experiences of hiv the seroconversion study annual report 2013

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The Seroconversion Study is a collaboration between the Kirby Institute, the Australian Research Centre in Sex Health and Society, the Centre for Social Research in Health and the AIDS Councils and people living with HIV (PHIV) organisations in each jurisdiction.

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EXECUTIVE SUMMARY

The Australian HIV sector is facing a challenging combination of factors (epidemiological, biomedical and behavioural) at the current stage of the ongoing HIV epidemic. Epidemiologically the number of cases of AIDS defining illnesses is near to zero; primarily due to the ongoing improvements in antiretroviral therapy (ART) coverage and efficacy. That being said, the number of new HIV diagnoses is increasing significantly year-on-year (both in terms of actual numbers per year and as a percentage of population). Biomedical advances mean that HIV-positive people are living longer lives with a better quality of life. Promising biomedical strategies such as Treatment as Prevention, Pre-Exposure Prophylaxis and Post-Exposure Prophylaxis have the potential to significantly reduce the risk of onward transmission of HIV, though structural changes will need to occur before the full benefit of these can be realised. Unsurprisingly these epidemiological and biomedical shifts are accompanied by behavioural changes in specific at-risk populations, particularly gay men. Behaviours accepted as high-risk (such as unprotected anal intercourse with casual partners: UAIC) have been increasing among gay men. However these behaviours have also been accompanied by an increase in other non-condom based risk management approaches suggesting an evolving calculus of risk among gay men.

To address the critical need for accurate, timely data in this dynamic environment, the Seroconversion Study (which has existed in various forms since 1992) continues to provide qualitative and quantitative data and research to government, the medical establishment, community stakeholders and the broader community.

Summary of the findings

In the last twelve months, a number of major findings have come out of the study:

- Few HIV infections among gay men are attributable to sex between regular male partners. HIV is far more likely to be transmitted via sex with a casual partner or a 'fuckbuddy'.
- On the occasion when they believe they were infected, gay men who acquire HIV showed little evidence of the use of risk reduction strategies including strategic positioning, serosorting or the use of viral load.
- There are multiple reasons why men avoid or delay testing in the months or years prior
 to their diagnosis, including the belief that they had not done anything 'risky', and fear of
 being told they were HIV-positive. Men who were less socially connected to other gay men
 were more likely to have avoided or delayed testing prior to their diagnosis.
- The decision whether or not to commence ART by those newly diagnosed continues to be a challenging one. The anxiety of coming to terms with their recent HIV diagnosis, the stigma still associated with HIV, their relationship with their clinician and the broader

community, and concerns and doubts about the ART treatment itself have all been raised by study participants and present very real challenges to health professionals, government and community organisations.

 Despite a tendency for the mass media to cast heterosexual women as the victim in heterosexually-acquired HIV, a review of the qualitative data found no evidence of recently HIV-positive women presenting as the victim or placing blame wholly on the HIV-positive man. Indeed, there is a far more ambivalent allocation of responsibility, highlighting the complex realities of sexual practice and gender.

The next twelve months

The Seroconversion Study continues with a change in orientation, to focus on the following areas:

- Testing: examine 'late diagnosis' in more detail, how people make their choices about getting tested and what they thought were the benefits of testing at that time.
- PEP/PrEP: Investigate why so few people use PEP, the reasons why they do use PEP in some cases, and what participants know and understand about using treatments to prevent HIV (PEP and PrEP).
- Experiences post-diagnosis: services used and service gaps, changes that may have occurred, experiences of telling people about being HIV-positive, outlook for the future and reflections on how their actual experience may differ from what they imagined at the time of diagnosis.
- Treatments: whether participants are on treatment, their viral load/CD4 count, their experience of treatments, what an undetectable viral load means and how treatments make them feel about sex with their partners (particularly in the context of a serodiscordant relationship).
- Sex post-diagnosis: their feelings about and experiences of sex since diagnosis, and whether any changes in sexual behaviour occur, and are sustained.

Introduction

Recent trends in infections and behaviour

The past year has been an eventful one, both in terms of the changing HIV epidemic in Australia and the response of government and community. Although Australia has a relatively low prevalence of HIV infections at 115 per 100 000, there has been a steady increase in the incidence of new HIV infections from 719 cases in 1999 to 1137 cases in 2011, Australia-wide. Notably, the vast majority of new HIV infections (86%) occur during male homosexual intercourse (The Kirby Institute 2012).

This being said, there appear to be high levels of both awareness and risk mitigating behaviour among gay men. Australia-wide data from the Gay Community Periodic Surveys (GCPS) presented in 2013 (de Wit et al. 2013) indicate very high levels of HIV testing with 86% of men having ever have had an HIV test and 61% of non-HIV-positive men having had an HIV test in the prior 12 months.

Looking at the sexual behaviours of gay men reported in the GCPS, predominantly stable trends emerge in both unprotected anal intercourse with regular partners (UAIR) and with casual partners (UAIC). The 2013 Australia-wide data demonstrate that UAIR is more common than UAIC (50% and 38% in 2012 respectively). The trend for UAIR is stable but there is a significant upward trend of UAIC. More recently in the Melbourne 2013 GCPS data (Lee et al. 2013), the most recent periodic survey demonstrated a slight decline in UAIR over time and a stable trend of UAIC. Similarly in the Sydney GCPS 2013 data (Hull et al. 2013), there has been a slight decrease of men engaging in UAIR over time however a shift was observed with UAIR being more likely to be observed in HIV-negative men in a seroconcordant relationship (with another HIV-negative man). Notably, there was an increase in the number of men having UAIC in Sydney (from 34% in 2012 to 36% in 2013). Examining this increase further, it appears to be particularly driven by an increase in UAIC among HIV-negative men (from 29% to 33%).

With these behavioural parameters in mind, in the 2013 Annual Surveillance Report (The Kirby Institute 2013), a 10% increase in the number of HIV diagnoses in 2012 (from 2011) is reported. Additionally, the rate of diagnoses of HIV per 100,000 population has increased 26% from 4.3% in 2011 to 5.4% in 2012. HIV continues to be transmitted far more during male homosexual contact (88%) than heterosexual contact (9%) or injecting drug use (1%).

Prior to the release of these data, a renewed push has been underway in community organisations, clinical settings and government. From a public health information perspective, both NAPWHA and ACON have launched major media campaigns. The NAPWHA campaign "What's it About?" focussed on encouraging HIV-positive individuals to start a conversation with their doctor about improvements to antiretroviral treatments (ART) and potential benefits including reduced risk of transmission for individuals on ART. The highly-visible "Ending HIV" program by ACON promotes "Test More + Treat Early + Stay Safe = Ending

HIV"(ACON 2013). Supporting this approach, there has been an increase in the convenience and availability of HIV testing across the country; however, there is more to be done in terms of making rapid testing more available including home testing.

