experiences of hiv

THE SEROCONVERSION STUDY

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FINAL REPORT 2007–2015

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Collaborating organisations

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 (PLHIV) organisations in each state and territory.

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Glossary

ART	antiretroviral therapy/treatment
ATSI	Aboriginal and Torres Strait Islander peoples
CLAI	condomless anal intercourse; previously referred to as unprotected anal intercourse (UAI)
CLAIC	condomless anal intercourse with casual partners; previously referred to as unprotected anal intercourse with casual partners (UAIC)
CLAIR	condomless anal intercourse with regular partners; previously referred to as unprotected anal intercourse with regular partners (UAIR)
Fuckbuddy	repeated sexual partner with whom one has sex on an ongoing basis, not necessarily involving an emotional attachment
HAART	highly active antiretroviral therapy
High-risk event	the event that a participant believes led to him acquiring HIV
HIV	Human Immunodeficiency Virus
PLHIV	people living with HIV
PEP	Post-exposure prophylaxis
PnP	party and play
PrEP	pre-exposure prophylaxis
RRS	non-condom based HIV risk reduction strategies
STI	sexually transmissible infection
TasP	HIV treatment as prevention
UNSW	University of NSW

Executive Summary

The Seroconversion Study has existed in several forms since 1992. This most recent version completed data collection in 2015. Seroconversion studies have played an important role in the Australian HIV response and are a useful research tool in understanding the current circumstances of HIV infection. This version of the Seroconversion Study occurred at a time of rapid and fundamental changes in our understandings, and implementation, of HIV treatment and prevention. As with previous versions of the study, it mainly targeted gay and bisexual men (GBM). However, some limited data were collected from women and heterosexual men in this current version.

As the Australian HIV sector faces the challenge of achieving the virtual elimination of HIV transmission, the insights those who have been recently diagnosed with HIV provide through this report will help to address the challenges posed by the changes in biomedical prevention, treatment, and testing. Until recently, the annual number of new HIV diagnoses has not decreased (both in terms of raw number per year and as a percentage of population). Testing rates in key populations had also changed little. Uptake of treatment, and viral suppression, among those living with HIV had, however, steadily increased over time. However, recent advances have begun to see some early signs of shifts in these long-term trends. Innovations to how HIV testing is delivered have provided a greater range of options for individuals to seek testing than was previously the case. Both Treatment as Prevention (TasP) and Pre-Exposure Prophylaxis (PrEP) offer effective methods of HIV-prevention that can complement condom use. The benefits of early initiation of treatment for the health of those with HIV have become increasingly clear, and are now firmly established. Combined, these changes offer a real possibility of achieving the virtual elimination of HIV transmission in Australia. Apart from structural limitations, the main challenge to achieving this goal is how at-risk individuals respond to these changes: Can they, and will they, make the necessary adaptations to these changes that will make them both effective and successful?

In this context, the Seroconversion Study has provided both qualitative and quantitative data from those individuals who have been diagnosed during this highly dynamic period of the epidemic, and as these innovations to and new knowledge about treatment and prevention have been introduced.

Summary of the findings

Since this version of the study commenced, in December 2007, a number of major findings have come out of the study:

- Online technologies provided an effective method to overcome barriers to participation in a seroconverter study. We were able to recruit at least twice as many participants per year to this version of the study than had been achieved in any of the previous versions. Among homosexually active men, this represented approximately 10% of annual diagnoses.

- 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.

- On reflection, most men were satisfied with how they were tested and how they received their positive diagnosis. Those who indicated they would have preferred something else tended to prefer various options, supporting the argument that a range of testing options are needed to suit individual needs.

- Knowledge of post-exposure prophylaxis (PEP) at the time of their HIV infection was surprisingly low among these recently diagnosed individuals.

- Few HIV infections among gay men are attributable to sex with their primary regular male partner (or ‘boyfriend’). HIV is far more likely to be transmitted via sex with a casual partner or a ‘fuckbuddy’. Indeed, HIV infection is most likely to occur in the context of sex with a new partner, with whom they have had no prior sexual contact.

- 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.

- Only a quarter of gay men who were in a relationship at the time of their HIV infection ascribed their infection to that partner, and very often when they did, their relationship had been only recently established.

- After diagnosis, and for some time thereafter, most gay men with HIV dramatically change their sexual behaviour in ways that would likely minimise the possibility of onward transmission. These changes included partner reduction, partner selection (serosorting), disclosure of HIV status, and reduced likelihood of condomless sex.

- Some individuals felt that their mental health had deteriorated since their diagnosis, and they also often reported other changes in their circumstances (relationships, sexual behaviours, personal networks) that may have contributed to this deterioration. A substantial number of those who had been recently diagnosed had not disclosed their HIV status to anyone, or to only a very few people, presumably contributing to a sense of isolation.

- Access to peer-support after diagnosis was a key predictor of changes in sexual behaviour, disclosure of HIV status to others, and access to information.

- The decision whether or not to commence ART by HIV-positive gay men 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, 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.

- There was little evidence of substantial differences across the jurisdictions, except those that would be expected. Access to services, for example, reflected the local availability of those services. Among homosexually active men, it appeared that gay community engagement was the more significant factor than jurisdictional differences per se. Specifically, men diagnosed in jurisdictions with more visible and larger gay communities tended to have greater awareness of and access to testing, treatment (including PEP), and support.

- There was also little evidence of substantial changes over time. Among homosexually active men, the types of men, and the circumstances of their HIV infection, appeared to remain much the same over time (though this could change substantially as the current National HIV Strategy is implemented). There was some evidence of growing optimism about HIV treatment and prevention over time, although, in these cases, that increased optimism had not protected them from HIV infection.

The future

The Seroconversion Study in its current format has come to an end. Funding is being sought to develop a new version of the study that will be more closely integrated into service delivery and peer-support for those who have been recently diagnosed with HIV. The focus of this work will be:

- To assess the role and impact of peer-support.
- To continue to identify the circumstances in which individuals are newly infected with HIV.
- To describe people's 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.
- To monitor treatments initiation after diagnosis and the barriers to treatment uptake.

Reflections on individuals’ experiences of HIV

This report anonymously tells the stories of 735 study participants. We also asked HIV organisations to invite some individuals who had been diagnosed with HIV during the study period to offer their own story about their experiences with HIV, outside of the context of the study. Some of their stories follow.

Ross, 45 years old from New South Wales.

I do not recall the exact incident [when I acquired HIV]. I know that it was likely one of several incidents; I had a set of rules that I used to follow to minimise the risk of infection, and I stopped following them. It was a conscious decision, not because I wanted to become HIV+ but because I wanted better sex. I don’t feel any antipathy towards the likely incidents that led to my infection.

[Receiving my diagnosis,] Part of me felt relieved even though I never wanted to be HIV+. The relief was because I felt that I could now continue to have the sex that I wanted without feeling guilty or ashamed. I was comfortable with the diagnosis because I have positive friends and know that they are healthy and fine. It felt quite normal to me, and that’s the same now. Lots of gay people are HIV+ so it is perfectly normal.

I’ve always been a “glass-half full” positive person and that has not changed. I also have no regrets in my life and that has not changed. (I’m not a reckless person, I see all of life as an opportunity to learn; regrets are wasted emotion.) My life now is great, which it was before I was HIV+ to be frank. Ironically my health is better than before because my immune system was always poor, I used to get lots of viral infections, colds, etc., I get very few now that I’m on meds.

Fabian, 30 years old from Victoria, speaking about how he felt when he was given his diagnosis.

Shocked. Stunned. Thinking back, it was like going through the grieving process - the disbelief, the denial, the acceptance and the moving on. The innocent me that I knew was now tainted and changed. I was suicidal and broken. I found that talking to people and giving it time meant that I felt better. Once I got through the dark period I regained my confidence and began helping other people who were newly diagnosed. Now I’m blossoming.

Mark, 36 years old, Queensland, on how his life has changed since receiving his diagnosis.

It’s changed a bit. I now have to bring it up when I think about dating or sleeping with someone. But in all honesty I’ve never been better in my whole life. Since diagnosis I look after my body much more than I ever did before. If I cut myself I do freak out a bit and automatically assume everyone is in danger but I clean myself up and calm myself down pretty easily.

Additionally, we asked Dean Beck, a broadcaster/producer with JOY 94.9 and an ambassador for ENUF (the HIV stigma campaign), to write about his own diagnosis which was revealed in a very public manner in 2015.

Dean Beck, 45 years old from Victoria.

The Seroconversion Study has existed in various forms since 1992, providing valuable insights into the lives of people recently diagnosed HIV-positive. It has charted the sexual behaviours, activities, relationships and attitudes of (mostly) gay men, as they come to terms with the reality of living with one of the most stigmatised chronic illnesses this world has seen.

From the mythological protection of monogamy and sexual positioning to the changing attitudes towards testing and biomedical intervention, the Seroconversion Study reflects the information and misinformation within our communities today. This final report will inform policy-makers, guide health communicators, and provide information to aid the development of targeted responses for those living with, affected by, or most at risk of HIV.

Over the six years that I have been producing and presenting radio, I have managed to carve out for myself a niche as a specialist commentator on gay men's health and HIV issues. As a commentator, this report is great content – pure gold. Almost annually I've waited with anticipation for this report to be published, providing me with hours of air time to debate, debunk, dissect, and disseminate the information contained within.

I can honestly say that being asked to write the preface for this final report is the greatest honour I wish I had never earned. As much as I would like to think I've been asked due to my priceless insights and rigorous analysis over the years, I know the real reason I've been asked is because I received my HIV-positive diagnosis within the last two years – just like every other research participant. I am also acutely aware that too few HIV-positive people are able or willing to declare their status publicly.

During the last two decades, I have been an advocate, an activist, an agitator, and an ambassador for sexual health issues. Throughout, my focus has always been the health and wellbeing of men who have sex with men and their communities. I cannot recall if it was by accident or a process of elimination, but at 11 years of age I discovered beats. It freaks me out to think about it now, but the allure of peering through a hole to watch an endless parade of grown men's penises meant that hundreds of hours went missing between school finishing and me arriving home, just in time for dinner.

It was a time when the nightly news bulletins featured stories of young men in the USA dying rapidly from a mystery 'cancer'. The discovery of HIV as the thing that caused AIDS made the headlines, and countless stories of infected blood killing people who had blood transfusions and haemophiliacs became routine fodder for newspapers globally. To a kid from Bendigo, all that seemed very far away. At the age of 19, having moved to Melbourne to study, I fell in love for the first time and from then on identified as gay. To come to that realisation in 1990 meant one thing only: condoms. Much of my 20s is a heady blur – seven years of working four nights a week behind the bar at Melbourne's iconic 90s gay venue 3Faces will do that to you.

In 2004, I contributed to the launch of the Victorian AIDS Council's ground-breaking campaign *Staying Negative*. Before I agreed to be a part of the campaign I consulted friends and family, all of whom said, 'Don't do it!' The stigma associated with HIV was so great, they feared putting my name and face alongside VAC's logo would mean people would assume I was HIV positive. But I did it anyway, I thought that if my story connected with just one person and empowered them to take responsibility for their own sexual health then it was worth it.

Regardless of peer-reviewed journals and statistical analysis about HIV, my lived experience seemed worlds apart. I had three fuck-buddies with whom I had spent many intimate nights of fun, all revealed in the same week that they had become HIV positive. I have counselled and cradled in my arms, more than a dozen close friends coming to terms with being HIV positive and on two occasions I frighteningly watched someone whom I have had sex with, seroconvert on my sofa. My former 'total top' boyfriend became HIV positive. My 19yo friend who had never engaged in anal sex did too. Yet I remained HIV negative.

Our national HIV response is complicated by the time lag incurred from data collection, interpretation, and publication of reports - often many years go by before policy is enacted. Then governments must fund the response, relying on agencies to creatively develop, test, and implement campaigns that by the time they get to the guy on the street, five or six years might have gone by and the core issues have changed.

Five years ago people were unclear how gay men's consumption of crystal meth was impacting on HIV seroconversion statistics. Whenever I raised the situation it got mixed responses. Thankfully I think most people now understand that it's an issue, even if it's unclear what it means and how to respond. It must be difficult to form an effective campaign when the issues aren't understood very well.

Infuriated with the lack of discourse about HIV in the community, frustrated with expensive HIV campaigns not connecting and filled with despair as one after another of my friends seroconverted, I decided to do something about it. After completing my eight-week basic radio training, I pitched my idea for a show. *'Hide and Seek'* was to be *'your show for exploring sex, sexuality and self'*.

One year, my *Hide and Seek* co-host and I got tested on World AIDS Day prior to appearing on stage at Federation Square in Melbourne's CBD. Whilst live to air and in front of the crowd that gathered to watch, we both revealed our arms and Band-Aids indicated where we had our blood tests earlier that day and saying 'Go and get tested, it's easy see, we've just had ours done'. It was not until I walked off the stage that the thought crossed my mind, 'What if my results come back positive next week? 'What if I fucked up? What happens if I discover I'm HIV positive?' I never pulled that stunt again.

Nine months prior to Melbourne hosting the world's largest scientific, medical and human rights conference - AIDS 2014 - I was appointed the co-ordinator of JOY 94.9's *World AIDS Day Worldwide* project, a global conversation about HIV. At 2pm on the 21st of November 2013 – ten days before World AIDS Day – I was diagnosed HIV positive.

It was like someone had slammed my head between two huge pillows – kind of a massive thud and queasy dizziness came over me. In the room was a Doctor and nurse and the first thing I said was 'So when can I start treatment?' 'Can we at least do your bloods first?' was the smart-arse reply from the nurse, trying to lighten things up a little.

As the sex-positive presenter of JOY 94.9's show about sex, I had never worried about being spotted in the waiting room of the Sexual Health Clinic. Hundreds of visits over the years waiting for a doctor to treat an infection or waiting to get my results never worried me. But now I was HIV positive and it felt like every single person in the place was staring straight at me.

Being so involved with the AIDS 2014 conference was both a blessing and a curse. There was always plenty of work to keep me distracted and avoid dealing with my situation. The conference itself meant being surrounded by the world's best scientists, doctors, researchers and community leaders so one could not help but be inspired and energised. What better time to reveal your positive status, than when surrounded by more positive people in the one spot than ever before? My secret remained.

In some ways though I felt like such a phoney. Only those closest to me were informed of my status while community associates and audiences remained none the wiser. Although the quality of my work on air was not an issue, I felt my ability to authentically deliver my position on issues concerning gay men's sexual health was somehow compromised, as I delicately tried to manage public and private personas.

Of all the interviews, presentations, plenary, and political pontificating captured during the AIDS 2014 conference, it's an interview that one of my JOY colleagues conducted with an HIV-positive, 14-year-old orphan boy from India named Babu that delivered me a much-needed reality check. Regardless of him having HIV, he saw some good that had come out of it. I was amazed by his humbleness and resilience. Babu's parting message was, 'Be happy and don't think that you have HIV. Think that you doesn't have [sic] – think that you are a negative and not a positive. But still, you have to build your happiness and your tabletness [sic]. Thank you.'

Unknowingly, Babu had called me to account. For at least three years I had publicly promoted the mounting evidence that treating HIV as early as possible delivered the greatest outcomes for both the individual and the community at large. Time and time again I had encouraged and supported friends as they took the life-long plunge into the bottomless lifesaving bottle of pills. Although my doctor had written the script for my antiretroviral medication more than three months earlier, I had not yet had it dispensed. It was clear that I was not 'building my happiness or my tabletness.' [sic]

My VAC appointed counsellor was truly amazing. Having had over 28 years of experience guiding people as they came to terms with their positive status, she had pretty much seen it all. Together we navigated my public and private juxtaposition. She constantly reminded me that the only time to start medication was when I was ready to do so. I just wasn't there yet but I just didn't know why? Throughout my 44 years on this planet, my Ventolin inhaler is never out of arms reach – my survival depends on it. Yet 'one pill a day' might just have well read 'I thee wed' for this commitment-phobe. After 12 months, I took the first pill. Of course, that means always taking that pill. Fully aware of the physical health benefits of taking my pill daily, I welcomed the relief that accompanied my undetectable viral load diagnosis.

Just like coming out as gay, disclosing is an ongoing process made awkward when you forget who knows and who does not. Coinciding with VAC's national campaign to get the Therapeutic Goods Administration to approve pre-exposure prophylaxis (PrEP), I revealed my positive status in an online article via starobserver.com.au on the 21st of April 2015, highlighting that if PrEP was available in Australia at the same time as it was in the USA, then I would not be HIV positive today.

It is true that Australia has one of the best HIV epidemic responses in the world. The political leadership, community activation, and peer-led education ensured our national diagnoses remained fairly stable and the population well informed. We should all be very proud of that. It is time for our nation's leaders to reconnect with HIV. I believe we will experience a tipping point with Treatment as Prevention (TasP) and PrEP where the light at the end of the tunnel is viewable by all.

For me, the AIDS 2014 conference marked the beginning of a new decade in the global HIV response. The decade of individual empowerment has begun, where TasP and PrEP drive a new paradigm in personal responsibility and community protection. People Living with HIV are again finding their voice; the tone is empowered and not victimised.

