easily deflected if people do not wish to 'hear' the message. For example, humour may be an appropriate manner to convey a confronting message. However, this should be the subject of research depending upon the aim of any marketing materials as misuse of humour can mean the message is deflected. The same principle applies to shock tactics.

12.6 Media / Channels

If a social marketing campaign is developed for younger men, web based marketing is an obvious channel, in particular viral marketing. A good creative idea will be easily passed around and / or watched on You Tube. Similarly, banner advertising via social networking sites where advertising can be tailored according to the information provided in profiles.

Many felt that it was necessary to target the emerging gay community to try and balance the factors that cause the negative attitudes to develop in the first place. For example, universities, the 'young' clubs, film festivals and cinema ads prior to screening of films that deal with issues of 'homophobia' in general. These types of films can attract the attention of youth.

Targeting websites where discrimination occurs, such as Manhunt and Gaydar, will be useful to reach older HIV negative men, as would information through publications.

Service providers have the main role as a channel for HIV positive men, albeit messages about HIV aside from 'prevention' do need to come from service providers also.



APPENDIX A: RECRUITMENT SCREENER

INTRODUCTION

Thank respondent for answering advert and reassure about confidentiality.

Establish that there are different groups being held with slightly different specifications and we need to make sure that we get them in the right group. Reassure that all information is confidential and is being used as part of making sure we have them in the appropriate group. The research will not ask them to reveal any personal information that they do not wish to.

1. What is your current occupation? **(RECORD)**

AIM FOR A MIX

DO NOT RECRUIT ANYONE WHO MENTIONS MARKETING / RESEARCH / ADVERTISING / WORKING FOR ANY HIV/ GAY ORGANISATION OR HEALTH PROMOTION

2. What is your age? (RECORD)

CHECK GROUP QUOTAS

3. The following question is a personal question related to your health status and HIV. You do not have to answer this question, we are asking it only to ensure we have a representation of a range of people. Please be assured that it will not be discussed in the group situation unless you raise it yourself.

Which of the following describes your HIV status?

I have been diagnosed as HIV positive	RECRUIT FOR POSITIVE GROUPS AND THEN MIXED / UNDISCLOSED	1
I am HIV negative	RECRUIT FOR NEGATIVE GROUPS AND THEN MIXED / UNDISCLOSED	2
I do not know or I am not willing to answer.	ONLY INCLUDE IN GROUPS WHERE MIXED/ UNDISCLOSED IS AVAILABLE	3

NSW ONLY – NOT A VARIABLE FOR OTHER STATES

4. Are you currently in, or have you previously been in a relationship with someone of a different HIV status to you at the time?

Recruiters, please ask sensitively, Example for clarifying if you need to are:

If Code 2 in Q3 (HIV Negative): Are you, or have you previously been, in a relationship with someone who is HIV positive at the time of relationship?

If Code 1 in Q3 (HIV Positive): Are you, or have you previously been, in a relationship with someone someone who is HIV negative since you have been diagnosed as positive?



If Code 3 in Q3 (undisclosed): ask the generic question.

- 1 Yes (NSW RECRUIT FIRST FOR GROUP 4)
- 2 No (CONTINUE FOR ALL REMAINING GROUPS)

DISCUSSION GROUPS

Please ensure that respondents know that any refusal is based on the need to get homogenous group of age and other variable together. Please let me know if any difficulties arise in terms of refusals – ie. groups are full.

Thank and ensure that they let us know if they are unable to make it so we can get a replacement person into the group. We will also be reconfirming their attendance on the day / day before groups.

- 6-8 respondents per group
- \$100 incentive per respondent for group attendance
- Groups will last about 1 ¾ hours
- Please ensure that respondents are aware that the groups will be audio-taped for analysis purposes.

APPENDIX B: DISCUSSION GUIDE

Note – the timing and order of questions have been included as a guide only. Discussions are likely to follow a different order, reflecting the priorities of different audiences.