These approaches are echoed in the current National and State HIV strategies (Australian Department of Health 2010, NSW Health 2012). Emphasis is on the need to make HIV testing more accessible, particularly to at-risk populations, and improved early access to HIV treatments, while maintaining current levels of harm minimisation through HIV prevention targeting at-risk populations.

Emerging HIV prevention technologies

Underpinning each of these public health campaigns and strategies is the consistent message that safe sex and regular HIV testing remain the cornerstones of Australia's response to the HIV epidemic. This being said, biomedical and social research are revealing new opportunities in, and challenges to, our response. Biomedical strategies including Treatment as Prevention (TasP - undetectable viral load monitoring) and pre-exposure prophylaxis (PrEP) both represent an opportunity to reduce the likelihood and incidence of ongoing infection. However, there is some concern that some at-risk individuals may reduce condom use (Eaton and Kalichman 2007); potentially resulting in a net risk increase. There are also challenges specific to biomedical strategies (such as drug regime adherence) that may also influence the efficacy of the strategy and the likelihood of onward transmission of the virus. Rapid testing is gradually becoming more available Australia wide and a trial of at-home HIV testing is about to commence in Sydney, Melbourne and Cairns.

Treatment as prevention

Also in the 2013 report on behavioural trends (de Wit et al. 2013) it was found that a large proportion of HIV-positive men are on ARV drugs (78% Australia-wide), though unpublished analysis suggests that as few as 54-70% of people in Australia who know they are infected are on treatment. Of the HIV-positive men on ARV, Australia-wide 78% reported having undetectable viral loads.

Of primary importance is the HIV-positive individual's health and the Australian Society for HIV Medicine (ASHM) reports (Australasian Society for HIV Medicine 2013) that there is strong evidence of reduced morbidity and mortality in individuals with a CD4 count of less than 350 (they found "moderate evidence" for individuals with a CD4 count between 350 and 500). For individuals with a CD4 count greater than 500, they reported that there is limited evidence regarding the balance of benefits and risks of ART for a single individual. A number of factors may influence this balance – notably the prevention of ongoing transmission of HIV. ASHM also report the growing body of evidence supporting Treatment as Prevention which encourages early consideration of treatment due to a significant reduction in the risk of secondary transmission by HIV-positive individuals who have undetectable viral load

(Australasian Society for HIV Medicine 2012). There is global research interest in TasP and support from community organisations when coupled with regular, easily accessed HIV testing and ongoing safe-sex practices.

If the target of having more people living with HIV (PHIV) initiate treatment earlier is to be achieved, then those men who are recently diagnosed with HIV must be willing to engage with therapy. Recently diagnosed men are uniquely positioned to help us understand what informs decisions around ART. Identifying the barriers and facilitators to the initiation of treatment will inform policy and program responses to help improve individual capacity to make informed decisions around treatments.

Pre-exposure Prophylaxis

Pre-exposure Prophylaxis (PrEP) remains in its formative stages in Australia. As part of the Kirby TAXI-KAB (Thinking About eXposure to Infection: Knowledge, Attitudes, and Beliefs) Study, gay men were surveyed to understand their perspectives and behaviours with respect to PrEP (Bradley et al. 2012). Only 4% of respondents had ever used ARV drugs for PrEP purposes, which is not surprising given PrEP is not officially available in Australia. The study also demonstrated a high level of scepticism in Australian gay men regarding the efficacy and reliability of PrEP with well over half of men not knowing of any evidence supporting PrEP and well over half believing that HIV medication was either "Likely" or "Very Likely" to fail as a preventative. That being said, over three quarters of HIV-negative men indicated they would use PrEP if they believed it would prevent infection and nearly half indicated they would consider ceasing condom use if they knew PrEP was effective. Finally, almost 90% of respondents felt that more research on the efficacy of PrEP was needed, demonstrating a strong interest in this promising risk-reduction strategy.

Rapid/At-home testing

Access to testing had been a recurring theme over the course of the Seroconversion Study and we know both qualitatively and quantitatively that the lack of a free, easily accessed test that rapidly produces an accurate result is a significant barrier to testing (Prestage et al. 2012). Since the last Seroconversion Study report we have observed a marked improvement across major Australian metropolitan centres. In New South Wales (ACON A-Test), Victoria (VAC Pronto), Queensland (QAHC Testing Point) and Western Australia (WAAC M-Clinic), fast and free community-based HIV testing has been made available. Additionally, at-home testing is currently being considered for introduction in Australia. This has obvious benefits in terms of convenience and privacy, however there are concerns around appropriate support being available in the event of a positive result and whether the lack of pre- and post-test counselling would have a deleterious effect. Interestingly, recently published research of a randomised clinical trial (Metsch et al. 2013) found no significant impact of risk-reduction

counselling on STI acquisition among sexual health clinic patients. This is an area of significant research and general interest going forward and the Seroconversion Study will continue to investigate this changing landscape.

As the technologies available to manage the risk of HIV infection become more sophisticated and complex, the community's response is becoming more nuanced. This is evidenced by ongoing increases in UAIC over time (despite some stability in recent years), and the proportion of men using some other form of risk-reduction than condom use (de Wit et al. 2013). Additionally, there is evidence that men who are at higher risk of contracting HIV appear more likely to use risk-reduction (Prestage et al. 2012). Finally, community organisations are taking a pragmatic approach to the changing HIV prevention landscape by providing information to at-risk men about relative risk (for example ACON's Know The Risk website).

Heterosexually acquired HIV

Although a large majority of new HIV infections occur during homosexual intercourse, there are a steady number of new infections (9%) attributed to HIV exposure during heterosexual intercourse (The Kirby Institute 2013). The study also continues to recruit heterosexuals who have recently acquired HIV and research their experiences. A recent paper utilising qualitative data from heterosexual participants (Persson 2013) found that despite a tendency for the mass media to cast heterosexual women as the victim in heterosexually-acquired HIV, a review of the qualitative data found no evidence of recently HIV-positive women presenting as the victim or placing blame wholly on the HIV-positive man. Indeed, there is a far more ambivalent allocation of responsibility, highlighting the complex realities of sexual practice and gender.

Change of study orientation

The study is currently funded by most states and territories until 2015 with the Northern Terrirory coming on-board in 2014. In the context of the many changes in HIV prevention and treatment, individuals who have recently been diagnosed with HIV have a very important story to tell that can help shape how we better respond to those changes and help to inform public policy and HIV prevention and treatment work into the future.