If I have learnt anything from my six years talking about gay men's sexual health in the media, it's that there is always another research study, new data, and an evolving narrative. What was the right thing to do two years ago is no longer the best way forward. There will be no end to HIV if we allow the stigma associated with HIV to exist. Manifestly unwarranted and grossly misguided, the ultimate result from stigma is death.

In the 1990s I lost more than half a dozen of my friends to suicide. They believed it to be the only option, unwilling to place their faith in experimental and emerging science, while exhausted by the endless stigma that living with HIV guaranteed. Today our options are many but stigma remains, impacting all regardless of HIV status. These days my work continues to be shaped by the communities I serve and I remain passionately dedicated to discussing gay men's health issues. The conversation must continue. Since disclosing my positive status publicly my communities, colleagues, family, and friends have been wonderful with their support, encouragement, and love.

My message today is no different from the day I began on radio and if one person gets it, then it's all worth it:

You are responsible for your own sexual health.

In doing so you are automatically being responsible for the health of others.

Get tested regularly.

It will give you peace of mind and is much easier if done regularly.

Should your test come back positive, you are in the best possible situation to ensure excellent health and wellbeing for the rest of your long life.

Introduction

By Paul Kidd

Most gay men in Australia have never known a time when sex did not come with the risk of HIV. The virus is part of us – in a social and cultural, as well as biomedical sense. It has been a ubiquitous and central issue in gay men's lives for more than 30 years; however, our understanding of HIV has not been static. It has changed and evolved. We have, collectively, moved from crisis to grief and on to acceptance of the virus as a long-term reality.

Since 1992, the various iterations of the Seroconversion Study have mapped the changes in gay men's (and, more recently, heterosexual men and women's) understanding of the factors that influence risk behaviour, testing, and coming to terms with an HIV diagnosis.

This section of the report provides a contextual background to the report's findings by outlining some of ways in which our understandings of HIV, risk, pleasure, and safety have evolved over the lifetime of the studies. It reflects on the intertwined ways in which the oft-vaunted partnership between research, community, and government has challenged and been challenged by gay men's sexual practice, shifts in sexual behaviour, and the determinedly tenacious way in which Australian gay men have resisted calls to shut down their sexual lives, and maintained a sexual culture that has consistently asserted a right to pleasure and connection in the face of disease, death, and stigma.

A key theme is the way in which gay men, as the group at greatest risk of HIV and most subject to its stigmatising effects have been able to integrate a sophisticated understanding of risk, and the scientific basis of HIV transmission, into the range of risk reduction practices adopted to prevent HIV transmission. Indeed, the need to continue to find ways to enjoy sexual intimacy in the face of the HIV epidemic has meant that communally-developed risk reduction practices have often been adopted by the Australian gay community well before research demonstrated their effectiveness, and often in the face of stern warnings against them from the medical and research establishment.

The current historical moment – in which highly effective treatment and biomedical prevention technologies combine to make the virtual elimination of new HIV infections feasible – can be seen as the end product of these intertwined processes of examination, reflection and incorporation, and represents a profound political outcome for the gay community. In the most recent development, HIV-negative and HIV-positive gay men have in the last 18 months begun to demand access to PrEP, which represents the latest in a long series of shifts in the way we manage risk in our sexual lives.

This is not to argue an uncritical approval of these processes. HIV infections have continued to occur in gay men, and remain at an unacceptably high level. HIV stigma continues to manifest itself as a destructive force both from outside our community and, sadly, within it. HIV stigma is at its most powerful when it is enacted within the HIV-affected community, and myths and misconceptions about HIV persist despite many years of education campaigns. Gay men whose sexual behaviour is seen as putting themselves or others at risk are seen as problematic, and are shamed, shunned, and criminalised in response. While treatments have made HIV a manageable illness and allow people living with HIV to enjoy healthy, productive lives, people diagnosed with HIV commonly still experience their diagnosis as a moment of profound crisis.

Australia's long tradition of integrating social research into its HIV response has meant that the evolution in community understanding of HIV risk and risk reduction has been described, analysed, and integrated into community HIV sector health promotion messages via a process of 'critical reflexivity' (Kippax and Kinder, 2002). While not unique to Australia, in our country the relationship between the various sectors has been particularly tightly integrated, creating a positive feedback loop in which gay men's understandings of HIV risk is integrated into sexual practices, these are described and analysed via social research, and then reformulated as health promotion messages drawing on scientific knowledge about risk.

We were early adopters of safe sex (i.e. the use of condoms for anal sex) in Australia, and it quickly became the mainstay of the HIV prevention message. Initially proposed by gay men in the US at a time when the causative agent of AIDS was still unknown (Berkowitz et al., 1983), safe sex had already become widely accepted by the time of the newly-formed AIDS Council of NSW's 'Rubba Me' campaign, launched in February 1985 (Sendziuk, 2003, p. 90). At the time condoms started to be embraced, the causative agent of AIDS was still the subject of speculation, and there was no empirical basis on which this early reliance on condoms could be based. But condoms had a considerable advantage over the other options being publicly canvassed as the sense of crisis took hold – quarantining affected individuals, total abstinence, criminalisation of 'high risk' sex acts (Sendziuk, 2003, p. 107). Safe sex meant we could continue to have sex.

'Rubba Me' and the safe-sex movement that followed it should be seen as a significant *political* moment in the history of the Australian gay movement, not just within the context of the HIV response. At a time when prominent AIDS researchers were talking openly about quarantining gay men and proscribing gay sex as mechanisms for containing the epidemic (Sendziuk, 2003, pp.107-110), gay men (and a significant number of lesbians) responded by forming community organisations to promulgate the message that sex could be both safe and hot.

This insistence by gay men on maintaining sexual autonomy, and on the need for culturally appropriate educational messages for the gay community, has been a consistent theme throughout the history of HIV/AIDS in Australia.

By the commencement of the first Seroconversion Study in 1992, the use of condoms and water-based lubricant had become entrenched as the foundation of a culture of safe sex broadly embraced by the gay community. It had a dramatic effect: new HIV diagnoses peaked in 1987 and then fell sharply. AIDS deaths, however, would not peak until 1994, encumbering the community with an escalating burden of illness, death, grief and despair. Michael Hurley has described the period up to 1996 as one of “increasing horror” that left deep psychological wounds in the affected community:

> *The figures do not describe the individual pain and trauma, the multiple hospitalisations, the despair, the courage, the bedside care by volunteers, the funerals or the endurance required of those involved (Hurley, 2011).*

Notwithstanding the universality of the safe-sex message (“Always use a condom. Always,” in 1987’s infamous Grim Reaper adverts; “If it’s not on, it’s not on” in the Ron Tandberg cartoon ads a year later) there were of course always gay men who adapted their sexual practice in response to their own understanding of situational risk. Negotiated safety, an adaptation of the safe sex message in which HIV-negative couples eschew condoms within their sexual relationship on the understanding that any sex outside the relationship must be safe, was first described in the late 1980s and early 1990s (Kippax, 2002) but undoubtedly existed for many years before.

While some commentators expressed alarm at this trend, arguing that it signalled a waning of the safe sex culture, Australian researchers argued that negotiated safety evidenced a sophisticated understanding of risk and a deliberate safe sex strategy, and one that could be considered safe in at least some circumstances (Kippax, 2002, p. 2).

The strong dialogue between social researchers and HIV community organisations meant that negotiated safety was not seen as merely deviant behaviour, but conceptualised as an alternative form of safe sexual practice, provided it was practiced under appropriate conditions. This led to the development, by ACON, of the ‘Talk Test Test Trust’ campaign (Kippax and Kinder, 2002, p. 100), which set out simple criteria for the adoption of a negotiated safety paradigm within male same-sex relationships.

This then is the context in which the first Seroconversion Study commenced. By 1992, gay men had experienced almost a decade of safe sex education, focused on promoting the use of condoms, a form of protection that, pre-AIDS, would have seemed faintly preposterous to most gay men, and which was adopted as a short-term response to the emerging AIDS crisis. As the toll of illness and death continued to rise, it was apparent that HIV would be a longer-term challenge than was at first envisaged, leading to the development of adaptations of the safe-sex message such as serosorting and negotiated safety.

The first Seroconversion Study enrolled 92 recently-diagnosed homosexually-active men between 1992 and 1998. Participants were interviewed and asked to describe the occasion on which they believe they contracted HIV. The intention of the study was to identify the context in which the individual’s seroconversion occurred and the nature of the risks taken, however the context in which the study was operating, with no effective treatment and in a climate of disillusionment with an epidemic that showed no sign of abating.

An analysis of the study data by Kippax et al. (2003) identified three dominant discourses within the participants’ retrospective narrative, in most cases used as a “warranting or a justification of” the participant’s infection.

The first of these contexts is described as ‘discourses of coupledom’ in which love, trust and the desire for intimacy overrode concerns about HIV transmission. These included the most common explanation given by participants for their seroconversion – misplaced or betrayed trust, most often in a regular rather than casual partner.

Secondly, the analysis identified ‘discourses of control’, in which participants attributed their seroconversion to an attenuation or rationing of control, either of their decision-making (such as when under the influence of drugs or alcohol), of their capacity to make safe sexual choices (such as where the participant was labouring under a misunderstanding or misapprehension of the risk associated with a sexual act), or of the sexual act itself (such as where the participant was sexually assaulted).

Some participants described their decision to relinquish control over their sexual wellbeing (perhaps via drugs or alcohol) as a means of coping with the traumatic impact the epidemic was having on their community:

> *A circle of friends all dead / except two of them . . . So I started medicating myself . . . just getting totally and utterly drug-fucked and going out. (Participant quoted in Kippax et al., 2003, p. 845)*

Some participants articulated a sense of fatalism, often entangled with notions of romantic love:

> *And it’s almost like, most of my friends in Sydney have got it and they’re all 10 years older than me . . . It wasn’t consciously wanting to try and capture R by getting positive, but looking back it was sort of like, I was so much in love with him and still am. (Participant quoted in Kippax et al., 2003, p846)*

Finally, Kippax et al identify ‘Discourses of risk’, in which participants who had a reasonable understanding of the risks of particular activities nonetheless either discounted the risk in their own circumstances or applied a maladapted calculus of risk, such as by relying on weakly-protective strategies such as withdrawal or strategic positioning as a form of complete protection. (Prophetically, this analysis also noted a small number of cases where participants referred to undetectable viral load as a risk reduction strategy, something that would ultimately be confirmed in the following decade).

> *Not caring, being or doing something stupid, taking a risk, fatalism or having a death wish or a naive hope of not getting HIV were themes which arose in many of the interviews. (Kippax et al., 2003,p. 847)*

The first Seroconversion Study was thus able to identify a number of areas of concern with gay men’s understanding of risk and their application of that understanding to sexual practice. Participants placed undue emphasis on weakly-protective risk reduction strategies, were at especially high risk during the early months of a regular relationship, and while they often had a very good understanding of safe-sex educational messages, their understanding of risk was derived from multiple sources and occasionally applied in an irrational way (Kippax et al., 2003).

The study was also able to identify an apparent correlation between participants who attributed their infection to oral sex and the presence of genital piercings (Richters et al., 2003), and an examination of the study data showed no evidence that circumcision was protective against HIV transmission in the study cohort (Grulich et al., 2001).

The arrival, in the mid-1990s, of highly active antiretroviral therapy (HAART) marked a turning point in the epidemic, while also throwing up new challenges for HIV prevention in an affected community that was simultaneously wearied by 15 years of death, grief and crisis.

At the 1996 International AIDS Conference in Vancouver, Dr David Ho unveiled stunning data showing the effect of a new class of antiretroviral drugs – protease inhibitors – in combination with existing drugs. Ho also ambitiously (and, as it turned out, wrongly) predicted that HIV patients who were able to maintain viral suppression for several years would be able to clear their HIV infection altogether.

These announcements, which attracted global news coverage, came to be known as the 'protease moment' – as if the entire landscape of HIV/AIDS had changed in an instant. While it's tempting to look at past events as watershed moments within a larger narrative, for those living within the moment the significance of these events is rarely as clear as the post-hoc narratives suggest.

The 'protease moment' story suggests that there was a single point in time when treatments improved, people stopped dying, and AIDS-the-killer-disease became HIV-the-chronic-manageable-illness. The reality was very different. There was no 'moment': new treatments became available progressively over several years, and while deaths from AIDS did fall, they didn't end. A significant number of PLHIV failed to benefit from new treatments because years of 'serial monotherapy' meant they had developed resistance to the background drugs needed to make up the HAART 'cocktail'. New treatments came with new toxicities and the need to take three or more drugs in combination meant that those toxicities were multiplied. And they were also regarded with justified suspicion: previous HIV drugs, initially hailed as life-saving, had ultimately proven to be disappointments.

From the perspective of gay men and PLHIV living in 1996, the 'protease moment' was not a single point in time, but the beginning of a shift in our understanding of HIV that took several years to complete. The US activist and author Eric Rofes, writing in the midst of this period, strongly criticised the failure of AIDS organisations and the gay community to grasp the enormity of what was happening, and particularly the way in which many established organisations continued to use the language of crisis at a time when the 'AIDS crisis' was clearly ending (Rofes, 1998).

Even before the arrival of new treatments, gay men's understanding of the place of HIV in their lives had already started to change. In a paper presented at the same AIDS Conference where the success of protease inhibitors was announced, Australian researchers Gary Dowsett and David McInnes coined the phrase 'post-AIDS' to describe the mindset of younger gay men in their research in Sydney and Adelaide who no longer saw HIV through the lens of crisis but who simply accepted it as a fact of life. They called for a move away from the crisis mentality that was the foundation of so much of the government and community response to HIV towards one that recognises the different ways in which gay men respond to the challenge of HIV prevention (Dowsett and McInnes, 1996).

Far from being a radical shift in the impact of HIV on the gay community, the arrival of HAART ushered in a period of uncertainty. Death rates fell and many PLHIV experienced dramatic improvements in their immunological health (but at the cost of increased, often very serious, side effects), but the idea of HIV as a 'chronic manageable illness' had yet to take hold.

The psychological impact of a decade and a half of death and disease on the gay community, especially the urban epicentres of the epidemic, is a challenge to describe. Death from AIDS-related illness is typically brutal, ghastly and undignified, all the more so because its victims were often young men in their twenties and thirties. For the gay men, lesbians and others involved in supporting and caring for the dying, the psychological trauma of living through such a lengthy period of crisis and grief was profound. And it endures. The 'protease moment' marked the beginning of a period of emotional recovery for our community that continues, especially for many older gay men, today.

By the end of the 1990s, mortality from AIDS had fallen considerably. Its visibility as a medical condition fell too – there were fewer men noticeably ill, fewer funerals, fewer obituaries in the papers (the *Sydney Star Observer* memorably announced on its front page in a massive banner headline, 'NO OBITUARIES'). But there were new challenges for HIV prevention: the fear of death from AIDS was receding, and gay men were adapting the safe-sex message in new, and sometimes problematic, ways.

The second Seroconversion Study documented the rise of a series of new risk-reduction strategies among gay men: serosorting, strategic positioning and viral load (Jin et al., 2007). More than a third of participants in the study reported using one or more of these strategies during the sexual encounter to which they attributed their infection.

Serosorting has been used by HIV-positive men since the beginning of the epidemic, and is an aspect of the negotiated safety practice first described in regular partners in the early 1990s. An analysis of the second Seroconversion Study expressed concern at the use of serosorting in casual sexual contexts, often based on assumptions about the partner's status, and in regular relationships of short duration.

Strategic positioning, in which the HIV-positive and HIV-negative partners take the bottom and top roles, respectively, in anal sex, is more controversial and has never been recommended, by itself, as a reliable strategy in Australia. A second analysis of the study found significant problems with strategic positioning – including the observation that, like serosorting, its reliability depended on assessments about the partner's serostatus that may be incorrect (Volk et al., 2006).

Intriguingly, the second study also noted a small percentage of participants to whom the viral load of their partner was part of their assessment of transmission risk. Viral load tests first become available in Australia about the same time as HAART, and while we know today that undetectable viral load substantially reduces HIV transmission risk, at the time this was thought not to be the case. It's not clear whether the small number of men in whom this was reported in this study had misunderstood the meaning of viral load (as it then was) or whether this was early evidence of the informed use of viral load as a risk reduction strategy.

It has now been almost thirty-five years since the first AIDS case was diagnosed in Australia. Gay men now unquestionably occupy the post-AIDS reality first described in the mid-1990s, and the promise of HIV as a chronic manageable illness has largely been achieved. HIV infections have plateaued at about 1000 a year. The sense of crisis that permeated the early years of the epidemic has largely dissipated (although it still rears its head from time to time, usually following the annual release of surveillance data). In place of crisis, we now have a sense of optimism and opportunity, with talk of virtual elimination of new HIV infections within a few years.

Behavioural surveys over more than 15 years have shown a clear trend towards decreasing use of condoms among gay men in all major cities in Australia, as has been the case in comparable places overseas. Falling condom use has been blamed for the increase in HIV notifications from their low-point in 1999, with accusations of 'complacency' and 'condom fatigue' levelled at gay men.