1 Introduction (5 minutes)

- Introduction of research topic and aims:
 - to understand their views about discrimination
 - they do not have to talk about their personal experiences if they choose not to.

Note – most questions have been framed in the third person to allow respondents to 'project' responses on to others if they are not comfortable talking about their own situation or experiences.

Explain that have done groups on this topic area before so please don't hold back on what you feel you want to say or the way you'd normally say it. Feel free to be as open and honest as possible.

- Researcher to explain anonymity, recording:
 - Audio recording only and only for moderator use etc
- Respondents to introduce self:
 - name
 - who live with – friends/ partner/ family etc...
 - occupation

2 Current issues that concern gay men in general (10 minutes)

Note – this section is intended to identify the extent to which HIV discrimination is spontaneously raised as a concern.

- What are the key issues that concern you as gay men at the moment?
- For each issue raised (briefly):
 - why is this important currently?
 - what are the different points of view that you have heard expressed on this topic?

3 Spontaneous issues in relation to HIV (5 minutes)

Note – this section is intended to explore the extent to which discrimination is spontaneously raised as an issue in relation to HIV.

Moderator will explain that the key topic we will be focussing on for the rest of the discussion is HIV.

- **Written response followed by discussion:** Are there any particular issues that are current regarding HIV?
- Why are those issues particularly important?

4 **Attitudes and behaviours regarding sexual partners / relationships (15 minutes)**

Note – Moderator to spend longer on this section with those specifically recruited as in sero-discordant relationships.

- How does HIV affect gay men's casual partner selection?
- How does HIV affect gay men's regular / long-term partner selection and relationships? (Fully explore spontaneous responses then probe:) how does this differ for:
 - regular / long-term partner selection?
 - casual partner selection?
- Do positive men have a duty to disclose before any sexual encounter?:
 - does it make a difference if it's protected sex?
 - is the expectation different in SOPV / on a first date?
- What is the responsibility of negative men around disclosure?

(Moderator to listen out for concerns that HIV positive men are unfairly burdened with this responsibility)

- What is the likely impact of sexual rejection on positive men?
- How do people become positive in 2009? Is it always from known-positive men?
- Do they know of current or past gay couples in which one member is positive and the other negative?

(Moderator to note whether they use the term 'sero-discordant' for this type of relationship?)

- What issues does this raise? How do people deal with these issues?
- What, if any, impact has your experience of this type of relationship (either personal or observed) had on your perceptions of PLHIV?
- Are there any lessons that could be learned that could be transferred to the wider gay community?

5 **Impact of shared physical and online spaces (10 minutes)**

- To what extent do you feel negative guys know how to protect themselves from transmission when they have sexual encounters with positive guys?
- How confident to you feel negative guys are about putting their knowledge (of how to protect themselves) into practice?

- How, if at all, is this different when they meet in online spaces (Manhunt, Gaydar etc.) versus physical spaces (sex on premises venues, clubs, sex parties)?:
 - how do HIV negative men feel about HIV positive men in these situations?
 - how does this affect partner selection?

Moderator note – try and identify whether there is this idea of going to particular venues/sites that only has 'positive' men, and only 'negative' men. The hypothesis is that there is no longer a gay community that is held together by the issue of HIV, but rather a divergence has occurred.

6 Changes in Attitudes to HIV (15 minutes)

- To what extent do you feel gay men's attitudes to PLHIV have changed over time?
- How have they changed? Why?
- Have your own attitudes towards positive men changed over time?
- What people or factors have contributed to any change?
- How do you feel about someone becoming positive in 2009 versus 1989?
- (Once spontaneous responses have been fully explored, probe:) what has influenced this:
 - criminal prosecutions for HIV transmission:

(Moderator to listen out for mentions of 'bug-chasing' and 'gift-givers' and to prompt on how these terms are understood)

- media coverage of criminal prosecutions
- serosorting
- use of online spaces and the dynamics of disclosure
- availability of treatments for HIV and changed life expectancy
- ageing and generational issues
- some personal relationship to HIV?
- To what extent have all of these issues affected the culture within the 'gay community'?
- How do they feel about this?