As such, an extensive review and update of the study questionnaire and interview schedule was conducted in 2013 which resulted in a change of focus to further investigate (among other things) participants' experiences post-diagnosis, rather than being primarily focused on risk factors leading up to the infection. Specifically, we will focus on the collection of information directly relevant to recent changes in HIV prevention and treatment as specified in the national and state-based strategies. These include a renewed focus on testing, PEP/ PrEP, beliefs about and uptake of treatments, and changes in circumstance and relationships after being diagnosed with HIV, including changes in risk-reduction practices.

Testing

Late diagnosis continues to be a significant issue with 18.1% of HIV diagnoses Australia-wide in 2012 having a CD4 count of 200-350 cells/ μ l and 19.1% having a CD4 count of less than 200 cells/ μ l (The Kirby Institute 2013), and the study will investigate this in greater detail. Given the focus from both government and community organisations on improving frequency and availability of testing, the study will explore in detail how people make their choices about getting tested and what they thought were the benefits of testing at that time and any difficulties they encountered.

PEP/PrEP

Education to improve community awareness of PEP remains a challenge. The study will investigate the reasons why people do use PEP in circumstances where they have engaged in risk behaviour, and what participants know and understand about using treatments to prevent HIV. The study will also look at awareness and perspectives regarding PrEP, which still remains in its infancy in Australia but presents an opportunity to reduce the onward transmission to at-risk individuals.

Experiences post-diagnosis

A major focus of the study going forward will be to investigate the needs and experiences of participants post-diagnosis. The study will examine services used and service gaps, changes that may have occurred, disclosure experiences (telling people about being HIV-positive), outlook for the future and reflections on how their actual experience may differ from what they imagined at the time of diagnosis.

Treatments

With the Australian and global focus on TasP, participants use of ART will be investigated in detail. The study will investigate participants' beliefs, attitudes and concerns about taking ART, and whether they are on treatment, their viral load/CD4 count, their experience of treatments, what an undetectable viral load means and how treatments make them feel about sex with their partners (particularly in serodiscordant relationships).

Sex post-diagnosis

Given the significant changes that are currently happening in the HIV detection and prevention landscape, a critical area of further study is the sexual behaviours of gay men who have recently seroconverted. In particular, there is a renewed focus in the study on beliefs about sex, HIV transmission and risk-reduction prior to diagnosis. There is already qualitative and quantitative evidence from the Seroconversion Study data on the changing sexual habits of participants, with two-fifths of respondents reporting reducing their number of sex partners following diagnosis, and one third having stopped having sex altogether. A number of men also describe changing how they look for their partners, through their online profiles on dating websites, and selecting partners based on their serostatus. The study now more broadly examines participants' experiences of sex since diagnosis, and whether any changes in sexual behaviour are sustained.

STUDY OVERVIEW

With these social and epidemiological contexts in mind, people in Australia recently diagnosed with HIV are invited to participate in the Seroconversion Study, conducted by the Kirby Institute (University of New South Wales) and the Australian Research Centre in Sex, Health and Society (La Trobe University). Currently, funding is generously provided by the Health Departments of New South Wales, Victoria, Queensland, Western Australia, the Australian Capital Territory and (from 2014) the Northern Territory. In previous years (2009-12), the Health Departments of South Australia and Tasmania also contributed to the study.

To participate in the study, individuals in the funded jurisdictions who were recently diagnosed with HIV complete an online survey about what they believe led to their infection and their experiences since diagnosis. At completion of the survey, participants are invited to volunteer for a face-to-face interview where they can share their story in their own words. Both the online survey and the interviews are discussed in more detail below.

Broadly, anyone is eligible for participation who is over 18 years old, living in Australia and was diagnosed with HIV within approximately two years prior to enrolment.

Aims of the study

The study has been running since 1992 and continues to make a real difference to the lives of people affected by HIV, including by:

- Providing information to support health promotion for those affected by HIV;
- Assisting with the prevention of HIV and support for those dealing with a recent HIV diagnosis; and
- Highlighting current gaps in policy and program development and implementation including opportunities for new research.

METHODS

During the course of the study, both qualitative and quantitative data collection and analysis were used involving in-depth interviews and survey questionnaires; however the focus for the most recent 12 months has been more quantitative. People who had recently been diagnosed with HIV infection were invited (through survey promotional material or by referral) to visit a website where they could find out more about the study and choose to enrol in the study by completing an online questionnaire. On completion of the survey, respondents were then invited to volunteer for a face-to-face in-depth interview at their convenience.

Ethics approval was obtained from the University of New South Wales and La Trobe University.

Eligibility

Eligibility criteria for the study include: Being 18 years of age or older; having been diagnosed as HIV-positive for the first time within two years prior to enrolment; and living in or having been diagnosed within one of the participating seven states or territories. Before June 2010, an additional eligibility criteria was that respondents be male. As we cannot distinguish from clinical records in the study whether someone has recently acquired HIV, we have opted to enrol all those who have recently been diagnosed and we ask a number of questions to determine how recently they may have been infected, such as date of previous test and CD4 count at the time of diagnosis. In jurisdictions where the Seroconversion Study has not been a regular feature of local surveillance activity, the requirement that the diagnosis had occurred within a maximum of two years prior to interview was somewhat relaxed.

Recruitment

Enrolments occurred through four main services: referrals from state AIDS Council staff; recruitment from state-based PHIV organisation staff; referrals from clinics (mostly sexual health services); or direct online enrolment by individuals who have found a link to the survey posted on another website (Table 2). Most of the referrals through community organisations were for clients participating in programs specifically targeting newly diagnosed individuals, such as the various Genesis and Phoenix programs. The state distributions of these referrals largely reflected which organisation's staff members had primary responsibility for these programs. In NSW, most of the referrals were through ACON, whereas in Victoria they mainly came through Living Positive (Victoria). In Queensland, where the Genesis-type program AWARE is in its formative stages, most referrals came through clinic sites (however initial indications are positive for recruitment from the AWARE program). Online referrals mainly occurred through links posted on the websites of state-based AIDS councils or PHIV organisations, or their national peak bodies – AFAO and NAPWHA. There were no such links on clinic websites.

Table 1: Referral source

N=551	n	%
AIDS Council website	121	22.0
Other online referral	91	16.5
PHIV organisation staff	67	12.2
PHIV organisation website	65	11.8
AIDS Council staff	57	10.3
Sexual health service	49	8.9
Workshop (e.g. Genesis, Phoenix, AWARE)	29	5.3
Medical practice	24	4.4
Press advertisement	9	1.6
Other/unknown	38	6.9

Although historically there was the opportunity for participants to complete the survey questions in hard-copy form, the questionnaire has moved to an online only format.