However, the number of new diagnoses among gay men has remained relatively steady for about a decade, despite an increasing population of sexually-active gay men with HIV and decreasing condom use. A series of developments in biomedical prevention of HIV have occurred in recent years that may provide some explanations for this seeming contradiction.

In 2008, a group of Swiss clinicians published the then-controversial 'Swiss Statement', arguing that positive people with undetectable viral load and no STIs were essentially non-infectious. This hypothesis has now largely been accepted following a number of clinical studies which showed high levels of efficacy for Treatment as Prevention (TasP).

In 2010, the CAPRISA 004 study showed the first proof-of-concept that pre-exposure prophylaxis (PrEP), in the form of a tenofovir-based vaginal microbicide, could significantly reduce the risk of HIV acquisition. A number of studies since (iPrEx, Partners PrEP, PROUD, IPERGAY) have shown extremely high efficacy for oral Truvada as pre-exposure prophylaxis. Truvada is now approved for use as PrEP in the USA and France, while in Australia, a number of pilot programs and the enthusiastic take-up of personal importation of generic Truvada have placed PrEP squarely into the minds of a large number of gay men.

As argued above, the so-called ‘protease moment’ was neither a moment nor was it solely about protease inhibitors. The arrival of HAART was accepted cautiously and slowly by a gay community wearied by a decade and a half of increasing despair and repeated disappointment. At the same time, we started to see gay men, especially younger gay men, shift their thinking about the place of HIV in their lives and evolving new strategies, some more successful than others, to pursue sexual fulfilment while reducing the risk of HIV to an acceptable, although usually non-zero, level.

Today we are in the midst of another great paradigm shift in HIV. It probably won’t be known as the ‘Truvada moment’ or the ‘prevention moment’ but, like its predecessor 20 years ago, it’s not a single point in time but an evolution over several years in how we understand HIV within the gay community. We’ve been in this ‘moment’ for at least half a decade already, since the Swiss Statement, since iPrEx, since PROUD, since we started to talk about HIV in a way that goes beyond latex barriers, behaviour change, and which, perhaps, is the beginning of the end of the association between sex and disease that has so burdened our community.

Since the start of the AIDS epidemic, gay men have acted to secure their right to sexual pleasure in the face of an unprecedented, almost unimaginable, challenge. Those actions, from the adoption of safe sex to the development of a post-AIDS understanding of HIV to the current advocacy demanding access to PrEP, should be seen as not only a social, sexual and cultural process, but a political one.

History of the Seroconversion Study

> “The Seroconversion Study has been an important resource where overlapping aspects of the Australian HIV epidemic have been investigated together. Clinical, behavioural, public health and (most recently) biomedical questions have been investigated and provided insight and guidance across the HIV sector.”

Andrew Grulich and John Kaldor
The Kirby Institute

History of the Seroconversion Study

Studies that collect detailed risk behaviour and attitudinal data from individuals recently diagnosed with HIV have the potential to provide unique insights into the contexts in which HIV infection occurs. There have been few HIV seroconversion studies internationally, and none that have been in continuous data collection for longer than a few years. Australia's HIV Seroconversion Study, has collected detailed information from gay and bisexual men recently diagnosed with HIV for most of the past 23 years. The study has had three distinct periods: 1992-2001; 2002-2006; and 2008-2015 (Jin et al., 2007, Kippax et al., 1998, Volk et al., 2006b). During that time, we have collected similar data throughout, but with slight modifications to the method, and content, of data collection. These data represent the perspectives of gay and bisexual men recently diagnosed with HIV spanning most of the epidemic in Australia.

Data collected from individuals recently diagnosed with HIV are usually through routine surveillance (Guy et al., 2011, Jayaraman et al., 2006, Weinstock et al., 2004). These are mainly basic clinical data (test results and testing history), and some demographic information. In some jurisdictions, routine surveillance includes some, restricted, behavioural data, such as likely mode of infection, and basic details about the person who was the likely source of infection (Pao et al., 2005). Clinical studies of recent seroconverters commonly provide clinical indicators and demographic details but rarely include behavioural or attitudinal data (Jin et al., 2008, Kippax et al., 1998). Cohort studies of HIV incidence that are not clinic-based often collect more comprehensive information about the types of risk behaviours, partners and contextual information prior to individuals' infection (Calzavara et al., 2003, Kippax et al., 2003).

HIV seroconversion studies differ from studies of HIV incidence or from routine surveillance because they aim to collect detailed information about the event/s leading to HIV transmission through interviews and/or surveys with individuals recently diagnosed with HIV. Data collected can include sexual and other risk behaviour prior to diagnosis, types of sexual partnerships, motivations for testing, and beliefs about HIV and risk, as well as information about the diagnosis experience and the impact of diagnosis on sexual behaviours, relationships, and expectations for the future (Volk et al., 2006).

1992-2001

The first seroconversion version of the study in Australia (1992-2001) recruited gay and bisexual men diagnosed from clinics for whom there was evidence of it being a recent infection, either by a previous HIV-negative test or a recent seroconversion illness. Cases were referred into the study by the diagnosing doctor. From 1992 – 2001 99 gay and bisexual men who had recently seroconverted were interviewed. There was a break in interviewing men between 1998 and 1999. Sixty-five men were interviewed up until the end of 1996, when ART became available, and 34 men were interviewed between 1999 and the end of 2001. Participants were interviewed outside the clinic setting by a trained interviewer. Participants were initially asked to complete a brief questionnaire that included questions about their demographic profile and the behaviours they engaged in that they believe had led to their HIV infection. Participants were then interviewed in depth and asked to describe in detail the event/s they believed had led to their HIV infection, their sexual, and other risk behaviour in the six months prior to diagnosis, their experience of testing (and diagnosis), and what had changed, or not, for them since diagnosis. Participants were also asked to reflect on their attitudes, beliefs, and expectations in relation to HIV and sexual risk at the time of the risk event/s, directly after the event/s and in the period leading up to the test at which they were diagnosed. Finally participants were asked about how receiving an HIV diagnosis had affected their attitudes to sex and HIV.

Mostly, those who were referred by their diagnosing doctors were successfully enrolled. The main limitation with the recruitment method was that relatively few referrals were made into the study by the diagnosing clinics. Clinic staff often reported that they lacked the resources to ensure that referrals occurred on a routine, and consistent, basis. The study lacked resources to support clinics in this. It nonetheless remained the responsibility of the clinic to contact these patients and make the referral. For the most part, this meant that a note was attached to their patient records to remind the doctor about the study at the patient's next clinic visit.

Another barrier to recruitment was that some staff felt concerned about referring their patients into a separate research project so soon after they had received the traumatising news that they had tested HIV-positive. Of course, their concerns had some merit, given that for much of the period of the first iteration of the study there were no effective treatments available and an HIV diagnosis was rightly interpreted as a probable death sentence. Nonetheless, as the interviewer (and study manager) reported, most of the men interviewed expressed their profound appreciation for the opportunity to participate in the study. For many participants the interview offered an opportunity to reflect upon and make sense of what had happened in a circumstance that was confidential safe, and non-judgemental. It should be noted that during the life of the study there have never been any adverse events reported or complaints made about the interview process to either the research team or the presiding ethics committee.

Reflections of an interviewer on the initial Seroconversion Study.

By Olympia Hendry

At the outset of the Seroconversion Study in the mid-1990s the epidemic was at its most hateful - friends, acquaintances and strangers were dying every week. Brett[1] wanted answers to the questions about how and why so many (mostly) men were becoming HIV positive. It was difficult to get referrals into the study, as the project wasn't universally supported and the focus was, understandably, on treatment.

The study recruited new seroconverters, as notified by their doctors, to participate in an in-depth interview to try to understand the circumstances around their seroconversion event. There was a set questionnaire plus a narrative which allowed the participant to explore and share their experiences. We met at different places, such as homes, park benches, cafés. There were those who told their story with urgency, others who had obviously rehearsed what they wanted to tell me and many who initially were reticent to relive the event.

Looking back, I remember the pain, the embarrassment, the shame, the honesty and the tears, but mostly the stories. The stories that the participants related to try to explain what happened. The interviews could be searing for the participant and were emotionally draining for me too, but with every interview I came away knowing that every story would help.

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[1] Brett Tindall, an investigator on the original study

2002-2006

The second version of the study (2002-2006) was conducted in conjunction with a clinical trial, the Primary HIV and Early Disease Research (PHAEDRA) trial. Men who attended a small number of selected clinics in Sydney and Melbourne with signs of acute HIV infection were asked to enrol into the trial. As part of the study protocol, all trial participants were invited to join the seroconversion study at approximately six weeks after diagnosis. The six-week timeframe was a compromise between the clinics' concerns about asking such sensitive questions 'too soon' and the researchers' preference that these data be collected early.

Participation in this version of the seroconversion study entailed the same two components as had comprised the first iteration of the study: an initial behavioural questionnaire followed by a subsequent in-depth qualitative interview. In the first version of the study the behavioural questionnaire had been very brief and was simply a set of questions asked at the outset of the in-depth interview and therefore, all participants completed both parts. In this second iteration, the behavioural questionnaire was more extensive, with some considerable detail about the sexual behaviour that men had engaged in at the event they believe had led to their infection, and it was completed within the clinic itself, although mostly by the men themselves. On completion of the questionnaire, the men were then informed about the qualitative component and offered the opportunity to be interviewed at a separate time and place, participants could contact the interviewer directly or give permission to the clinic nurse to pass on their contact details.

The content of the interview remained much the same as it had been in the earlier version of the study described above. However, this second version of the study occurred in the context of effective HIV treatments, so some of the issues around the prospect of illness and death no longer applied, at least not in the same way. Most men in the PHAEDRA trial completed the behavioural questionnaire, probably because it was a routine, if delayed, part of the study protocol, however only about one quarter of those who completed the behavioural questionnaire were also subsequently interviewed for the qualitative component of the study. A large proportion of men newly diagnosed in the selected clinics during the PHAEDRA trial were enrolled into the trial. Of those, a majority completed the opt-in behavioural questionnaire, and of those men 42 in Sydney and 11 in Melbourne did the interview.

Throughout both of these first two versions of the study findings have been highly influential in the Australian response to HIV and have informed the development of policy and programmatic responses of both health departments and community organisations. Key findings have included: that HIV infection among gay and bisexual men often occurred in the early, establishment, phases of a regular sexual relationship; that among gay men, recent HIV seroconverters often were highly sexually active compared with other groups of gay men; that newly diagnosed men often lacked current information about HIV and were fearful for their future; that the majority of infections among men appear to have occurred outside the context of a regular relationship. The seroconversion study has brought the unique voices and perspectives of the newly diagnosed, to the attention of policy makers, clinicians, educators and researchers across the different stages of the epidemic in Australia. This has occurred via conference presentations, community forums, staff workshops, journal articles and by the repeated use of material from the study in the context of broader presentations.

Establishing the most recent study

> “The Seroconversion Study has been integral to us understanding the ways and contexts in which people contract HIV. The 2007 increase in HIV notifications in Queensland was the stimulus for this version of the Study and given the large distances between population centres in Queensland, an online version of the Study was essential.”

Darren Russell
Cairns Sexual Health Service

Establishing the most recent study

In 2007, the Kirby Institute was approached by Queensland Health to extend the concept of the Seroconversion Study to Queensland. The state of Queensland is more geographically diverse than other Australian states, with HIV diagnoses occurring in Brisbane and Cairns, as well as on the Gold Coast and Sunshine Coast and therefore a study structure that could accommodate this geographic diversity was needed. Queensland was not part of the PHAEDRA trial and there was no other existing study or trial to which the Seroconversion Study could be attached. This meant we needed a different way to recruit men who had been recently diagnosed into the study. Direct recruitment via clinics was a possibility but this had already proven to be a slow and difficult process in the implementation of the first version of the study. In the case of Queensland, however, the number of new diagnoses each year was even smaller than had been the case in NSW where the first version of the study had been located.

The survey component in the previous two versions of the study had been completed using a pen-and-paper questionnaire. However, by 2007 when a new and expanded version of the study was being planned, online options for recruitment and data collection existed. Internet-based technology meant that online platforms could be used, and created opportunities to use methods of data collection that were more accessible and flexible, and reduced some aspects of data entry and management. We constructed an online questionnaire that retained the questions about men's sexual risk behaviour and the circumstances in which risk occurred prior to diagnosis. However, we also included questions about their attitudes and beliefs, intimate relationships and well-being both before and since diagnosis.

The construction of the questionnaire, and indeed, the general focus of the study was directly affected by the significant advances in biomedical prevention, knowledge about treatment, and changes in testing access and technology, during the life of the study. At the commencement of the study, Treatment as Prevention (TasP) was not a fully formed concept, pre-exposure prophylaxis (PrEP) was at the clinical trial stage only, and no results had been reported, there was fundamental disagreement about the optimal time to commence treatment, and HIV testing in Australia was restricted to clinic settings using standard blood tests. As these changes occurred, we adapted, by making changes to both the focus of the study and the types of questions that were being asked to reflect these biomedical changes. The questionnaire was revised on two occasions, in 2010 and in 2013. Consequently, there are three periods and questions asked in each period were not necessarily asked in the other study periods. The interview guide was also revised in 2013 to include specific questions about TasP and PrEP and to place more emphasis post diagnosis experiences such as sex, disclosure, and treatment.

In the first two versions of the study, eligibility had been restricted to those whose infection had been due to homosexual contact. However, in the Queensland context, it was argued that the larger indigenous population and fly-in fly-out workers meant that individuals who had been infected through heterosexual contact or injecting drug use were also potential candidates for the study. Initially, we attempted to resolve some of the issues around referral into the study by trying to adapt the PHAEDRA trial concept. We sought to utilise the existing diagnosis and surveillance mechanisms so that every person who was diagnosed with HIV would be provided with information about the study and invited to enrol. However, the number of referrals into the study from this method were small, with the notable exception of Cairns, where most of those who were diagnosed were enrolled into the study. In that particular case, the local clinic set in place procedures to ensure that every person that was diagnosed would be provided with information about the study by the research nurse, who would then follow through by personally completing the consent process with every patient that agreed to participate and by providing them with the data collection instruments. Upon completion of the questionnaire, the nurse then invited each participant to take part in the interview component of the study. About half of the Cairns participants were interviewed. Ideally, the Cairns approach should have been replicated elsewhere, but that would have required the same level of commitment at every site, which required a level of resourcing that was not available.

After a few months during which the limitations of referral and enrolment became clear, we considered other options and decided to use the study website and online questionnaire as a direct recruitment tool. We opened recruitment to allow referral through HIV community organisations and their specific programs for newly diagnosed individuals, and self-referral. This proved to be an effective strategy, and enrolments increased substantially.

This more effective method for recruiting eligible participants into the study, and the use of an online survey instrument that was not geographically bounded, also created an opportunity to open the study to other jurisdictions. We therefore approached all of the states and territories to seek funding to allow local implementation in all Australian states and territories. Over the following years, every jurisdiction provided funding to support local implementation of the study and it became for the first time in its history a national study.

This method of recruitment into the study did raise issues about how we would determine participant eligibility in relation to recent HIV infection in the absence of referral from a clinic. In response we decided to remove the criteria that it be a recent infection and instead decided to include all individuals recently diagnosed with HIV, on the basis that we would be able to separately analyse the data collected from those who were able to provide information that indicated a recent infection if it was needed. It meant that referring agencies, whether they were clinical or non-clinical, did not need to determine the specific eligibility of individuals before referring them into the study, thereby reducing the burden of time and resources required. It also meant that individual participants could be asked a set of guiding questions to determine whether they qualified as a new, or recent, infection or not, instead of requiring them to make that determination themselves before enrolling into the study: being able to determine whether they had ‘recently’ been diagnosed was not difficult, whereas determining when they were actually infected is a considerably more challenging task.

This open, broadly targeted process of recruitment also meant that individuals who had not been infected as a result of sex between men needed to be identified. Again, rather than asking individuals to determine this for themselves before enrolling into the study, we allowed all those who had been recently diagnosed to join the study, and then used guiding questions to determine whether they had been infected through sex between men, or otherwise. Based on the epidemiology we knew that the numbers of newly diagnosed who would enrol that had been infected through contact other than sex between men would be small, limiting the capacity for separate analysis of the quantitative data. To address this situation, we actively encouraged these participants to opt for the interview, where forms of qualitative analysis could be undertaken with smaller numbers.

Methods

Like its predecessors, this most recent version of the Seroconversion Study collected both quantitative and qualitative data, through an online survey questionnaire and in-depth interviews. People who had recently been diagnosed with HIV infection were directed to a study website where they could find out more about the study. Gay and bisexual men, could then choose to enrol in the study by completing an online questionnaire. On completion of the survey respondents were invited to volunteer for a face-to-face in-depth interview. Women and men whose transmission was not through male-to-male sex could also enrol in the study through completion of a shorter questionnaire designed to identify mode of transmission and were then invited to participate in the face-to-face in-depth interview. During the early years of the study they also completed the full questionnaire, but the numbers were small and the research team decided to invite them directly for interview only. Ethics approval has been obtained from the University of New South Wales (UNSW) and La Trobe University.