7 Awareness and experiences of discrimination and stigma (15 minutes)

Note – moderators will probe fully to ensure we get detailed examples of experiences.

Please note, much of this section may have already been covered extensively in the earlier section where we asked for spontaneous responses.

- (If not already raised) to what extent are you aware of any of the following in relation to HIV being an issue within the gay community i.e. between gay men?:
 - labelling, stereotyping, us-and-them thinking

- status loss
- power issues

Moderator to listen for the use of the terms 'stigma' and 'discrimination':

- (In addition to those already discussed) What examples of these types of issues in relation to HIV within the gay community / from other gay men have you come across? *Moderator to remind respondents that they do not have to talk about their own experiences but can draw on observations of what has happened to others (probe):*
 - in daily life e.g. in gay chat and personals sites or in social gossip between friends?
 - professionally?
 - in sexual interactions / negotiations?
 - with service providers?
- For each example / experience:
 - what exactly happened?
 - why do you think this happened?
 - what are the attitudes and beliefs people hold that caused this to happen?
- In what situations is labelling / stereotyping (*or any other words respondents use*) most problematic / most negative?
- Are you aware of good experiences that PLHIV have in these situations?
- What could be done to help encourage this type of good experience?
- (If not raised) Are the circumstances we've been talking about related to stigma and/or discrimination? (Moderator – challenge respondents to identify how this differs if necessary)
- What barriers do feel there are that prevent stigma and discrimination being addressed? (Relate to the 'good experiences').

8 Existing strategies and support and gaps in this area (15 minutes)

- What strategies do PLHIV use to cope with labelling / stereotyping etc.?
- What strategies do HIV negative men use to overcome fear of HIV and / or PLHIV?
- Does this vary according to the setting e.g. work, social, sexual?
- How confident and resilient do you feel PLHIV who you know are in dealing with discrimination and stigma?
- What support is currently available for PLHIV? Probe:
 - networks
 - professional advice
- What are the advantages and disadvantages of each type of support?

- Is there anything missing in terms of support?
- How could these gaps be filled?
- Are there any groups that are particularly in need of help? Probe: What about younger / older gay men? Any other specific groups?

9 Perceptions of service providers (10 minutes)

- What is the local AIDS Council / PLHIV organisation here?
- How much contact have you had with these?
- **Written response followed by discussion:** To what extent do you feel it / they adequately deal(s) with the needs of:
 - PLHIV?
 - HIV negative men?
- Do you feel there is any discrimination within these types of organisation, either overt or under the surface?
- If so, what do you think drives this?
- Which of these attitudes and behaviours will be easiest / hardest to change?

10 Potential Communications messages and media (15 minutes)

Moderator to explain this research is intended to feed into the development of a social marketing campaign aimed at addressing stigma and discrimination in relation to PLHIV among gay men.

- What messages do you feel are important to get across to gay men on this issue?
- What assumption around sexual negotiation should be promoted e.g. 'assume everyone else is positive'
- (If time allows), gain brief reactions to a range of existing anti-discrimination campaigns:
 - what are the strengths and weaknesses of these?
 - what lessons can be learnt from these materials?
- Where / how do you feel these messages should be presented? (Once spontaneous responses are explored, probe):
 - university open days
 - IDAHO anti-homophobia campaign
 - partnering with local councils
 - screening at gay film festivals
 - user-generated content competitions
 - bus ads / billboards



- Would other approaches work (e.g. a community development approach):
 - eg. discussion forums
 - development through organisations.

11 Summary (5 minutes)

Moderator to explain the research is for AFAO.

- What are your final thoughts on HIV discrimination and stigma?
- What is the most important message that we should go back to AFAO with?

Many thanks.