Online survey

Participants completed an online questionnaire to enrol into the study. The questionnaire included demographic characteristics, details of their diagnosis with HIV, sexual relations at the time of their HIV infection, details of what occurred on the occasion they believe led to their HIV infection, details of the person from whom they acquired their infection, their sexual and drug use behaviour in the six months prior to their HIV infection, their beliefs about HIV and risk both prior to their HIV diagnosis and currently, sources of support and contact with the community and measures of mental well-being. There were a number of open-ended questions in the survey, which allow respondents to provide detailed responses; some of those responses are presented in this report to help illustrate common themes and patterns or in some cases, of uncommon or atypical cases.

In-depth interviews

In-depth interviews were conducted with participants who volunteered for these interviews after completing the online survey. While the focus of the interview was similar to that of the online questionnaire – a description of the occasion when they believe they were infected with HIV, and of the person from whom they acquired HIV – they were also asked to compare this event to similar events at that time when they had not put themselves at risk and to reflect on what was different about those occasions and why they had made different decisions. They were then asked to describe how they felt about their HIV diagnosis at the time and what effect it had on their lives and their behaviour, both then and more recently.

Just under a third (30.0%) of participants volunteered to participate in the qualitative component of the study. In particular, female and heterosexual participants, and those from less populous jurisdictions, are encouraged to participate in the qualitative component to ensure that the study can adequately account for these situations and reflect the circumstances of these participants, despite their small numbers.

ABOUT THIS REPORT

A substantial study report was released in 2012, which provided a comprehensive look at the data collected to that date. Since that report was released there have been a further 88 survey responses from men who acquired their infection through sex with another man. However, a significant effort was also made during this past year to re-orient the study to reflect the recent changes in emphasis with HIV prevention.

In this report we have chosen to focus on the following key areas:

- The relationship between the participant and the person from whom they contracted HIV.
- Use of risk-reduction strategies
- History of HIV testing
- Participants' perspectives on HIV treatment decisions

Table 2: A description of the sample

	n (%)
All men	551 (100.0)
State	
New South Wales	202 (36.7)
Victoria	144 (26.1)
Queensland	111 (20.1)
Western Australia	35 (6.4)
South Australia	26 (4.7)
Australian Capital Territory	16 (2.9)
Tasmania	6 (1.1)
Northern Territory	3 (0.5)
Overseas	5 (0.9)
Not provided	3 (0.5)
Age at diagnosis (years)	
Under 25	78 (14.2)
25–29	103 (18.7)
30–39	190 (34.5)
40-49	111 (20.1)
Over 50	36 (6.5)
Not provided	33 (6.0)
Sexual identity	
Gay/homosexual	497 (90.2)
Bisexual	38 (6.9)
Heterosexual	9 (1.6)
Other	1 (0.7)
Not provided	6 (1.1)
Education	
Less than university level	253 (45.9)
University undergraduate level	179 (32.5)
University postgraduate level	110 (20.0)
Not provided	9 (1.6)
Country of birth	
Australia	393 (71.3)
Other	152 (27.9)
Not provided	6 (1.1)
Relationship status at time of high-risk event	
In regular relationship	180 (32.7)
Not in regular relationship	267 (48.5)
Not provided	104 (18.9)

HIV INFECTIONS BETWEEN REGULAR MALE PARTNERS

Historically, Australian studies of recently HIV-diagnosed gay men have found that between a quarter to half of infections occurred as a result of sex with a regular partner. Little is known about the relationship with that partner.

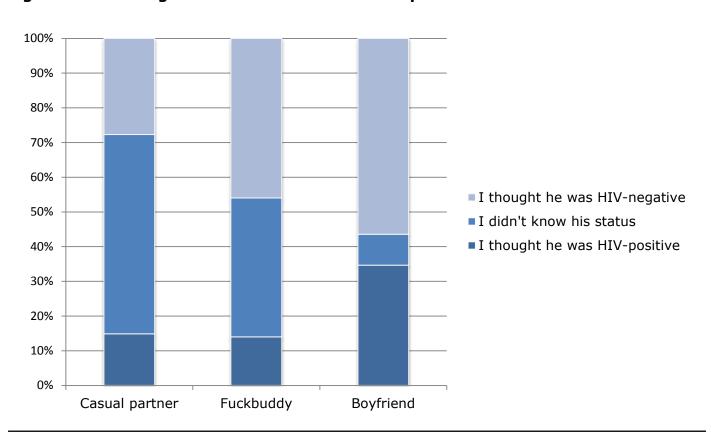
In contrast to what has been observed in earlier findings from the Seroconversion Study, the majority (62.4%) of men report sex with a casual male partner on the occasion they believe they acquired HIV. For another 22.0%, this was through sex with a fuckbuddy, while just 11.4% indicated it was through sex with their 'boyfriend'.

Table 3: Type of partner considered the source person

N=460	N	%
Casual partner	287	62.4
Fuckbuddy	101	22.0
Regular partner/Boyfriend	49	10.7
Other	18	3.9

When compared with those men who acquired their infection from their boyfriend, men who believed a fuckbuddy to be the source of infection were less likely to describe that person as someone they knew well (33.7% versus 79.2%; p<0.001), and more likely not to know the HIV status of that partner (40.2% versus 8.7%; p<0.001). Only 6.4% reported that the source of their infection was a boyfriend of more than three months standing.

Figure 1: Knowledge of HIV status of the source person



Few gay men appear to acquire HIV from long-term committed regular partners. This reflects a similar finding from the HIM study that men in a negotiated safety type relationship are not at significantly increased risk of infection (Jin et al. 2009). In earlier versions of the Seroconversion Study "regular partners" were not separated into "boyfriend" and other types of regular partners such as fuckbuddies. This may account for the smaller proportion of regular partners being responsible for transmission in this version. However, it is also possible that the information provided to gay men about how to effectively manage a negotiated safety agreement with their regular partner helped to make such arrangements more effective than was the case in the past, and assisted in increasing the proportion of men in relationships who know their HIV status.

Tools to assist gay men in negotiating more effective agreements in short-term and non-committed relationships may further assist in HIV prevention. Also, PrEP may eventually offer an appropriate alternative option for some men in these situations.

LITTLE EVIDENCE OF RISK REDUCTION STRATEGIES

Typically, HIV-negative gay men report being more likely to take the insertive rather than receptive role in unprotected anal sex (UAI) (Prestage et al. 2005, Van De Ven et al. 2008). Also, many HIV-negative gay men restrict incidents of UAI to partners they believe to also be HIV-negative (Mao et al. 2006). Given that taking the insertive position and serosorting present less risk for acquiring HIV (Jin et al. 2010), we set out to explore whether men who recently seroconverted also employed these strategies on the occasion when they believe they were infected.