Eligibility

Eligibility criteria for the study include being over 16 years of age; having been diagnosed as HIV-positive for the first time within the two years prior to enrolment; and living in Australia. In jurisdictions where the Seroconversion Study had not been a regular feature of local surveillance activity before 2007, the requirement that the diagnosis had occurred within a maximum of two years prior to interview was relaxed to allow people who had been diagnosed up to five years prior to participate. Until 2014, only those over the age of 18 years were eligible to participate in the Seroconversion Study. However, given that 16 is the age of consent in most parts of Australia, we sought and were granted approval from the UNSW ethics committee to include people aged between 16-18 years to participate.

Recruitment

Enrolments occur through four main sources: referrals from state AIDS Council staff; recruitment from state-based PLHIV 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. Among men in this most recent wave of recruitment, the majority found the survey online and enrolled in the study directly.

Table 1 Method of referral to the study (2007-2015)

	Frequency	%
Other	148	20.9
AIDS Council website	122	17.3
PLHIV organisation staff	70	9.9
Other online	67	9.5
AIDS Council staff	60	8.5
PLHIV organisation website	53	7.5
Sexual Health service	49	6.9
Workshop	42	5.9
Doctor	23	3.3
Not provided	73	10.3
TOTAL	707	100.0

Online survey

The online questionnaire includes demographic characteristics, details of participants' diagnosis with HIV, sexual practices 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 they believe infected them, their sexual and drug use behaviour in the six months prior to their HIV infection, their beliefs about HIV and risk both prior to, and since their HIV diagnosis, sources of support and contact with the community and measures of mental well-being. There are a number of open-ended questions in the survey, which allow respondents to provide more open-ended and detailed responses; some of those responses are presented in this report to help illustrate common themes and patterns or in some cases uncommon or atypical cases.

In-depth interviews

In-depth interviews were conducted with participants who volunteered to participate in the interview after completing the online survey. The focus of the interview is similar to that of the online questionnaire – a description of the occasion when they believe they were infected with HIV, and of the person they believe infected them, their sexual practices in the months prior to diagnosis and about how they managed and understood HIV risk. Participants were also asked about their initial reaction to diagnosis and for their reflections on the ways in which the diagnosis had affected their life in the immediate period after diagnosis and over time. They were also asked about their attitudes towards HIV treatments, and any decisions they may have made about commencing treatment, as well as their knowledge about viral load and its implications for risk of HIV transmission. The interview component of the study took a different methodological approach to the questionnaire by posing questions in a more open-ended and conversational style with the aim of gaining insights and understandings about the factors, contexts, experiences and perceptions that shape HIV transmission. Approximately one quarter of survey participants volunteered to participate in the qualitative component of the study.

About this report

> “Findings from the Seroconversion Study have been a rich source of quantitative data and insights into those at risk of and people living with HIV. It has informed our approach, allowing us to appropriately target and successfully implement HIV prevention and care programs.”

Jo Holden and Tim Duck
NSW Ministry of Health

About this report

This is the final report to be produced from the most recent incarnation of the HIV Seroconversion Study 2007-2015. Recruitment to the study ended in August 2015.

In 2010, the study was adapted to enable participation by anyone in Australia who was recently HIV-diagnosed. A sub-study was established to collect data on the experiences of women as well as men who had not acquired their infection through sex with another man. Thirteen women and fourteen men enrolled between 2010-2012. The study found it difficult to recruit women and heterosexual men and this may in part be due to the fact that we overall found it difficult to recruit participants through clinic settings, which would be the most likely way in which women and heterosexual men could learn of the study.

Since December 2007, when the current Seroconversion Study relaunched, 707 gay and bisexual men have completed an online survey, while more than 100 have been interviewed in-depth. The previous versions of the Seroconversion Study conducted between 1992 and 2006 recruited just over 300 respondents in that time. Using the primarily online method of enrolment in this most recent version of the study has allowed us to reach, and enrol, over twice as many recently diagnosed individuals in half as many years as was achieved in all previous versions of the study combined. This method of recruitment is clearly highly successful and should remain an important component in any future work with this population.

Women and heterosexual men

The report includes a separate section on the experiences of women, and men who did not report acquiring HIV through homosexual contact. This section draws on questionnaire data, including free text responses and a small number of in-depth interviews with women.

Interviews with gay and bisexual men

The report includes data drawn from the qualitative interviews with gay and bisexual men in relation to key topics including HIV diagnosis, contexts of risk and HIV transmission, understanding and managing risk, testing, treatment, PEP and PrEP and the role of peer support. Findings from the qualitative data are presented alongside findings from the online survey. The narrative accounts of newly diagnosed men offer insight into the experiences, meanings and understandings of HIV and compliment and enrich the quantitative findings.

Table 2 Interview participants, by location and year

Jurisdiction	2009	2010	2011	2012	2013	2014	2015	Total
Australian Capital Territory		1	1					2
New South Wales	12	4	5	12	3	9		45
Queensland	3	2	4			3	2	14
South Australia	2		2					4
Tasmania		1	2					3
Victoria	5	8	9	2		2		26
Western Australia	1	2	3	12		1		19
Total	23	18	26	26	3	15	2	113

Note: Interviews in each jurisdiction were dependent on funding availability, local referrals, and individuals volunteering to be interviewed. Interviews did not occur in all locations every year.

About the men who were interviewed

Of the men enrolled in the study 113 participated in an in-depth interview. Participants in the in-depth interview ranged from 19 years to 70 years of age, with a median age of 37, higher than the men in online sample. The majority (n=109) identified as gay, three men described themselves as bisexual, one man identified as queer and one described himself as ‘confused’. Consistent with the online sample, the majority of men (99) were employed, were well educated with 40 having completed a university undergraduate degree and 29 having completed a post-graduate degree. The majority of men described their ethnic or cultural background as Caucasian or Anglo Australia. Men were interviewed from all Australian States and from the Australian Capital Territory; there were no participants from the Northern Territory.

Comparison across jurisdictions and over time

Towards the end of this report we compare some key variables across states and territories and, where possible, changes that may have occurred over the duration of the study.

Participation and Referral

> “We value the commitment of the Seroconversion Study to include the voices of PLHIV in regional locations such as Far North Queensland. Many community members live outside of capital cities and their stories and experiences also contribute to our national understanding of HIV in Australia today.”
>
> Carla Gorton and Joanne Leamy
> *Cairns Sexual Health Service*

Participation and Referral

Since December 2007, 707 men have participated in the Seroconversion Study. Over time the questions that participants were asked have been updated as the epidemic and research questions changed, and as new information and technologies have emerged. As such, four versions of the questionnaire were used, and the timing and numbers of responses are found below. While many questions were common to all versions of the questionnaire, some were not asked in every iteration of the questionnaire. So, the relevant sample sizes for each question will vary accordingly. Additionally, about one in five respondents did not fully complete their questionnaires. While they provided responses to most items, many of those who failed to complete the questionnaires dropped out toward the end. These men provided sufficiently complete information to enable them to be included in most analyses, but for analyses relying on certain questions toward the end of the questionnaire this may not be the case. In those circumstances, some of these men may be excluded from particular analyses.

Table 3 Seroconversion Study questionnaire

Questionnaire	Study period	Responses
1	December 2007 - June 2010	232
2	June 2010 - March 2013	260
3	March 2013 - February 2014	84
4	February 2014 – August 2015	131

Note: Includes only male participants who attribute their infection to sexual contact with another male.

The number of men participating in the Seroconversion Study per year has varied over time. After slower years in 2007 and 2008 as participation ramped up, the study had its busiest year in 2009 and participation hovered around the 100 person mark until a dip in 2012/2013 and a partial year in 2015.

Table 4 Study participation over time

	Frequency	Percent	Valid Percent	Cumulative Percent
2007	12	1.7	1.7	1.7
2008	35	5.0	5.0	6.6
2009	136	19.2	19.2	25.9
2010	115	16.3	16.3	42.1
2011	103	14.6	14.6	56.7
2012	77	10.9	10.9	67.6
2013	83	11.7	11.7	79.3
2014	111	15.7	15.7	95.0
2015	35	5.0	5.0	100.0
Total	707	100.0	100.0	

Note: Includes only male participants who attribute their infection to sexual contact with another male.

The study team used a number of different ways to reach men who had recently seroconverted including via community organisations, clinics (private surgeries and public sexual health services), and working with state health departments. Both face-to-face and online techniques (including website and Google advertising) were employed to maximise recruitment and representation.

Table 5 How participants were recruited

	Frequency	Percent
Other	148	20.9
AIDS Council website	122	17.3
PLHIV organisation staff	70	9.9
Other online	67	9.5
AIDS Council staff	60	8.5
PLHIV organisation website	53	7.5
Sexual Health service	49	6.9
Workshop	42	5.9
Doctor	23	3.3
Not provided	73	10.3
Total	707	100.0

Note: Includes only male participants who attribute their infection to sexual contact with another male.

Participants were asked how much time had elapsed since the date of their HIV diagnosis to the date of completion of the survey. Despite often expressed concerns by clinicians about referring participants to the study shortly after diagnosis, well over a quarter of the participants completed the survey questionnaire within the three months following their diagnosis, including some men who completed the survey within days of their diagnosis, usually as a result of their own online searches. Overall, most men (80.6%) completed the survey within two years of diagnosis.

Table 6 Time from diagnosis to completing survey

	Frequency	Percent
Within one month	83	11.7
2-3 months	133	18.8
4-6 months	101	14.3
7-12 months	110	15.6
1-2 years	102	14.4
More than 2 years	127	18.0
Not provided	51	7.2
Total	707	100.0

Demographics

Participants were highly likely to be recruited for the study in the state where they resided at the time of participation. The high-risk events and diagnoses also tended to be in the state of residence but not quite so consistently (due to the number of participants who did not identify where the high-risk event occurred and the number of participants who were diagnosed overseas).

Table 7 Geographic distribution

State	Residence (%)	Recruited (%)	High-risk event (%)	Diagnosis (%)
New South Wales	257 (36.4)	262 (37.1)	182 (25.7)	223 (31.5)
Victoria	190 (26.9)	191 (27.0)	132 (18.7)	171 (24.2)
Queensland	139 (19.7)	138 (19.5)	95 (13.4)	129 (18.2)
Western Australia	47 (6.6)	48 (6.8)	32 (4.5)	40 (5.7)
South Australia	29 (4.1)	30 (4.2)	17 (2.4)	26 (3.7)
Australian Capital Territory	20 (2.8)	17 (2.4)	8 (1.1)	12 (1.7)
Northern Territory	6 (0.8)	6 (0.8)	1 (0.1)	8 (1.1)
Tasmania	6 (0.8)	6 (0.8)	4 (0.6)	7 (1.0)
Overseas	7 (1.0)	-	114 (16.1%)	42 (5.9)
Not specified	6 (0.8)	9 (1.3)	122 (17.3%)	49 (6.9)

Most participants lived in a major city with less than one in ten (9.0%) residing in either regional or remote locations.

Table 8 Geographic location of residence based on postcode

	Frequency	Percent
Major city	605	85.6
Regional	63	8.9
Remote	1	0.1
Not provided (including overseas)	38	5.4
Total	707	100.0

The mean age of participants was 34.8 years (SD = 9.58) and the median age was 34. The youngest participant was 16 years old and the oldest participant was 73. The distribution of ages appears to be roughly normal - i.e. there are more people with ages around the mean age than at the two extremes. Nonetheless, the average age in this sample is slightly younger than has been found among newly diagnosed men in the reports of the annual surveillance data during the same years of the study, where the mean ages have fluctuated between 35 and 38 years.

Table 9 Age at diagnosis

	Frequency	Percent
Under 25 years	89	12.6
25-29 years	119	16.8
30-39 years	251	35.5
40-49 years	143	20.2
50 years and over	50	7.1
Not provided	55	7.8
Total	707	100.0

Just over two thirds of participants were born in Australia.

Table 10 Country of birth

	Frequency	Percent
Australia	501	70.9
Elsewhere	200	28.3
Not provided	6	0.8
Total	707	100.0

Two thirds identified as being of Anglo-Celtic background.

Table 11 Ethnicity or cultural background

	Frequency	Percent
Anglo-Celtic	540	76.4
Other	135	19.1
Not provided	32	4.5
Total	707	100.0

Only a very small number identified as being Aboriginal or Torres Strait Islander, although this was a similar proportion to that reported in the annual surveillance data.

Table 12 Aboriginality

	Frequency	Percent
No	586	82.9
Yes	16	2.3
Not provided	105	14.9
Total	707	100.0

Participants tended to be well-educated, with a third of participants having a university undergraduate degree as their highest level of education and one in five having a post-graduate university degree. These results are similar to other studies of gay and bisexual men in Australia.

Table 13 Highest level of education

	Frequency	Percent
Less than Year 12 high school	103	14.6
Completed high school (Year 12)	67	9.5
Tertiary diploma or trade certificate	157	22.2
Undergraduate university degree	232	32.8
Post-graduate university degree	140	19.8
Not provided	8	1.1
Total	707	100.0

Almost three quarters (72.8%) of participants were either full- or part-time employed and almost one in seven (14.5%) were either on some kind of social security or were unemployed.

Table 14 Employment status

	Frequency	Percent
Employed full-time	307	64.6
Employed part-time	39	8.2
On pension/social security	33	6.9
A student	28	5.9
Unemployed	36	7.6
Other	25	5.3
Not provided	7	1.5
Total	475	100.0

Note: Employment status was asked in questionnaires 2, 3 and 4

As is commonly found in studies of gay and bisexual men in Australia, over half of participants (54.9%) were employed as either a manager/administrator or a professional capacity. Only small proportions of participants were employed in trade, clerical, production and labourer roles.

Table 15 Employment type

	Frequency	Percent
Manager/Administrator	113	25.7
Professional	144	32.7
Associate professional	14	3.2
Tradesperson	18	4.1
Advanced clerical/Service worker	14	3.2
Intermediate clerical/Sales and service worker	25	5.7
Intermediate production/Transport worker	4	.9
Labourer	11	2.5
Unemployed	23	5.2
Other	53	12.0
Not provided	21	4.8
Total	440	100.0

Note: Occupation was asked in questionnaires 2, 3 and 4

Sex Work

About one in six participants indicated they had ever been paid for sex. However, it is important to note that they were asked specifically about payment for sex. Exchanges for sex that were not necessarily cash-based may not have been included.

Table 16 Ever having been paid for sex

	Frequency	Percent
No	394	82.9
Yes	76	16.0
Not provided	5	1.1
Total	475	100.0

Note: Ever paid for sex was asked in questionnaires 2, 3 and 4

Participants were then asked how long it had been since they had last been paid for sex and nearly one quarter had done so within one year of diagnosis.

Table 17 Time since was last paid for sex

	Frequency	Percent
Within one year of diagnosis	20	26.3
More than one year before diagnosis	56	73.7
Total	76	100.0

Note: Time since last paid for sex was asked in questionnaires 2, 3 and 4

Sexuality

“Creating an environment for clients to openly discuss their sexual behaviour is very important. It ensures we can make an accurate risk assessment so they receive appropriate treatment and are comfortable coming back for ongoing care.”

Ren Del Rosario
Canberra Sexual Health

Sexuality

How participants identified their sexuality and sexual debut, coming out, and sexual practices/preferences were also investigated. Nine in ten men identified as gay and 97.7% of men identified as either gay or bisexual. Less than one percent identified as heterosexual (but nonetheless reported that the person they believe infected them was a man).

Table 18 Sexual identity

	Frequency	Percent
Gay	647	91.5
Bisexual	44	6.2
Heterosexual	5	0.7
Other	4	0.6
Not provided	7	1.0
Total	707	100.0

Among the subset of men who were asked about age of their first sexual contact with a man, most indicated either 14-16 or 17-19 years. Very few indicated that they had their first sex with a man at an age over 25.

Table 19 Age of first sexual contact with a man

	Frequency	Percent
Under 14 years	76	15.4
14-16 years	133	27.0
17-19 years	97	19.7
20-24 years	67	13.6
25 years and over	26	5.3
Not provided	93	18.9
Total	492	100.0

Note: Age at first sexual contact with a man was asked in questionnaires 1 and 2

Commonly, homosexually active men tend to experience their first sexual contacts with other men before coming out – that is, before acknowledging their homosexuality to others. So it is unsurprising that in this sample, compared to age of first sex with a man, participants tended to indicate an older age when asked about coming out (with 17-19 years old being the most frequent response). Additionally, the age of coming out tended to be more diverse than was the age of first sex with a man.

Table 20 Age when came out

	Frequency	Percent
Under 14 years	22	4.5
14-16 years	84	17.1
17-19 years	125	25.4
20-24 years	94	19.1
25 years and over	69	14.0
Not provided	98	19.9
Total	492	100.0

Note: Age when came out was asked in questionnaires 1 and 2

Given the differing levels of potential HIV risk across different anal sex positions, participants were asked their preferred anal sex position. About one third preferred to take the receptive (bottom) position and a third were versatile. Only one in nine expressed a clear preference for the insertive (top) position. This is a somewhat lower preference for the ‘top’ position than is found in most surveys of gay and bisexual men in Australia (Crawford et al., 2006, Mao et al., 2013).