Most (460; 83.5%) respondents described an occasion when they believe they were infected. Of these men, 63.5% report having engaged in receptive UAI on the occasion they believe they acquired HIV, including 42.6% who reported their partner ejaculating in their rectum, compared to 32.4% who reported only insertive UAI. A small number did not report UAI on the occasion they believe they were infected.

Nearly half (46.9%) reported not knowing the HIV status of their partner on that occasion, while 32.4% reported he was HIV-negative and 16.3% that he was HIV-positive.

Table 4: Sexual behaviour at the high-risk event

N=460	n	%
Any anal intercourse	419	91.1
Any unprotected anal intercourse	357	77.6
Receptive anal intercourse	345	75.0
Receptive unprotected anal intercourse:	292	63.5
withdrawal	105	22.8
with ejaculation	196	42.6
Insertive anal intercourse	188	40.9
Insertive unprotected anal intercourse	149	32.4
Reciprocal anal intercourse	116	25.2
Reciprocal unprotected anal intercourse	94	20.4

Note: Items not mutually exclusive. Includes only those men who reported sex with another man at the high-risk event

Among recent seroconverters there is little evidence of the use of any risk reduction strategies during the event they believe led to their infection. Given that risk-reduction strategies offer some protection, men's failure to employ such strategies may be a significant factor in why these men were infected by HIV on those particular occasions. Increasing community understanding and acceptance of risk reduction practices may help men more consistently apply methods to reduce their risk of acquiring HIV.

Comparing occasions of unprotected anal intercourse with casual partners in the Seroconversion Study with those described in the PASH Study

The Pleasure and Sexual Health (PASH) study was an online survey of 2,306 Australian gay men recruited during mid-2009 (Prestage et al. 2010). Men in PASH were asked to describe recent sexual events, both with and without a condom. Men in PASH provided details about their most recent occasion of UAIC and these were compared with events of UAIC that the men in the Seroconversion Study (SCS) described as the event they believe led to their HIV infection.

There were 229 men in the SCS who described a sexual risk event involving UAIC that they believe led to their HIV infection and there were 343 HIV-negative men in PASH who described an occasion of UAIC that had occurred in the previous six months. These two groups of men were compared, both demographically and in terms of their sexual practice, and were found to be remarkably similar. For both groups, their mean age was 37 years and more than half were university educated.

The contexts in which the sexual risk event occurred were broadly similar but in SCS it was more likely to have occurred during group sex (38.1% versus 11.7%).

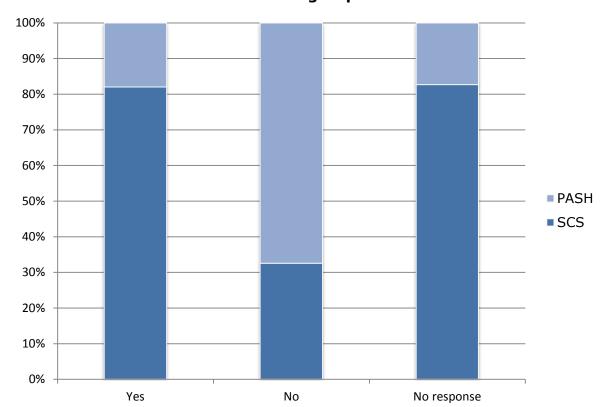
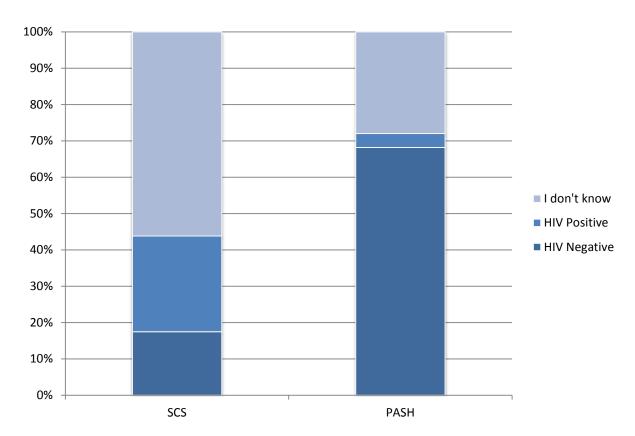


Figure 2: UAIC occurred in the context of group sex

The men in PASH were more likely to engage in UAI with partners they believed to be HIV negative (67.6% versus 26.6%).

Figure 3: Knowledge of HIV status of UAIC partner



The men in SCS were more likely to have been the receptive partner (83.8% versus 63.0%), and more likely to allow their partner to ejaculate inside them (50.0% versus 32.1%). Also, the men in SCS were less familiar with the men with whom they had engaged in UAIC. They were also more likely to report drug use, particularly amphetamine use, on the occasion they believe they were infected.

Table 5: Differences in UAIC events, SCS & PASH

Sexual Position at UAIC Event	SCS (%)	PASH (%)
Any receptive UAI	83.6	63.0
Familiarity with UAIC Partner		
Just met on this occasion	71.7	39.7
Someone I had met recently	20.5	17.5
Previously well know to me	7.9	39.9
Previous Sex with UAIC Partner		
No previous sex with this person	79.9	51.3
Drug Use at UAIC Event		
Amyl	37.6	28.6
Crystal	18.8	1.7
Ecstasy	10.5	6.4
Viagra	13.5	11.7
GHB	9.2	2.0

So, overall, men who reported UAIC on the occasion they believe they were infected with HIV tended to have done so in the context of group sex and drug use, with partners with whom they were less familiar and whose HIV status tended to be unknown or even HIV-positive. They also tended to take the receptive position on that occasion. These characteristics did not apply to occasions of UAIC reported by HIV-negative men in PASH who had not been infected as a result of that sexual encounter.

Men's history of HIV testing

Here we report on men's testing practices prior to their diagnosis with HIV including their testing history, factors associated with a history of having ever tested, or having recently tested.

Three quarters (76.7%) of the men indicated they had had a prior HIV test, which had returned a negative result, including over half (52.6%) having been tested within the twelve months prior to their HIV-positive diagnosis. Men who had been tested more recently were: more likely to identify as gay or homosexual; more socially engaged with other gay men; more optimistic about the consequences of an HIV infection; less concerned about HIV transmission; and more confident in the use of undetectable viral load to lower the risk of HIV transmission. In multivariate analysis, only the level of social engagement with other gay men (p=0.002) remained independently associated with having recently tested prior to HIV diagnosis.

Table 6: Factors associated with recent HIV testing

	Tested in previous	Not tested in
	12 months	previous 12 months
Sexual identity	n (%)	n (%)
Not gay or homosexual	16 (32.0)	34 (68.0)
Gay or homosexual	250 (54.8)	206 (45.2)
Education		
Not university educated	123 (51.7)	115 (48.3)
University educated	143 (53.4)	125 (46.6)
	mean (SD)	mean (SD)
Age	33.8 (9.26)	34.9 (9.88)
Level of social engagement with gay men	4.34 (1.61)	3.66 (1.63)
Health optimism	10.13 (2.54)	9.19 (2.47)
Transmission optimism	5.37 (1.78)	4.93 (1.54)
Viral load optimism	2.11 (0.79)	1.92 (0.76)

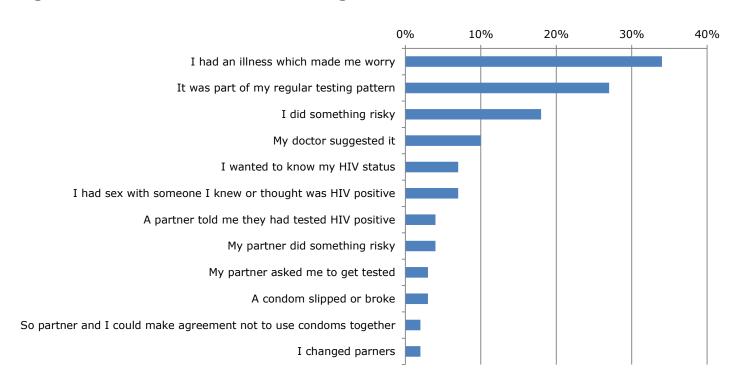
We asked the men who had not tested for HIV in the twelve months prior to their diagnosis why they had not been tested in that time. The two most common reasons men provided were: not having experienced any symptoms of possible seroconversion; and being afraid of testing HIV-positive (Figure 5). Other men reported not testing because they 'didn't want to know', or they did not believe they had put themselves at risk. More practical barriers, such as difficulty in finding the time and concerns about the costs involved, were also cited by some men.

Figure 4: Reasons for not having tested in the 12 months prior to diagnosis



When asked about what had led them to be tested for HIV at the time of their eventual HIV diagnosis, men most commonly cited concerns about symptoms they were experiencing, or they indicated that it was part of their regular testing pattern (Figure 6). Few men (one in six) reported that they were motivated to test due to concerns that they had engaged in behaviour that may have put them at risk of acquiring HIV, despite the fact that most of them reported having actually engaged in UAI on the occasion they believe had resulted in their HIV infection, and often this was with a partner whose HIV status they did not know.

Figure 5: Reason for test at time of diagnosis



In these data, men who were more socially engaged with other gay men were more likely to have been tested in the twelve months prior to their diagnosis with HIV. This finding demonstrates the continuing important role that peer networks and gay community have in the Australian response to HIV (Dowsett 1993). A history of engagement with the epidemic has provided gay men with high levels of technical knowledge, which combined with lived social experience, has helped maintain relatively low levels of HIV infection (Race 2003).

Men who are more socially and sexually connected with other gay men are more likely to have stronger support networks, which may help allay some of their fears about testing, as well as reinforce knowledge and beliefs about benefits of knowing one's HIV status. On the other hand, men with limited social engagement with other gay men have fewer opportunities to benefit from the knowledge and experiences of their peers, while feelings of isolation and lack of awareness of support services for gay men or people with HIV may contribute to some men reporting they 'do not want to know' if they are HIV-positive. Uninformed fears about the realities of what it means to live with HIV today may exacerbate men's reluctance, both of testing and of knowing their status. These could be alleviated by increasing awareness of the realities of living with HIV in the context of more tolerable and effective treatment options, along with work to reduce HIV stigma. Additionally, ongoing HIV prevention efforts must address the needs of non-gay community identified men.

For many men, the waiting period between having their blood taken and returning for their result can be a particularly stressful time; while for others the need to discuss their sexual behaviour with a health professional may be challenging or uncomfortable (Prestage et al. 2012). Alternative testing options, such as better access to rapid testing, community-based and peer-based testing sites that are convenient and confidential, or home testing, could encourage those men who have not (recently) tested to do so (Pedrana et al. 2011, Bavinton et al. 2013).

The fact that few men reported concern that they had engaged in behaviour that they considered 'risky' as a reason for having sought testing at the time they tested HIV-positive suggests a disjuncture between many of the men's perceptions of HIV-risk practices and their actual sexual practices. Further education about relative risk, including access to the sophisticated educational tools that are available to help men assess the level of risk involved in particular sexual practices (ACON 2012) would likely address this issue.

Many of the barriers to HIV testing described by the men in this study could be lessened to some extent through community development and mobilisation interventions. Community outreach and engagement strategies by peer educators has been effective in increasing sexual health awareness, reducing stigma, and increasing the uptake of sexual health services among men attending gay community venues (Williamson et al. 2001). Peer education workshops have played a crucial role in community-based HIV prevention for more than 25 years and have been demonstrated to increase the perceived sexual health capacity of participants (Bavinton et al. 2013).

DISCUSSING HIV TREATMENT DECISIONS

In participant interviews we ask men about their perceptions, understandings and expectations of ART, and explore how these influenced their decisions and attitudes towards the commencement of treatment. Here we present a selection of their narratives about any decisions they may have made about ART. In order to preserve the anonymity of participants, pseudonyms are used throughout.

About half of the men interviewed had begun treatment, while the other half had chosen to wait. Among those who had chosen to defer treatment, all acknowledged that they would eventually be required to take ART. There was no difference in the average time between diagnosis and time of interview, nor in the participants' age and their likelihood to have begun treatment.

Those men who had not yet begun ART spoke about their concerns regarding the prospect of treatment. Themes that emerged included: concerns about possible side effects; uncertainty in decision making; maintaining a sense of control over health and body; anxiety over treatment commitments; and infectiousness, both in the context of established relationships, and for the benefit of the community more broadly.

Even those men who appeared to have little knowledge about the advances of HIV medicine prior to their diagnosis were encouraged by discussions with their doctor about the evidence around benefits of early treatment – both on their own long-term health, and in reducing their infectivity to others.

Brian, 27: [My doctor] explained to me a bit about HIV and [that] there is a way to live a healthy life - like normal people's life. And, like [HIV] wasn't, it is a big deal but it is not that big anymore. I mean it's something we have to be aware and to be careful, and to, you know, protect all the people of, but it's not because I am HIV positive that I would die in the next six months - and that was my main concern, I thought I would be dead by now. I started the medication three months after [being diagnosed], so - a short time. And the studies show that, if you take the medication within six months of the infection, you actually have longer life expectancy, less risk to spread the disease, better chance to live well. So when the doctor told me, suggested me to be on medication, I thought it was a good idea.