Table 21 Anal sex preference

	Frequency	Percent
Prefer to fuck	79	14.3
Prefer to be fucked	236	42.8
I like both equally	230	41.7
Neither - I don’t like anal sex	7	1.2
Total	552	100.0

Note: Only includes those who provided a response to this item

Given that (lack of) circumcision has been cited as a risk factor for HIV infection among men, we asked participants about their circumcision status. Slightly more men had been circumcised than not, which is more closely balanced than the 65% of men who reported being circumcised in the Health In Men (HIM) survey (Templeton et al., 2009).

Table 22 Circumcision status

	Frequency	Percent
No	282	46.3
Yes	326	53.5
Other	1	0.1
Total	609	100.0

Note: Only includes those who provided a response to this item

Social Engagement with Gay Men

Men were asked about their levels of engagement with different social groups. When asked how many of their friends are gay men, nearly two thirds (64.2%) indicated either some or most of their friends were gay, similar to what is found in other samples of Australian gay and bisexual men. Relatively few had more than a handful of lesbian friends. The majority of participants indicated that some or a few of their friends were straight men or women. Participants tended to have more straight female friends than straight male friends.

Table 23 Number, proportion, and type of friends

	Proportion of friends who were:			
	Gay Men	Lesbians	Straight Males	Straight Females
None	15 (3.2)	163 (34.3)	36 (7.6)	16 (3.4)
A few	137 (28.8)	214 (45.1)	153 (32.2)	125 (26.3)
Some	134 (28.2)	55 (11.6)	172 (36.2)	171 (36.0)
Most	171 (36.0)	4 (0.8)	77 (16.2)	119 (25.1)
All	10 (2.1)	0	4 (0.8)	13 (2.7)
Not provided	8 (1.7)	39 (8.2)	33 (6.9)	31 (6.5)
Total	475 (100)	475 (100.0)	475 (100.0)	475 (100.0)

Note: Number and type of friends was asked in questionnaires 2, 3 and 4

Broadly, men tended to spend their free time with each group (gay friends, lesbians, and straight male and female friends) in roughly similar to proportion to whether they were included among their friends – that is, they spent more time with those groups that formed a larger proportion of their friendship network. The amount of time spent with gay friends was similar to what has been found in other samples of Australian gay and bisexual men.

Table 24 Amount of free time spent with each social group

	Gay Men	Lesbians	Straight Males	Straight Females
None	32 (6.7)	206 (43.4)	40 (8.4)	32 (6.7)
A little	134 (28.2)	172 (36.2)	158 (33.3)	138 (29.1)
Some	138 (29.1)	52 (10.9)	172 (36.2)	165 (34.7)
A lot	163 (34.3)	3 (0.6)	71 (14.9)	104 (21.9)
Not provided	8 (1.7)	42 (8.8)	34 (7.2)	36 (7.6)
Total	475 (100.0)	475 (100.0)	475 (100.0)	475 (100.0)

Note: Amount of free time spent with each social group was asked in 2, 3 and 4

Contact with the epidemic

Participants were questioned about their contact with the HIV epidemic prior to being diagnosed HIV-positive. Of the men who responded, over a third did not know anyone who was HIV-positive and another quarter knew one or two HIV-positive people.

Table 25 Number of HIV-positive people known in 12 months prior to diagnosis

	Frequency	Percent
None	193	36.8
One	66	12.6
Two	86	16.4
3-5	105	20.0
6-10	43	8.2
More than 10	31	5.9
Total	524	100.0

Note: Only includes those who provided a response to this item

These proportions were further decreased when participants were asked whether they knew someone who had been diagnosed with HIV in the 12 months prior to their own diagnosis. Few men knew anyone who had recently seroconverted.

Table 26 Number known who were diagnosed with HIV in the 12 months before diagnosis

	Frequency	Percent
None	356	74.9
One	62	13.1
Two	31	6.5
3-5	19	4.0
6-10	3	0.6
More than 10	4	0.8
Total	475	100.0

Note: Only includes those who provided a response to this item

Finally, participants were asked how many people they personally knew who had died from AIDS in the 12 months prior to their own HIV diagnosis. Although few indicated knowing anyone who had recently died of AIDS, given that AIDS is an unusual condition nowadays, and that death from AIDS is a rare event, this was a surprisingly large number, perhaps indicating some ongoing confusion about the definition of AIDS.

Table 27 Number of people known who had died from AIDS

	Frequency	Percent
None	432	82.4
One	35	6.7
Two	25	4.8
3-5	17	3.2
6-10	5	0.9
More than 10	10	1.9
Total	524	100.0

Note: Only includes those who provided a response to this item

Relationships at the time of infection

“Less than a third of study participants reported being in a regular relationship when they acquired HIV. This is also consistent in Canberra, with its urban character and highly educated population; despite the fact that men in Canberra are more likely to report having a regular partner.”

Philippa Moss
AIDS Action Council of the ACT

Relationships at the time of infection

When asked if they had a relationship with a regular partner (partner, boyfriend, girlfriend, or spouse) at the time of the event at which they believe they had become infected with HIV, two fifths of those who answered the question indicated that they were not in a relationship. Of those remaining two fifths who were in a relationship, almost all indicated they were in a relationship with a man.

Table 28 Relationship with regular partner at time of high risk event

	Frequency	Percent
No	310	57.6
Yes	228	42.4
Total	538	100.0

Note: Only includes those who identified a high risk event during which they believed they had acquired HIV.

Those men who reported being in a relationship with a regular partner were asked the HIV status of that partner. Three quarters of participants reported that he was HIV-negative at the time of the event in which they believe they had acquired HIV.

Table 29 HIV status of regular partner

	Frequency	Percent
HIV-positive	33	14.3
HIV-negative	169	73.2
I didn’t know	29	5.4
Total	231	100.0

Note: Only includes those men who reported being in a relationship at the time of their HIV infection.

Those men who reported being in a relationship with a regular partner were also asked how long they had been in this relationship at the time of the high-risk event. The relationships tended to be longer term, with over half reporting more than two years and nearly three quarters (70.0%) of men indicating that they had been in the relationship one year or longer.

Table 30 Length of relationship at the time of the high-risk event

	Frequency	Percent
Less than one month	10	4.5
1-3 months	22	9.9
3-6 months	11	4.9
6-12 months	14	6.3
1-2 years	35	15.7
More than 2 years	121	54.3
Not provided	10	4.5
Total	223	100.0

Note: Only includes those men who reported being in a relationship at the time of their HIV infection.

Sexual behaviour prior to diagnosis

Participants were asked about their sexual practices (including HIV status disclosure to and by their sexual partners) in the six months prior to their HIV diagnosis. Among the men who answered this question, just over half (53.9%) indicated that they had had between one and ten male sex partners in six months prior to diagnosis and two fifths (40.0%) indicated they had had sex with more than ten partners. Only 6.1% of men who responded indicated that they had had no male sex partners in the six months prior to diagnosis.

Table 31 Number of male sex partners in 6 months prior to diagnosis

	Frequency	Percent
None	33	6.1
1-10 men	292	53.9
More than 10 men	217	40.0
Total	542	100.0

Note: Only includes those who provided a response to this item

Over half (59.0%) of participants responding to questions about sex with men in the six months prior to their diagnosis indicated having had sex with any regular partners during that time. Men were then asked if they had had sex with any casual male partners in the six months prior to diagnosis and most men indicated that they had done so.

Table 32 Sex with any casual male partners in the 6 months prior to HIV diagnosis

	Frequency	Percent
No	65	13.1
Yes	433	86.9
Total	498	100.0

Regular male partners

Men were asked to indicate the types of sex in which they had engaged with their regular male partners (selecting multiple options where appropriate). Of the men who reported having a regular male partner (boyfriend or fuckbuddy) at the time, nine in ten reported any anal intercourse and almost three-quarters reported any condomless anal intercourse. Notably two thirds of men reported any condomless receptive anal intercourse and half of the respondents reported condomless receptive anal intercourse with ejaculation.

Table 33 Type of sex with regular male partners in the six months prior to diagnosis

N=328	n	%
Any anal intercourse	297	90.5
Insertive anal intercourse	194	59.1
Receptive anal intercourse	259	79.0
Reciprocal anal intercourse	156	47.6
Any condomless anal intercourse	242	73.5
Insertive condomless anal intercourse	144	43.9
Receptive condomless anal intercourse:	211	64.3
withdrawal	142	43.3
with ejaculation	170	51.8
Reciprocal condomless anal intercourse	113	34.5

Note: Items not mutually exclusive. Includes only those men who reported sex with a regular male partner in the six months before diagnosis

Casual male partners

As with regular partners, participants were asked to indicate what types of sex they had had with casual male partners (selecting multiple options where appropriate). Results were similar to sex with regular partners. However, fewer men reported any receptive condomless anal intercourse or receptive condomless anal intercourse with ejaculation with casual partners than was the case with regular partners. This is a pattern that has previously been noted among gay and bisexual men in general. However, among these men, the actual proportions engaging in condomless anal intercourse, particularly in the receptive position, and particularly with casual partners, was substantially higher than has been the case in other samples.

Table 34 Type of sex with casual partners in the six months prior to diagnosis

N=433	n	%
Any anal intercourse	370	85.5
Insertive anal intercourse	281	39.7
Receptive anal intercourse	318	73.4
Reciprocal anal intercourse	171	39.5
Any condomless anal intercourse	301	69.5
Insertive condomless anal intercourse	221	51.0
Receptive condomless anal intercourse:	251	58.0
withdrawal	202	46.7
with ejaculation	165	38.1
Reciprocal condomless anal intercourse	229	52.9

Note: Includes only those men who reported sex with a casual male partner in the six months prior to diagnosis; Items are not mutually exclusive

Looking at the kinds of condomless anal intercourse (CLAI) participants had with casual partners by their partner's HIV status, similar proportions of participants reported receptive and insertive CLAI with both HIV-positive and HIV-negative casual partners. With partners of unknown status, men were more likely to report receptive CLAI than insertive CLAI.

Table 35 Condomless sex with casual partners, by partner's serostatus.

N=433	n	%
Receptive CLAI		
With HIV-positive partners	38	8.8
With HIV-negative partners	125	28.9
With partners of unknown status	269	62.1
Insertive CLAI		
With HIV-positive partners	35	8.1
With HIV-negative partners	122	28.2
With partners of unknown status	162	37.4

Note: Items not mutually exclusive. Includes only those men who reported sex with a casual partner

Disclosure of HIV status with casual male partners

Participants who responded to questionnaire 2, and who also reported having had sex with casual partners during the six months prior to their infection with HIV, were asked whether they had divulged their HIV negative status to those partners prior to sex. About a third did not divulge to anyone and another third divulged to some casual partners. The remaining third was mostly participants who divulged their HIV negative status to all their casual partners and a relatively small number only divulged to one casual partner.

Table 36 Participants' disclosure of their HIV negative status to casual partners before sex

	Frequency	Percent
None	63	37.7
One	8	4.8
Some	60	35.9
All	32	19.2
Not provided	4	2.4
Total	167	100.0

Note: Only includes those men recruited between 2010-2013 who reported sex with casual partners in the six months before diagnosis.

Participants were asked how many of their casual partners in the six months prior to their infection with HIV had told them their HIV status prior to sex. The proportions who had been told their partners' HIV status were very similar to the proportions who had told their partners their own HIV status.

Table 37 Number of casual partners who disclosed their HIV status to participant before sex

	Frequency	Percent
None	63	37.7
One	11	6.6
Some	64	38.3
All	25	15.0
Not provided	4	2.4
Total	167	100.0

Note: Only includes those men recruited between 2010-2013 who reported sex with casual partners in the six months before diagnosis.

Meeting men for sex

Participants were asked how they met men for casual sex. An additional option was added in 2013 to account for the recent growth in the use of mobile phone apps to meet men for sex. Looking across all responses, meeting men for sex online (half of men) or on a mobile app (two fifths of men) were more common, but nonetheless, one third of men reported using saunas or gay bars, and one quarter used sex clubs or beats, to meet men. Face to face meeting was still very common among these recently diagnosed men.

Table 38 How he met casual male partners in the 6 months before testing HIV positive

N=707	Frequency	Percent
Online	370	52.3
Saunas	250	35.4
Gay bars	219	31.0
Sex clubs	192	27.2
Beats	179	25.3
Dance parties	125	17.7
Private sex parties	109	15.4
Gym	60	8.5
Commercial sex parties	20	2.8

N=215	Frequency	Percent
Mobile apps	88	40.9

Other sex practices

Participants who responded to questionnaires 1 and 2, and who reported sex with casual partners in the six months prior to their HIV diagnosis, were asked if they had had group sex with any casual male partners. Nearly two thirds of the men who answered the question indicated having engaged in group sex with casual partners, including about half who did so “occasionally”, and one in eight who did so often.

Table 39 Group sex with casual male partners in the 6 months before HIV diagnosis

	Frequency	Percent
Never	106	33.0
Occasionally	133	41.4
Often	35	10.9
Not provided	47	14.6
Total	321	100.0

Note: Question asked 2007-2013, includes only those men recruited during that time, who reported having sex with casual partners in the previous six months

Participants who responded to questionnaires 3 and 4, and who reported sex with casual partners in the six months prior to their HIV diagnosis, were asked further questions to determine participation in other, more ‘adventurous’ practices. Two fifths indicated that they had participated in rough play while a third indicated PnP (Party and Play) and another third had engaged in water sports. One quarter of men indicated they had participated in BDSM (bondage and discipline/ sadomasochism), one fifth indicated they had fisted someone, and less than one fifth indicated they had been fisted.

Table 40 Participation in other sex practices

	Yes	%	No	%	Total
Any rough play	64	39.3%	99	60.7%	163
Any PnP	53	32.7%	109	67.3%	162
Any water sports	51	31.5%	111	68.5%	162
Any BDSM	38	23.3%	125	76.7%	163
Did you fist anyone	30	18.4%	133	81.6%	163
Did you get fisted	23	14.0%	141	86.0%	164

Note: Question added July 2010, includes only those men who reported sex with casual partners in the previous six months.

Drug Use before Diagnosis

“Gay men are experienced pleasure pursuers and for many celebrate substance use-sex with regularity. The task at hand is to protect the interplay of sex and substance use with gay men, while preventing substance use harm and the acquisition of infection.”

Craig Cooper
Positive Life NSW

Drug Use before Diagnosis

Drug use in the six months prior to diagnosis was also examined and participants responding to questionnaires 1 and 2 indicated what types of drugs they had consumed. Two thirds (65.4%) reported any drug use in the six months prior to diagnosis. As is typically found in surveys of Australian gay men's drug consumption, amyl nitrate was the most prevalent with two thirds of respondents indicating use. Over a third of men reported marijuana use, a third of men reported using ecstasy and nearly as many had used erectile dysfunction medication. One quarter of men indicated crystal use and one in seven used GHB, both of which were higher than is typically reported within the gay community. Even in this high risk sample of men, heroin use was negligible.

Table 41 Drug use in the six months before diagnosis

N=430	Frequency	%
Amyl	246	57.2%
Marijuana	153	35.6%
Ecstasy	137	31.9%
Erectile Dysfunction Medication	126	29.3%
Crystal	114	26.5%
Speed	69	16.0%
Cocaine	59	13.7%
GHB	65	15.1%
Special K	43	10.0%
LSD	22	5.1%
Heroin	4	0.6%

Note: Question included until March 2013, includes only those men who responded to items about drug use in the previous six months.

About one in twelve men (8.7%) reported having injected drugs in the six months prior to their HIV diagnosis. About half of them had done so at least weekly. Sharing injecting equipment was uncommon among men who injected drugs, with only about one in five of those who had injected drugs indicating that they had shared any injecting equipment.

HIV and STI Testing History

> “Most men in the study had previously tested for HIV, with a majority testing within the 12 months prior to their diagnosis; however 20% said they were afraid to test. We need to continue to dismantle barriers to testing, including challenging HIV stigma and discrimination if gay men are to feel comfortable about testing more often.”

Michael West
Department of Health and Human Services (VIC)

HIV and STI Testing History

Participants were asked in some detail about their previous testing experiences – both HIV and general sexual health checks.

Most men (79.9%) report having previously tested for HIV, before the test that resulted in their diagnosis. This proportion is lower than that reported through the Gay Community Periodic Surveys (88.2% in 2014; CSRH, 2015). However, just one in ten men clearly indicated never having previously tested for HIV, which could suggest the rates of previous testing among our sample, and gay community attached men in Australia are similar.

Table 42 Ever previously tested for HIV

	Frequency	Percent
No	75	10.6
Yes	565	79.9
I don't know	7	1.0
Not provided	60	8.5
Total	707	100.0

Among those men who reported having previously tested for HIV, most (69.2%) had tested within twelve months of their HIV-positive test.

Table 43 Previous HIV-negative test result

	Frequency	Percent
Within the 12 months prior to diagnosis	391	69.2
More than one year prior to diagnosis	166	29.4
Not provided	8	1.4
Total	565	100.0

Note: Includes only those men who report having previously tested.

When participants were asked about their most recent HIV-negative test (prior to their diagnosis), we see again that just over half (55.4%) of men had tested any time in the previous twelve months. However, only about a third (37.3%) had tested in the previous six months. Given current testing guidelines (which would actually suggest these men should have been testing quarterly), and the clearly high risk behaviour among these men (in the period prior to their HIV diagnosis), this suggests there remains considerable scope for improving testing frequency in at-risk men.

Table 44 Last time tested negative for HIV before HIV positive test result

	Frequency	Percent
1-4 weeks	24	3.4
1-6 months	240	33.9
7-12 months	128	18.1
1-2 years	109	15.4
2-4 years	22	3.1
Over 4 years	36	5.1
Never (had no previous test)	75	10.6
Not provided	73	10.3
Total	707	100.0

The testing patterns prior to diagnosis reported by participants broadly reflect what might be expected based on when they had last tested (prior to diagnosis).

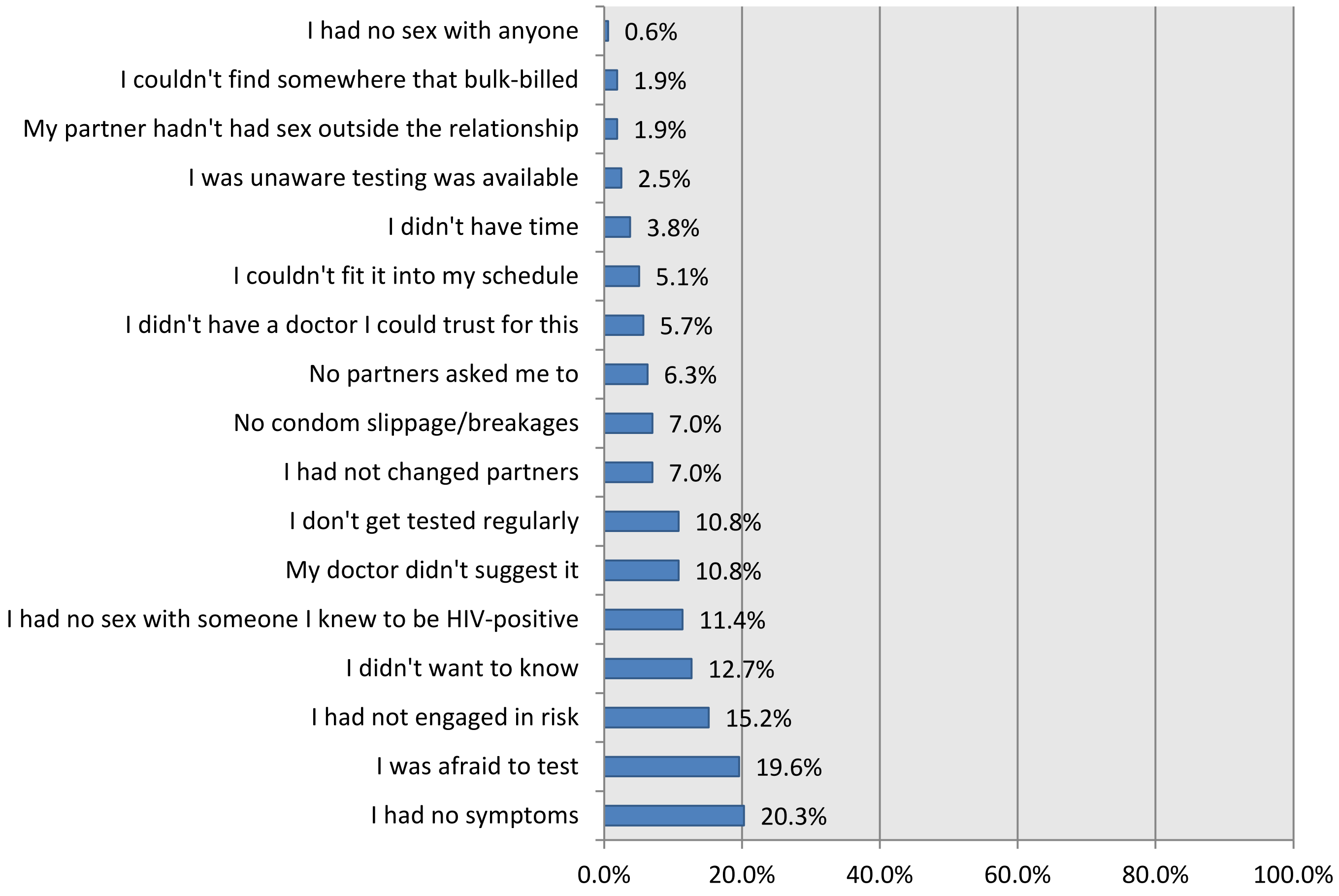
Table 45 Usual pattern for HIV testing prior to diagnosis

	Frequency	Percent
Monthly	1	0.5
Every three months	46	21.4
Every six months	56	26.0
Annually	31	14.4
Less than once a year	43	20.0
Not provided	38	17.7
Total	215	100.0

Note: Question added March 2013.

Those participants who had not tested for HIV in the previous twelve months were asked about their reasons for not testing. About one fifth of men indicated that they had no symptoms and a similar proportion indicated that they were afraid to test. A number of men believed they had not engaged in any risk (or, perhaps, sufficient risk to warrant being tested), and one in nine believed they had not had sex with anyone who was HIV-positive. Some men simply did not want to know their HIV status. These results suggest that there is still scope for education about HIV (i.e. that seroconversion may be asymptomatic and the benefits of early treatment) and continuing to address HIV stigma. Interestingly, convenience and ease of access to testing did not appear to be a major issue.

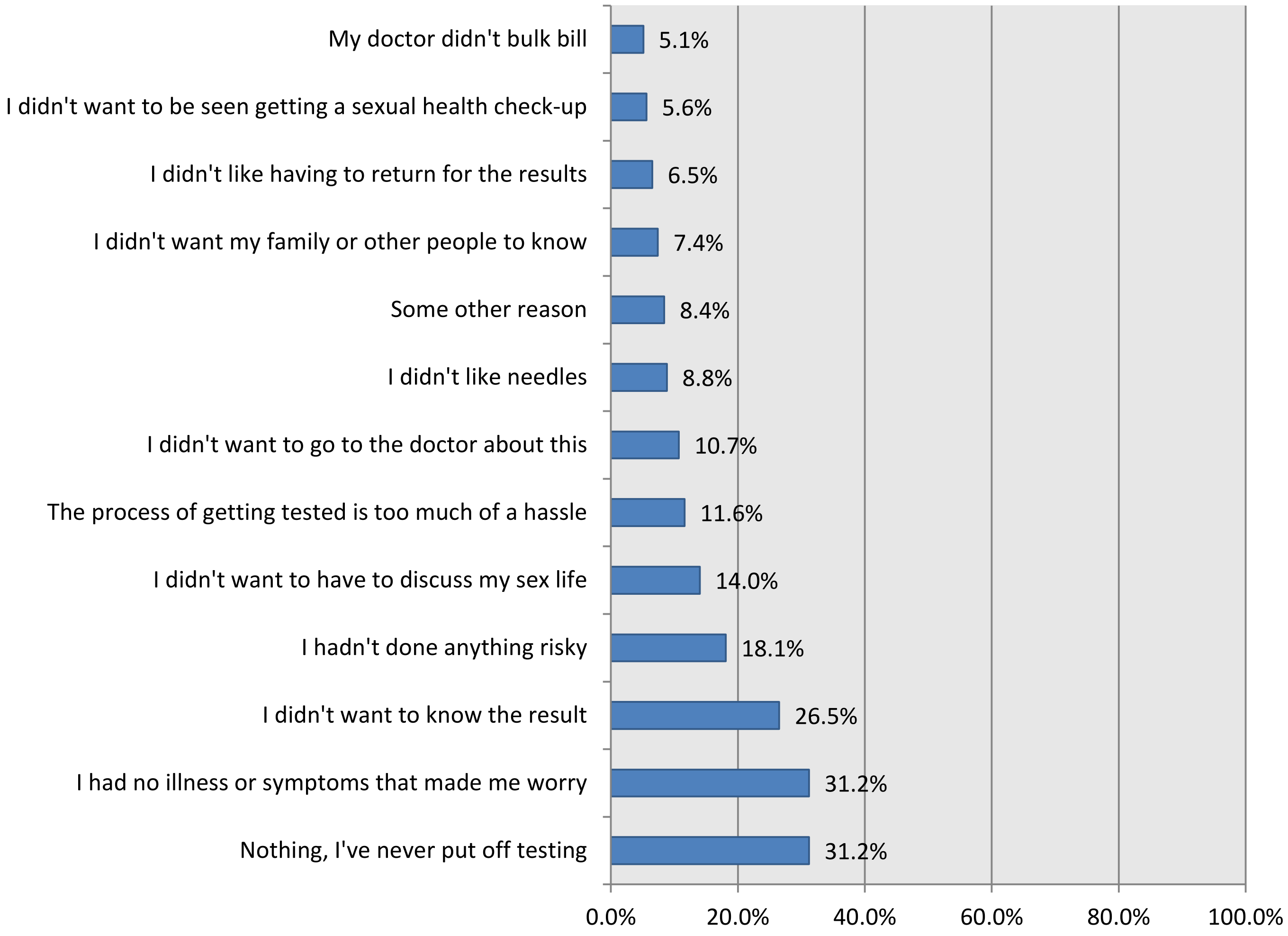
Figure 1 Reasons for not testing for HIV in previous 12 months



Note: Includes only those men who had not tested for HIV in the 12 months prior to diagnosis.

The respondents were asked their reasons for ever delaying testing prior to their HIV diagnosis. Almost a third indicated they had never put off testing. About as many indicated they had no symptoms that made them worry. One in six indicated they thought they had not done anything 'risky'. About a quarter did not want to know the result. There were some issues relating to the participants' relationship with their clinician with one in eight not wanting to discuss their sex life and one tenth not wanting to go to the doctor about testing. Logistical barriers to testing were an issue for a small proportion, with one in nine respondents reporting the testing process to be a 'hassle'.

Figure 2 Reasons for delaying HIV testing prior to diagnosis



Note: Question added March 2013.

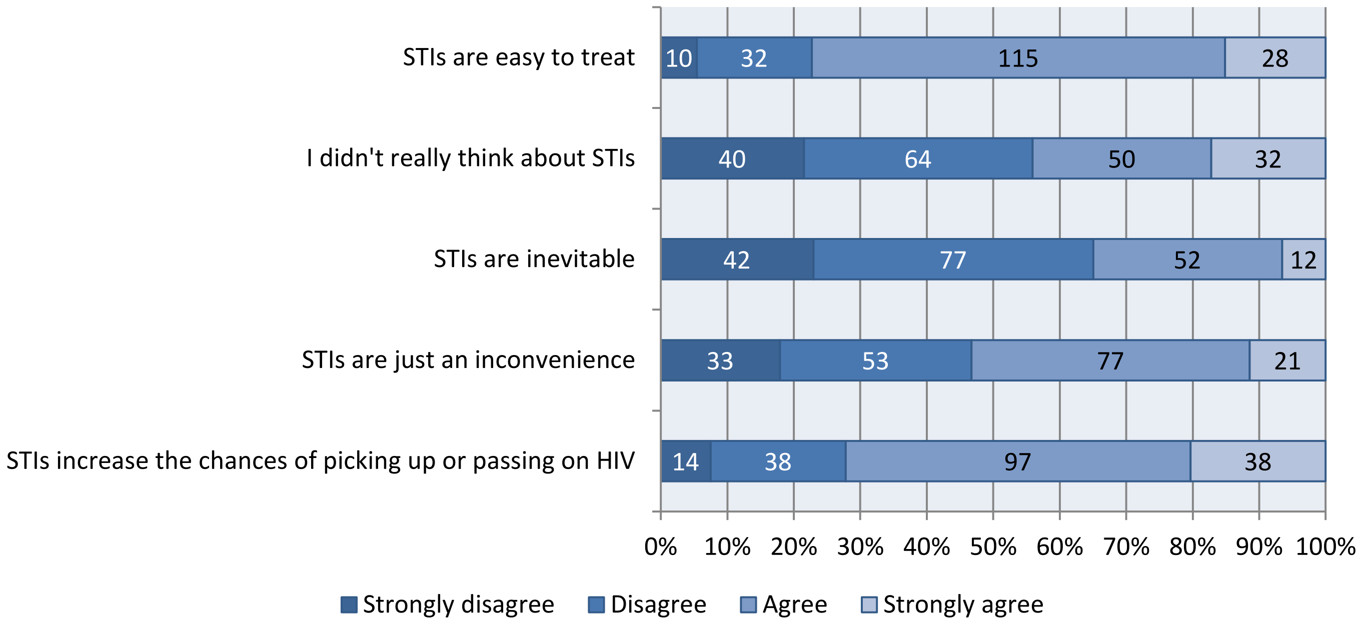
The men in the sample appeared to test for HIV with greater regularity than they did for other sexually transmissible infections (STIs). As with HIV testing, we see a relatively small number were being screened for STIs at least four times a year. Nearly half (41.0%) were tested for STIs at least twice a year. Almost a quarter of men reported never having had a general STI screen, which is of particular concern given the increased risk of acquiring HIV when an active STI is present.

Table 46 Testing for sexually transmissible infections in 12 months before diagnosis

	Frequency	Percent
Never	167	23.6
Once	130	18.4
Twice	130	18.4
Three times	94	13.3
Four or more times	66	9.3
Not provided	120	17.0
Total	707	100.0

Participants were asked what they thought about STIs prior to their diagnosis with HIV. Nearly two thirds (62.2%) correctly agreed that STIs increased their chances of picking up or passing on HIV. Participants were divided when asked whether STIs are just an inconvenience with 45.2% agreeing and 39.6% disagreeing. Participants did however appear to feel more strongly when asked whether STIs were inevitable with only 29.5% agreeing at all. Participants did tend to have at least some awareness of STIs with only 15.2% strongly agreeing with the statement that "I don't really think about sexually transmissible infections", however, 23.0% did agree with this statement. Thinking about the treatability of STIs, most respondents felt that STIs are easy to treat.

Figure 3 Thoughts about sexually transmitted infections



HIV and STI testing history: Reflections from the interviews

Men were asked about their HIV and STI testing history and it was common for participants to define their testing history as ‘regular’ or routine. What constituted regular or routine testing varied and it was not always clear what underpinned the chosen timeframe between tests. For some men regular meant every 12 months, while for others it was every six months and for some it involved testing every 2-3 months:

> *I was being tested for it regularly.*
>
> ***How regularly would -***
>
> *Every two to three months.*
>
> ***That’s pretty regular. [Yeah, yeah]***
>
> *That’s the guidelines…*

Later in the interview he explains his thinking around testing further:

> ***…was HIV something you wanted to avoid?***
>
> *Something that I wanted to avoid but it’s not something that I necessarily proactively avoided, if that makes sense. I tried, I, I did, I … Basically, having condomless sex I knew the risk that I was undertaking. So practising unsafe sex was just something that I did and I understood the risk that I was sort of engaging in and, and what it could mean for me - probably not in its entirety - but I guess that’s one of the reasons why I was getting tested so frequently was because I knew it was a very real possibility of contracting. But I wanted to make sure that, if it happened, I was at least on top of it straight away, basically (SS1140-B, 29, QLD 2015)*

In this case, the testing routine was consistent with testing guidelines for men who had higher numbers of partners and engaged in condomless anal intercourse with casual partners. For other men, their testing routine was determined by time only and was often incorporated into their other routine health checks:

> ***How often in the last say couple of years do you get tested for STIs and/or HIV?***
>
> *Yeah, at least every 12 months. [Okay] So I have a, I sort of try to aim for it to be around my birthday so I can remember to do it. So I do it every 12 months.*
>
> ***Okay. And do you get tested for, what, what do you ask for when you go and get tested?***
>
> *Well it’s called, is it called the “STIGMA test” or something? It’s the Sexually Transmitted Infectious Gay Man’s Assessment… So most, you know, most will be STIs plus HIV. But it does all the other things like, you know, cholesterol and … (SS0100-S, 38, NSW, 2010).*

Incorporating HIV testing into routine annual doctor’s visit is, as the participant notes, a good way to ensure that HIV and STI testing happens at least every 12 months. However, it can also increase the time between infection and diagnosis if men do not also test outside of their routine if they are having frequent and high risk sex such as condomless anal intercourse with casual partners. One participant experienced symptoms of seroconversion shortly after having condomless sex with a ‘fuck buddy’ who he thought was negative:

> *...rash on my inner thigh, inner leg. And, and my face is turning red; started on my right, my right cheek and then progressed to the, to the next. Like as if I was, like I've been sitting in the sun. What else? And my cold sore, like a cold sore, I'd have a cold sore that would last me two, two days. It lasted me like a, a good month when, when it should disappear within what? two or three days. And then I thought, "Oh gee. I've gotta do something." So ... [the high risk event happened in mid June and he did not test until August} and I tested at the sexual health clinic on the 1st of August [year removed]. And because, and then, and then got the results on the 15th of August, [year removed](SS0290-S, 39, NSW, 2010).*

In this case, even with fairly severe symptoms starting soon after the high risk event the participant still waited over a month to be tested.