While doctors were the most important source of advice about when to start treatments, there was considerable variation in the advice that men received from their doctors. When provided with information about potential harmful consequences, such as side effects and developing resistance, these were considered alongside the men's own feelings and instincts to inform their decisions to treat.

Chris, 35: Personally, I don't know, I'm not a doctor but, I thought it would be good to start straight away because it stops your immune system from getting attacked in the first place. But then, as my doctor explained to me, the, the toxic-ness of some of the medication that, if you're on it for an extended amount of time, it could lead to kidney failure, that sort of stuff. So she said the debate is, she goes, "Not everyone will have those symptoms," but she goes, "The debate is whether to leave you without the medication so you don't get a resistance or anything like that to it." Me, personally, I thought straight away would be the best bet, to start it straight off and stop the HIV from attacking your body to start with. And then that way your immune system's not damaged. But I'm not sure if that's how it works. That's just me guessing, yeah.

Adjusting to being HIV-positive, coming to terms with illness and their potential to transmit their virus to others, was a difficult time for many. For some, initiating treatment restored their feelings of health and wellbeing, and reduced their anxieties around their own infectiousness.

Brian, 27: [After my diagnosis], it was quite a rough time; rejecting myself and being worried about my health every morning, every hour, every single time of every second. [Since I started medication, I'm] feeling better, not feeling as tired every day, and starting to feel like I'm not gonna spread the disease every time I would open my mouth or every time I would do anything. Starting to feel like safe for myself and for the others.

About half of the men spoke about some of their reasons for choosing to delay starting treatments. Many of the men had learned how to interpret clinical markers such as viral load and CD4 count and relied on these as an important indicator of the time to treat.

Keith, 29: I'm not gonna pretend that I understand what the retroviral treatments do. I don't know. I wish I could do my CD4 count every day. 'Cause as soon as it starts to drop, that's when I will be like [Clicks fingers] getting signed up [to treatment].

Some described a preference to work at supporting their own health through other means; maintaining their clinical markers within a healthy range became a priority, and a source of pride. Concerns about treatments appeared to be based on things they had heard about others' experiences.

Eric, 31: I don't know if 'proud' is the right word but I'm very satisfied that my viral loads and CD4 are good. And I intend to do anything I can to maintain that. So that's an absolute mission, goal of mine. There was quite a fear at first for me of going onto treatment. I don't want to go onto treatment. I want to avoid that as long as I can. Part of that was the perception of, you know, reading of other peoples' experiences of being on treatment.

To try to process all information about potential benefits or harms of early treatment was overwhelming for some. Though there were men who wanted to learn a great deal about HIV medicine, others chose not to allow this to take up a great deal of their time. While the idea of controlling viral replication was appealing, men considered this against other priorities in their lives, monitored their health and sought the advice of their doctors, accepting that a time would come when they would begin treatment.

Sean, 27: I've purposely not done the research on the medications, because I don't need to at this stage. So I'm finding out what I need to know and what people tell me, and there's a part of me that would love to be on medications 'cause it means I'm undetectable but there's a part of me that also goes, I'm healthy, you know? Let me get my life set up before I start medication 'cause it's like a couple of times during the day type of thing.

Even for those who accepted treatment as an inevitability, the decision to begin treatment was considered a significant milestone, and a reminder of their illness.

Corey, 24: Medication I thought was always a given. It was always going to happen and I was quite prepared to, you know, to take medication. However, it was sort of like being diagnosed all over again when she said, "I've got your bloods back. We really, really need to start talking about medication and treating it."

Concerns around the practical aspects of taking ART, such as adherence, remain a source of anxiety for some:

Jim, 54: I was pretty apprehensive at first and that's probably why I didn't want to start at first as well, 'cause I, I didn't know how many tablets and when, and how often they were gonna be required to be taken. And yeah, it was pretty daunting the thought of starting treatment.

While for others, the burden of ART was insignificant, when considered against the alternative of not having treatment.

Kevin, 47: Take medication once a day. But to be honest with you, I don't think about having HIV. It's like it doesn't come into mind at all. Whatever you have do - you do what you have to do, don't you? It's either that or die. I don't think taking three pills a day is such a big ask. It's either that or die in five years'.

Despite hesitations about taking medication, information men had heard about reduced viral load, and the potential for this to reduce their infectivity to others was a sufficient motivator to encourage them to commence treatment.

Garry, 29: Initially, I didn't want to 'cause I don't like taking pills at the best of times. But then yeah, the doctor was saying, "Look, this is probably a, a good thing to be on it," and explained why, why they put people on treatments and what it all does. Then

I'd heard about the, the Swiss study, about the people with undetectable viral loads were almost 'safe' so to speak. Or that it was what seemed to be shown, you know, or significantly safer. So yeah, I thought, "Actually, that sounds like a much better idea." ... now on medication, undetectable viral load and, and good CD4 counts – or health in general, actually, is probably better now than it was before I was diagnosed.

Others were aware of community discussion and education about the evidence of treatment as prevention, but remained sceptical.

Sam, 42: Well, if my numbers keep staying the way they are, it'll be a long time since I even need to think about treatment. Whilst yes I know the discussion and I saw the ads, and everything else about, you know, the whole thing about going onto treatments early. ... I was explaining to somebody the other day, 'undetectable' does not mean you don't have it anymore or you can't catch it; it just means that it's a lot harder to or it's, it's more, you don't have as much virus to, to pass on.

This uncertainty was also felt by Jim, who chose to continue to rely on other precautions to reduce his risk of onward transmission.

Jim, 54: I think it's less of a risk passing it on with undetectable but it is still a risk. And it's not like well it's undetectable, we don't have to take precautions now. Yeah, that's, still gotta, gotta take precautions.

As well as doubts of the evidence of treatment as an effective tool in prevention, Bill expressed caution about promoting this public health aspect of treatment as prevention, feeling that to mandate that someone go on treatments was unethical, and risked the marginalisation of those men not on treatments.

Bill, 30: I don't think you can force anyone to take medication anyway. Yeah, I don't know. I mean, you know, there is still a risk that someone with an undetectable viral load can pass it on anyway. Like it's not a prevention. The prevention is, you know, either not having sex or using a condom and getting tested. And getting tested regularly I think is just really, really important. They're probably the best ways I could think of. Yeah. I mean I don't think, to have that imposed on you I think would be, I don't know, I don't think it would be right.

While scientific evidence of the benefits of early treatment is driving considerable shifts in HIV treatment policy, little is known about the extent to which PHIV have accepted that science, or its implications. The success of attempts to increase initiation of treatment will rely on their having some resonance with those being asked to make decisions around treatments.