Men who test in response to illness symptoms are likely to have their HIV infection detected relatively soon after infection and will therefore be able to take advantage of the health benefits of early initiation of treatment and also take action to reduce the risk of onward transmission. In contrast, men who do not experience illness symptoms or misrecognise their symptoms may not be diagnosed for months after infection even if they are testing 'regularly'. In the following quote, the participant had been having condomless anal intercourse, although he believed all of his partners to have been HIV-negative but he delayed testing for a number of reasons, including being overseas, and not experiencing any symptoms:

> ***Did you test in that period, that 18-month period?***
>
> *No. Largely because in [country in Asia], like there was ... I didn't really know how to go get tested necessarily. I found out about six months before I left a place that did anonymous testing. 'Cause the big thing was, "I don't feel sick," you know. Like, "I know I was negative before because I tested negative. Trust him."...And, and there was an element of, if you get, if I tested positive, that's it. Like you're on the next plane out.*
>
> ***Why is that? Is that ...***
>
> *It's [country in Asia]. Like if you're foreign and you test, you're out... And so there was that. And then I found the anonymous place and I was like, "Okay, if it's anonymous, I should go and do it." And I would have found out about them November 09 I think, which was just before we went into intensives again.*
>
> ***Did you, did you have other sexual partners in this time?***
>
> *Yes. [Did] Always with protection though and it was more ... off the internet.*
>
> ***So all with protection?***
>
> *Yes. No. There was one guy (SS0300-S, 39, WA, 2010).*

Among this sample of men, delays in testing or frequency of testing did not appear to be related to service models, costs, or dissatisfaction with available models of HIV and STI testing. However, some men did experience disruptions in their testing routine due to being overseas for work or extended travel:

> *I underwent pretty regular testing. So probably every half year at least. It might be slightly longer, depending on whether I was overseas for a period of time. But, generally, it was at least every half a year (SS1130-B, 32, Qld, 2015).*

While this participant had access to HIV and STI testing when working overseas, his preference was to wait until he was back in Australia, particularly as getting tested overseas often involved paying large out of pocket expenses and then waiting to recover the costs from his workplace insurance.

A small number of men did not have a routine around HIV and STI testing because of anxiety around the results. One participant described a pattern of irregular testing and fears around the potential result:

> ***Yep. And I wonder if you could tell me a bit about your testing history? …***
>
> *Let's see. The tests that I have had with, when I met the boyfriend, I did actually go every three months for that space of time, just because I know I'd been exposed. But before that it was a case of, "Well I've done something that you're really put at risk for and I'm really scared of catching it. I'm too scared to go for a test," so I delay it. (SS0740-P,35, WA, 2012)*

Another participant had never tested due to his fear of needles and it was only when he applied for permanent residency in Australia that he had an HIV test and was diagnosed with HIV:

> ***And had you ever tested for HIV previously?***
>
> *No, because I've got a, needle phobia. I never had any tests in my life, so that's the problem…the thought of it going through my skin. So I can have a needle near me now. I can look at needles, can hold them… but the actual, the part of it going through the skin, I just freak out (SS0300-S, 39, NSW, 2010).*

This delay in testing meant that he had a late diagnosis and also that he was not easily able to identify a high risk event.

Greater availability and promotion of home testing for HIV may be one strategy for increasing the frequency of testing among gay men who travel overseas for work, study, or extended holidays. Promotion of this strategy would need to include information about what do in terms of reducing transmission risk if the test was reactive until they were able to access a confirmatory test. Rapid HIV tests were not available in Australia for most of the period that this study was being conducted. These rapid tests may also assist some men who are anxious about receiving results by reducing the waiting time and they may also be helpful for the minority of men who are fearful of needles as the testing process is less invasive.

During the latter part of the study, HIV rapid testing had become available in Australia. The availability of HIV rapid tests has enabled a number of state-based AIDS Councils to establish peer-led HIV and STI testing services in community settings. The introduction of community-based testing may encourage some men to test more frequently as illustrated in the following example:

> ***So how long had you delayed testing for?***
>
> *God, this is going back. I can't remember. I've never, basically, gone every three months. Like I said before, it was like six months or something. [Yeah] And then one year like 2010 I didn't get, have sex for most of that year, so I didn't get tested at all. It wasn't 'til I knew I'd been exposed, potentially exposed, when I actually did go and seek testing. I was always too scared to go for a test. And the one, first couple of experiences with going for a test was through my GP, family GP that I'd been seeing since I was a teenager, and they didn't know much about HIV. And they were kind of, I can remember some of the things they'd say to me, like, "You're playing Russian roulette." I didn't feel comfortable. And it wasn't until that, that scare and I met the boyfriend, I actually did a test through WAAC, the AIDS Council, when I actually felt more comfortable knowing the support would be there. So*

> *earlier on, I wasn't getting tested regularly – it was only 'til I had the scare – and then I got tested regularly. And then, like I said, 2010 I didn't get tested (SS0740-P,35, WA, 2012)*

This participant had earlier in the interview talked about avoiding testing (above quote) because he was anxious about the result. Finding a testing service that was non-judgemental, where the staff had sound information about HIV, was gay-friendly and the overall testing experience was comfortable was highly valued by some participants:

> ***...what was it about M Clinic that, that made you decide to come here for your testing?***
>
> *Because it's a place for gay men and it just, in [country in western Europe] I was going to hospital and the nurse, I, when I was in [country in western Europe] and when I got tested the first time, yeah, I was, I was not having a lot of fun because I was just out, so I was just discovering. And I had probably ten partners in a year. And for me it was a lot and for her I was like ten partners is what you have to get in your life. She was like making me a moral about having sex with ten guys in one year, you big slut. Like I was a whore, like a, a big slut. And I was taking so much risk and stuff... But in Perth, yeah, the M Clinic is a place for gay men. You can talk pretty much open and people won't judge. Or, even if they judge, I think they have an understanding of what can, what the gay life is because I think very much everybody here is gay. Or, if they're not gay, they're gay-friendly. So I don't think anybody is judging anybody and it's a good feeling. (SS0810-P, 27. WA, 2012)*

In this case even after testing HIV-positive he continues to visit M-Clinic every few months for STI screening.

PEP and PrEP

> “It is essential that we continue to build community awareness of PEP and PrEP so that our community have the opportunity to exercise even greater control over their sexual health. Access to PrEP, in particular, will provide significant opportunities to greatly reduce the number of new infections in the near future.”
>
> Nic Parkhill
> *ACON*

PEP and PrEP

Over the course of the Seroconversion Study, PEP and then PrEP have emerged as effective biomedical technologies to reduce the risk of HIV transmission. Participants were asked about their knowledge of PEP and, of those who responded, only a little over half knew of PEP at the time of HIV exposure.

Table 47 Knowledge of PEP at the time of exposure to HIV

	Frequency	Percent
No	237	42.2
Yes	324	57.8
Total	561	100.0

Note: Includes those men who responded to this question.

About a quarter of those who responded indicated they had used PEP previously.

Table 48 Previous use of PEP

	Frequency	Percent
No	228	70.4
Yes	90	27.8
Total	324	100.0

Note: Includes those men who responded to this question.

In versions 3 and 4 of the questionnaire, men were also asked about their use of PrEP. As PrEP was generally unavailable in Australia at the time, it was unsurprising that very few men reported they had used it at all.

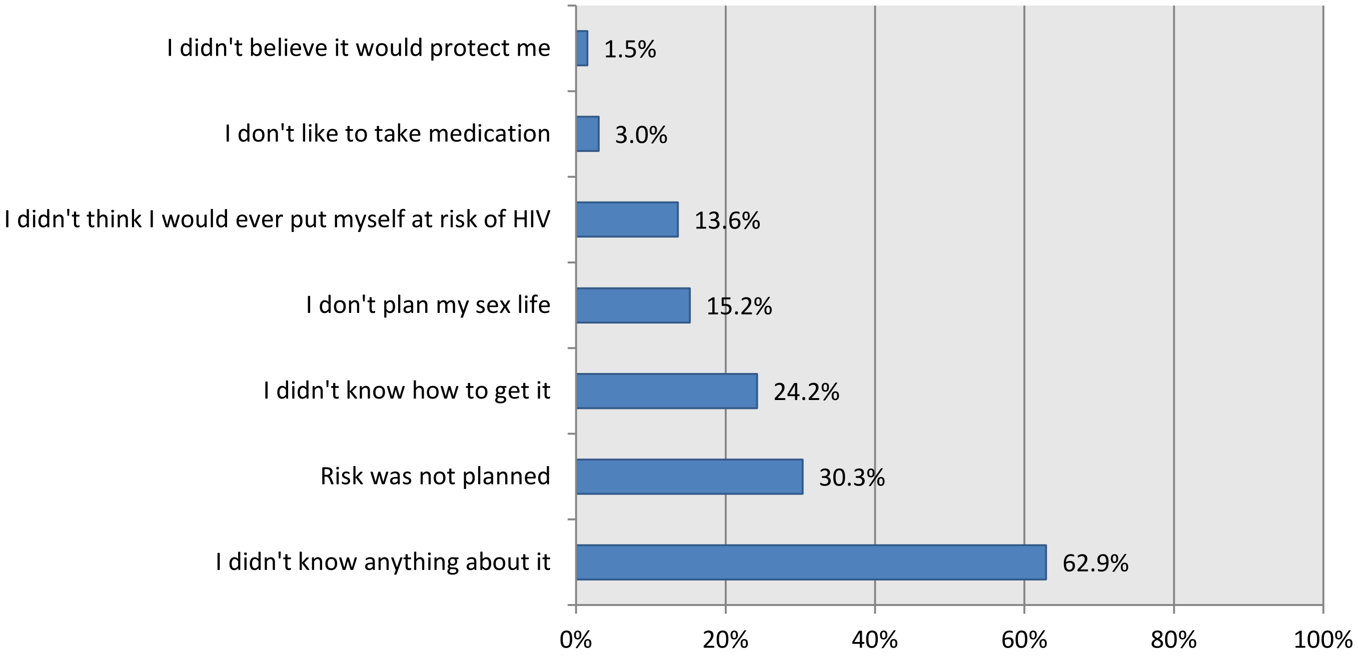
Table 49 Use of anti-HIV medication before sex to reduce the chance of getting HIV (PrEP)

	Frequency	Percent
No	129	97.7
Yes, once	1	.8
Yes, several times	2	1.5
Total	132	100.0

Note: Question added in March 2013. Includes those men who responded to this question.

Participants were then asked their reasons for not using PrEP at the time of the high-risk event. Two thirds of men indicated that they did not know anything about it and one third indicated that the risk was not planned. Lack of access was also a problem with one quarter of men indicating that they did not know how to access PrEP at the time.

Figure 4 Reasons for not using PrEP at the time of the high-risk event



Accessing PEP

Men were asked why they did not access PEP following their high-risk event. Among free-text responses to this question, many men reported not feeling as if they had put themselves at sufficient risk to warrant accessing PEP. Another reason for not accessing PEP appeared to be bad experiences of having accessed PEP on a previous occasion.

> *"Hard to get from hospital emergency room as you're deemed as not important."*

The experience of presenting for PEP can be stressful in itself. The experience of accessing PEP at hospital emergency departments seems to be particularly difficult, possibly due to a lack of understanding of emergency department personnel.

> *"The last time I had asked about taking PEP at the local hospital I was met with attitude and condescension. This made me feel like asking for PEP was a crime and that I was taking up valuable resources by asking."*

It is important that clinicians respond to each presentation in a non-judgemental way, using non-stigmatising language, to ensure that people are comfortable re-presenting for PEP, if and when required.

> *"Obtaining PEP was horrendous and one of the worst experiences of my life. [It's] easier just to accept getting HIV, hence my decision not to go a third time"*

Some suggested a willingness to pay for PEP, so as to avoid the process of presenting at a health service and having to justify their request.

> *"On my previous two occasions I was grilled to a point I felt like I was begging; I would rather have just bought them over counter even if [for] $400"*

It is important to note that these experiences were expressed by a minority of men. Nonetheless, these infections may have been prevented, had their experiences been different.

PEP and PrEP: Reflections from the interviews

The online survey results show that knowledge about PEP was relatively low and this was also the case with the men in the interview sample, with only about half the sample having knowledge of PEP. Of the men who were aware of PEP, including men who had accessed PEP in the past, only a small number thought about using it at the high risk event/s they believe led to their HIV infection. The interviews reveal a number of explanations as to why men did not access PEP including not perceiving their sexual behaviour to be risky, fears about being judged, uncertainty about where to access it, concerns about side-effects, prolonged sexual partying that took them outside of window period for PEP access, and engaging in frequent sexual risk that made the event based/one off nature of PEP as an impractical strategy. In the following extract, the participant was worried about having potentially put himself at risk but cites travel and uncertainty about whether the man he had sex with was HIV-positive as reasons why he did not access PEP after the high risk event:

> *A little bit worried. Concerned. And so that's why I texted him immediately. I thought, "Well I better clear this up." And then when, then when he said, "Oh yeah, nothing to worry about," I thought, "Oh well, okay. Well it just must be bitchy malicious gossip."*
>
> ***Was this a small town?***
>
> *[name of Regional City] So ... smallish but not so small. And I thought well it's likely that everyone knows each other. And it's likely that there is to be a certain level of gossip. Like I remember having difficulty getting to sleep that night and worrying about it again in the morning, but not so much. And so, because I was down there for a conference, I just went about the ordinary, my ordinary day. And I didn't really think about it anymore to try and get to, to a clinic. Because the conference was on and I thought, "No, should be okay," you know. So, and I was tossing up should I go, should I not go. And eventually I just thought, "Oh no, it'll be okay. I won't, I won't have contracted HIV. I'll just wait until I get back to Brisbane. I'll do an STD check. Get everything checked out then. I'll be, I'll cross my fingers and it should be all fine."*
>
> ***In this case by the time he returned home, he was outside the window period for assessing PEP, he was however, still somewhat concerned and a few days later had an HIV test, which came back as in "indeterminate" and a subsequent test came back as HIV positive (SSO210-B, 34, QLD, 2009).***

A few participants talked about PEP as something they could indirectly use post diagnosis to reduce their risk of onward transmission, for example if a condom broke:

> *If anything I'm like I know I am not going to take any risk should something go horribly wrong – should a condom break or something. I actually have the knowledge of, you know, like well you need to call, you know, RPH or Free-o Hospital. Get PEP. Like know what to do (SSO460-P, 27, WA, 2011).*

Another man described suggesting PEP as an option to an HIV-negative man with whom he had anal intercourse with condoms because he felt conflicted about having not told the man that he was HIV-positive prior to sex:

> *...got home and chatted to him on the internet probably a few hours later. And I just sort of couldn't come to terms with myself not telling him. So I said, "Look, by the way, I'm positive. You know, don't worry, nothing was unsafe. You wouldn't have got anything." And he said, you know, "My God, you should have told me beforehand." And I said, "Well yes, I should have but I'm sorry, but, you know, I'm confused about it myself at the moment. And, you know, if you're worried about it, you've got 72 hours to get PEP. Here's the telephone*

> *number." … "Look, if you need to call me, here's my phone number. Ring me anytime. You know, if you want me to come with you, whatever, that's fine… (SS0040-M, 32, Victoria, 2009).*

Here PEP is articulated as a way for the negative partner to manage anxiety around HIV transmission, and as a way for the participant to manage his own feelings of anxiety and 'guilt' around not disclosing his HIV status:

> *I was going through trial and error, … I didn't know what was right and what was wrong. And I still don't know. And I was like, "If I told them beforehand maybe he'll reject me. If I didn't, you know, should I tell him up-front then would he tell other people, and other people would know that I am?" So all these sort of things go in your head. And so I thought no … And then you do it and then felt guilty afterwards. So then you tell him and then I thought, "Well … I've done the wrong thing by him. Who's to say that I've done the right or wrong thing? You know, all that I can do is offer what I know and, you know, that he's got 72 hours to get PEP if he's that concerned about it." Put on the table that I haven't, can't be blamed if he does get it, for not trying to help or assist him. So … then a few days later he, I got another message and he was fine about it,… (SS0040-M, 32, Victoria, 2009).*

This quote also illustrates the complexities for newly diagnosed men around negotiating sex and disclosure and the importance of biomedical prevention technologies such as PEP for both HIV-negative and HIV-positive men.