While about half the men interviewed in the Seroconversion Study had embraced ART, a significant proportion of men expressed negative perceptions about treatments, including fears of harmful side effects, doubts about their need to be on medication, frustration over their inconvenience, and anxiety around the need for strict adherence (Gold and Ridge 2001, Cooper et al. 2002, Kremer et al. 2006, Horne et al. 2007).

Community apprehension around ART acts as a barrier to informed discussions about treatment options. Some men's doubts about the benefits of treatment appear to be based on an underlying skepticism of medicine generally, and a lack of knowledge of HIV medicine specifically. The unease many men in this study had about choosing to begin treatment suggests there is a lack of current, accurate information available to counter their fears. HIV medicine has historically been perceived as volatile. A 2006 review of Australian community-based HIV media described their tendency to portray developments in treatment strategies framed in uncertainty, doubt, detachment, and scepticism (Newman et al. 2006), though it must be acknowledged that more recently, advances in HIV treatments have been framed in a more positive way. Nonetheless, we do not have all the answers about long-term side effects, and indeed we know that there are some long-term side effects for some. As such, it is important that the considerable advances in ART made over the last fifteen years, and their health benefits (both at the individual and population level), are accurately and effectively communicated.

It is well documented that effective communication between clinicians and patients is central to better health outcomes (Beach et al. 2007, Mallinson et al. 2007, Gregory et al. 2011). These findings highlight the relationship between the patient and their doctor as a critical component of starting ART, and demonstrate the importance of doctors providing information to patients that is easy to understand, individualised and based on medical, social and other impacts of decisions around treatments.

The role of the doctor remains key; in none of the interviews did any participant mention that they were choosing to defer ART against the advice of their doctor, or in spite of clinical markers indicating that treatment was required. The decision to defer treatment may be a logical and understandable response to the individual's preexisting beliefs about ART.

Some PHIV choose to defer treatment based on rational, legitimate and well thought through reasons with the help of their doctors and by using other sources of information such as the Internet. The primary purpose of ART is to constrain disease progression in PHIV, and ultimately the individual must choose if and when they engage with it. While the preventive effect of ART on HIV prevention continues to generate substantial debate (Mayer and Venkatesh 2010, Smith et al. 2011, Jia et al. 2012, Smith et al. 2012, Nosyk et al. 2013), the significant evidence cannot be ignored (Cohen et al. 2011, Murray et al. 2011, Nosyk et al. 2013). Altruism, and appealing to men's potential role in reducing HIV transmission may be factors when making decisions about when to begin treatment. Promoting treatment for public health goals and individual goals are not mutually exclusive. Most men express

a personal desire not to feel infectious, and accept that feelings of infectiousness can be relieved by being on treatment. While public health goals need not be a primary motivator for initiating treatment, it carries this additional, complementary benefit.

Conclusions

Sex with unfamiliar partners

- Strategies and tools to assist gay men in negotiating more effective agreements in shortterm and non-committed relationships may further assist in HIV prevention.
- PrEP may eventually offer an appropriate complementary option for some men in these situations.

Applying risk reduction

- There is little evidence of the use of any risk-reduction strategies among the men during the event they believe led to their infection.
- Men at high risk may benefit from tools to assist them in consistently applying methods to reduce their risk of acquiring HIV.

Encouraging earlier testing

- The Seroconversion Study demonstrates the value gay men derive from being connected to networks of support and information, to address their fears and lack of knowledge.
- Community-based, peer-focussed programs have a role to play in strengthening the
 capacity of gay men to reduce the spread of HIV, challenge negative beliefs about testing
 and treatment, as well as diffuse and reinforce attitudes about the benefits of knowing
 one's HIV status.
- Importantly, HIV testing policy should remove structural barriers that restrict men from accessing testing.

Concerns about HIV treatments

- Health departments, community organisations and clinicians should consider appropriate
 ways to successfully articulate the true experience of what it means to be on ART, by
 facilitating more accurate discussions around the realities of HIV treatments, and the
 benefits of early treatment.
- Men's perceptions of HIV treatments vary greatly. Doctors should actively investigate their patient's feelings about treatments and tailor their intervention accordingly.
- Any efforts to encourage more men to initiate treatment must respect that the individual makes the choice that is right for them, and avoid stigmatising those who decide not to treat.

RECOMMENDATIONS

For the Seroconversion Study

- Continue the investigative focus on the areas highlighted by national and state HIV Strategies. This is particularly critical for areas where the current trend is running counter to the intention of the strategies (e.g. increasing UAIC among gay men).
- Further investigate both biochemical and behavioural risk mitigation including PEP, PrEP,
 TasP, other serostatus/viral load related strategies (strategic positioning, serosorting) and the interrelationship between these strategies.
- Continue to investigate the barriers to testing with a view to reducing the lag between infection and diagnosis.
- Specifically explore the use and experiences of treatment following diagnosis particularly given the recent push for earlier treatment and the centrality of effective (and compliant)
 ART for a number of the emerging risk mitigation options.
- Further examine the psychological and sexual well-being of men post-seroconversion (particularly given the rapidly changing treatment and prevention environment). Questions of disclosure after diagnosis and the peer/family support of men post-diagnosis also require further investigation.
- Explore issues related to contact tracing immediately post diagnosis; particularly given
 what is now known about onward transmission among men with undiagnosed infection,
 and changes in sexual behavior post diagnosis.

For policy and program development

- Continue to incorporate the new HIV infection risk mitigation technologies into future public health policy, planning and program implementation. The question of the relative merits of condom use versus other risk mitigation strategies remains a fraught one requiring further research. What is unarguable is the shift in the perspectives and behaviours of at-risk populations towards more nuanced risk decision making.
- Continue to support research into new testing and biomedical prevention technologies with a particular focus on how broad and accessible implementation can positively contribute to the established outcomes described in the various HIV Strategies.
- Continue to address the structural and psychological barriers to testing. The importance of an individual being able to conveniently and unproblematically access a fast and free HIV test cannot be overstated.
- Similarly to testing, continue to address the structural and psychological barriers to treatment uptake.
- Ensure at-risk individuals have access to accurate and current information on the HIV epidemic, how infection risk can be managed and treatments available.
- Provide both clinical and community support for PHIV initiating and continuing with treatment.
- Further investigate ways that risk-reduction behaviours can be promoted in the community in concert with health promotion efforts to destignatise HIV and PHIV.

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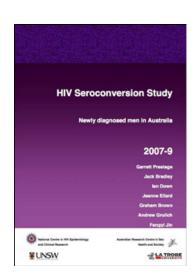
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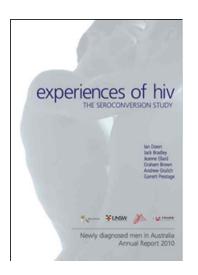
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Three earlier reports from the Seroconversion Study can be found on the study website: www.hivss.net.









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