As noted elsewhere in this report there has only been limited access to PrEP in Australia. Therefore it is not surprising that PrEP features rarely in the interviews. A few participants interviewed post-2010 were aware of PrEP, although only two knew anything about it prior to their own diagnosis. One man speculated that price would have his influenced his decisions around using it:

> *PrEP is something that I didn't really, I wasn't aware of PrEP until after I seroconverted and it's, although it can be, it can be prescribed in Australia, it's something that's not on the PBS so you'd have to pay for it yourself. But yeah I wasn't aware of it at the time of seroconversion. If I was, it, it might have been something I considered until I found out the price of it and then I think I probably wouldn't have, so … But, if it was prescribed on the PBS and I was aware of it, I definitely would have taken it(SS0970-S, 43, NSW, 2014).*

Another man knew about PrEP prior to his HIV infection and was exploring ways to get access to it however, he did not manage to do so before becoming HIV-positive:

> *PrEP had come out and I actually tried to go on the NSW PrEP study … but the government cut the funding on it so … [note the study was funded but was delayed starting]. I got a, I received an email saying, "Do you want to go on the PrEP study?" Like, "Oh that horse has bolted. You're a bit late."*
>
> ***So you were aware of PrEP before?***
>
> *I was aware of PrEP and I, and I'd actually talked about it to some of my pos friends and they'd mentioned that Truvada was the one that people were using for, for PrEP. So I kind of talked to friends who had been on Truvada and I knew that. And I'd been in [city in Asia] in the December …I tried to buy it and they said, "Oh no, you need a prescription," … So it was all getting too hard. But I was actually going to go and buy Truvada and just use it for episodic events.*
>
> ***So, and you didn't consider accessing it from your positive friends?***

> *No, I never thought of that. I don't want to pinch their meds. But, then it was how stupid am I? All you do is go down and go on PEP. I mean I didn't, I thought, "Duh." It's, it's, you know, you just rock up and say, "I've been exposed," and they give you a month's supply (SS01010-S, 53, NSW, 2014).*

It is not useful to speculate as to whether the men in this study would have used PrEP had it been available, and therefore avoided becoming HIV-positive; we cannot know. However, it is useful to treat these accounts as a source of valuable information for researchers, health communicators and clinicians in identifying the potential targets of PrEP. Arguably, PrEP may be a useful and potentially effective option for gay and bisexual men who are like the men represented in this study: those who sometimes or even always have condomless anal intercourse; men who travel overseas for extended periods of work and may therefore have limited access to PEP and HIV testing; and men who have sex in contexts where it is not always possible to negotiate condom use or have explicit discussions about HIV status.

The High-Risk Event

> “Many of our M Clinic clients receiving a positive diagnosis are fairly sure of when and how their infection occurred. This may be a result of testing frequency and perhaps further underscores the value of peer-based services in a community clinic.”

Andrew Burry
Western Australia AIDS Council (WAAC)

The High-Risk Event

Participants were asked whether they could identify a particular high-risk event or events where they were most likely to have acquired HIV. One third of men identified a single high-risk event and a further half identified more than one such events. Where men identified more than one high-risk event, they were asked to select the most likely transmission event to discuss in further detail.

Table 50 Number of high risk events

	Frequency	Percent
One	228	32.2
More than one	355	50.2
Not provided	124	17.5
Total	707	100.0

Geographic location of the high risk event

Participants who had been able to identify a high risk event described where the high risk event occurred. Four fifths (80.9%) of those who responded indicated the event had occurred in Australia.

Table 51 National location of high risk event

	Frequency	Percent
Australia	473	81.1
Overseas	108	18.5
Not provided	2	0.3
Total	583	100.0

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection.

The men who indicated the high risk event occurred in Australia were asked in which state the event had occurred. The distribution broadly agreed with HIV notification data. New South Wales had the highest with almost two fifths of the high-risk events, Victoria followed with over one quarter and Queensland with one fifth. One in ten men who indicated that the high risk event had occurred in Australia reported that their diagnosis occurred in a different state or territory to where they believed they had acquired HIV infection.

Table 52 Australian state where the high risk event occurred

	Frequency	Percent
NSW	182	37.8
VIC	132	27.4
QLD	95	19.7
WA	32	6.6
SA	17	3.5
ACT	8	1.7
TAS	4	0.8
NT	1	0.2
Not provided	11	2.3
Total	482	100.0

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection, and that this event had occurred in Australia.

Overseas acquired HIV

Men who indicated that the high risk event had occurred overseas were asked in which country the event had occurred. One in five said that it had occurred in the United States and one in eight said it had occurred in the United Kingdom. One third (33.6%) indicated that the high risk event had occurred in an Asian country.

Table 53 Overseas location of the high risk event

	Frequency	Percent
Asia	28	24.6%
Europe	24	21.1%
North America	19	16.7%
South America	5	4.4%
New Zealand	4	3.5%
Not provided	34	29.8%
Total	114	100%

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection, and that this event had occurred outside Australia.

When asked why they were in the country at the time of the high risk event, two fifths of participants whose high risk event had occurred overseas indicated they were there on holidays and another two fifths indicated they were living there at the time. Over one quarter indicated they were there for work. Very few men indicated they had met someone over the internet or had travelled for sex.

Table 54 Reasons for being in the country at that time

N=114	Frequency	Percent
I was there on holiday	49	43.0%
I was living there at the time	47	41.2%
I was there for work	31	27.2%
I had arranged to meet someone over the internet	2	1.8%
I was there for sex	1	0.9%

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection, and that this event had occurred outside Australia.

The amount of time these men had been in the country before the high-risk event tended to be either very short (one fifth of men indicating less than a month) or relatively long (one fifth of men indicating greater than two years). Basically, the amount of time they had spent overseas reflected their reasons for being overseas at the time: those who had been there for an extended period of time generally reported living there, while those who had only been there briefly were mostly there on holiday.

Table 55 Length of time in the country

	Frequency	Percent
Less than a month	25	33.8
1-3 months	10	13.5
4-6 months	3	4.1
7-12 months	5	6.8
1-2 years	7	9.5
More than 2 years	24	32.4
Total	74	100.0

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection, and that this event had occurred outside Australia. Only includes those who responded to this question.

When asked how many times they had visited the country where the high risk event had occurred in the previous year (including the occasion of the high-risk event itself), about half (45.0%) said just once and this proportion increased to three fifths (61.7%) for men who visited once or twice. At the other extreme, one fifth (20.0%) of respondents reported visiting the country more than five times.

Table 56 Number of visits to that country in the previous year

	Frequency	Percent
Once	27	45.0
Twice	10	16.7
Three times	2	3.3
Four times	4	6.7
Five times	5	8.3
More than five times	12	20.0
Total	60	100.0

Note: Includes the visit when the high-risk event occurred. Includes men who identified a high risk event at which they believe they acquired HIV infection, and that this event had occurred outside Australia. Only includes those who responded to this question.

Physical location of the high risk event

Looking now at all men (irrespective of whether the high-risk event occurred in Australia or overseas), participants who had been able to identify a high risk event were asked specifically where the high-risk event occurred. One quarter of respondents indicated a partner's or friend's home and another quarter indicated their own home. One in ten indicated a sauna, another tenth indicated a sauna. Smaller numbers indicated a beat or public place, or a sex party. So, overall, under a third of the high risk events occurred in a sex-on-site venue of some sort. Another tenth indicated that the high risk event took place in a hotel/motel room.

Table 57 Where the high risk event occurred

	Frequency	Percent
My partner's or a friend's home	154	26.4
My home	148	25.4
A sauna	61	10.5
A sex club	58	9.9
In a hotel/motel room	56	9.6
A beat or other public place	41	7.0
A sex party	20	3.4
Other	39	6.7
Not provided	6	1.0
Total	583	100.0

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection.

Sex at the high risk event

Virtually all participants who were able to identify a high-risk event indicated that they had sex with a man at the high risk event. Those who had not had sex at the high-risk event may have engaged in other activities that the participant believed put them at risk such as injecting drug use and needle sharing.

Table 58 Sex with a man at the high-risk event

	Frequency	Percent
No	7	1.2
Yes	581	97.5
Not provided	8	1.3
Total	596	100.0

Note: Includes only those men who could identify a high-risk event

Those men who indicated that they had had sex with another man at the high-risk event were asked what kind of anal sex occurred. They tended to report receptive anal intercourse more than insertive anal intercourse. Two fifths of men reported receptive condomless anal intercourse with ejaculation (the highest risk sexual practice for HIV transmission). The greater likelihood to have engaged in receptive than insertive anal intercourse, and the high rate of ejaculation in the rectum, contrasts sharply with what is usually reported by gay men, particularly HIV-negative gay men (as these men presumably were on the occasion of the high risk event). In most other research conducted among gay men in general, HIV-negative men tend to be at least somewhat more likely to engage in insertive than receptive anal intercourse and the rates of ejaculation in the rectum are considerably lower than what is reported here.

Table 59 Sexual behaviour at the high-risk event

N=583	Frequency	Percent
Any anal intercourse	518	88.9
Insertive anal intercourse	220	37.7
Receptive anal intercourse	434	74.4
Reciprocal anal intercourse	136	23.3
Any condomless anal intercourse	468	80.3
Insertive condomless anal intercourse	180	30.9
Receptive condomless anal intercourse:	403	69.1
withdrawal	138	23.7
with ejaculation	249	42.7
Reciprocal condomless anal intercourse	115	19.7

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection.

Those men who reported no condomless anal intercourse at the high-risk event were asked whether they had engaged in oral sex with ejaculation: one fifth of men (19.5%) who answered the question indicated that they had.

Table 60 Oral sex with ejaculation among men who did not report condomless anal intercourse

	Frequency	Percent
No	52	70.3
Yes	22	29.7
Total	74	100.0

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection, but who reported no condomless anal intercourse at that event.

Decisions about condom use and perceptions of risk

Those men who reported condomless anal intercourse were asked who made the decision to not use a condom on this occasion. One fifth of men indicated that they had both agreed not to use a condom and another fifth indicated that they had simply done so (i.e. not used a condom) without discussion. Smaller numbers of men indicated that the partner had asked him not to use a condom or that they had made the request themselves of their partner.

Table 61 Condom decision at the high-risk event

	Frequency	Percent
I asked him not to use one	6	1.6%
He asked me not to use one	20	5.2%
We both agreed not to use one	81	21.1%
Neither of us said anything	85	22.2%
Total	383	

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection and who reported condomless anal intercourse at that event. This question was introduced in 2010.

We further asked the men who reported that condomless anal intercourse occurred what condom-related events transpired during the course of the high-risk event. One third of men reported that condoms were not used from the start and one quarter of men indicated that neither party said anything. Much smaller numbers of men reported that they only noticed during sex that a condom was not being used or had been removed, that nothing was said when a condom was removed during sex, or that a discussion happened during sex that resulted in stopping condom use.

Table 62 Process of non-condom use at the high-risk event

n=383	Frequency	Percent
We never used a condom from the start	125	32.6%
Neither of us said anything	102	26.6%
I noticed after sex that he hadn't used a condom	14	3.7%
I noticed during sex that he hadn't used a condom	12	3.1%
He took it off, and I didn't say anything	9	2.3%
He took it off when I wasn't looking and I didn't notice until later	7	1.8%
During sex, we talked, and decided not to keep using condoms	6	1.6%
I took it off, and he didn't say anything	2	0.5%

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection and who reported condomless anal intercourse at that event. This question was introduced in 2010.

So, overall, it appears that when a condom was not used at the high risk event, this was most commonly a mutually unstated decision from the outset.

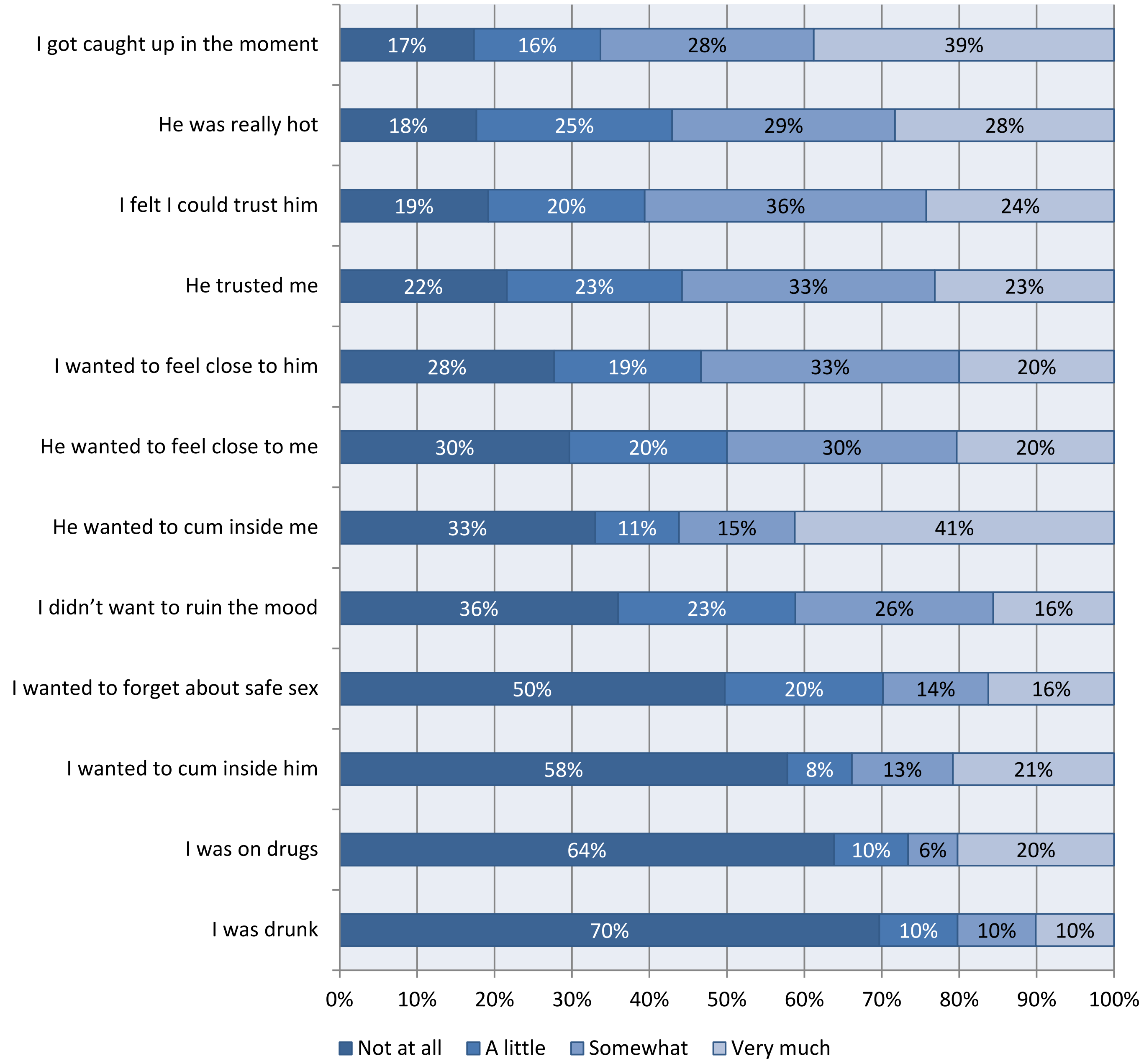
Those participants who reported condomless anal intercourse were asked their perception of the degree of risk of acquiring HIV to be during the high-risk event. A third of men reported that they did not think about it at all while those who had considered the issue of risk tended to believe the risk was very low or low.

Table 63 Perceived risk at the high risk event

	Frequency	Percent
Didn't think about it	127	33.2
Very low risk	93	24.3
Low risk	71	18.5
Moderate Risk	19	5.0
High Risk	30	7.8
Very high risk	7	1.8
Not provided	36	9.4
Total	383	100.0

Participants were asked about their feelings at the high-risk event, particularly regarding factors that may have influenced the decision whether or not to use a condom. Many respondents felt they were 'very much' "caught up in the moment" and also that "He was really hot". Additionally the two statements relating to trust ("I felt I could trust him"/"He trusted me") seemed to apply for many men but the two statements relating to closeness, or intimacy ("I wanted to feel close to him"/"He wanted to feel close to me") were less commonly cited. Few respondents blamed what had occurred at the high risk event on their use of alcohol or drugs ("I was on drugs"/"I was drunk").

Figure 5 Feelings at the high-risk event



Note: Question added in July 2010, includes responses only from those men who have enrolled since then, and reported sex at their high-risk event

Alcohol and drug use at the high risk event

One third of participants who had identified a high risk event indicated that they had consumed alcohol at that event.

Table 64 Alcohol use at the high risk event

	Frequency	Percent
No	374	64.2
Yes	209	35.8
Total	583	100.0

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection. This question was introduced in 2010.

Use of some drugs has been associated with HIV transmission, though the particular relationship is likely indirect and probably has more to do with participation in particular gay subcultures than a direct and immediate effect on men's risk behaviour. The drugs most commonly, and clearly, associated with HIV infection, have been crystal methamphetamine, erectile dysfunction medication (such as Viagra™ or Cialis™), and amyl nitrite, all of which are commonly used to extend and enhance sexual experience. Over half (52.9%) of men who were able to identify a high risk event indicated that they had used drugs at that event. When asked which drugs they had used at the high-risk event, amyl nitrite was the most common with over a third reporting its use. About one in eight men reported crystal use and a similar proportion reported erectile dysfunction medication use. Fewer men reported other drugs, such as marijuana, ecstasy, and GHB.

Table 65 Type of drugs used at the high-risk event

n=583	Frequency	Percent
Amyl	220	37.7
Crystal	78	13.4
Erectile dysfunction meds	73	12.5
Marijuana	62	10.6
Ecstasy	48	8.2
GHB	42	7.2
Speed	22	3.8
Special K	13	2.2
Cocaine	10	1.7
LSD	2	0.3

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection.

One in ten (10.9%) of those who answered the question indicated that they had injected any drug(s) at the high-risk event.

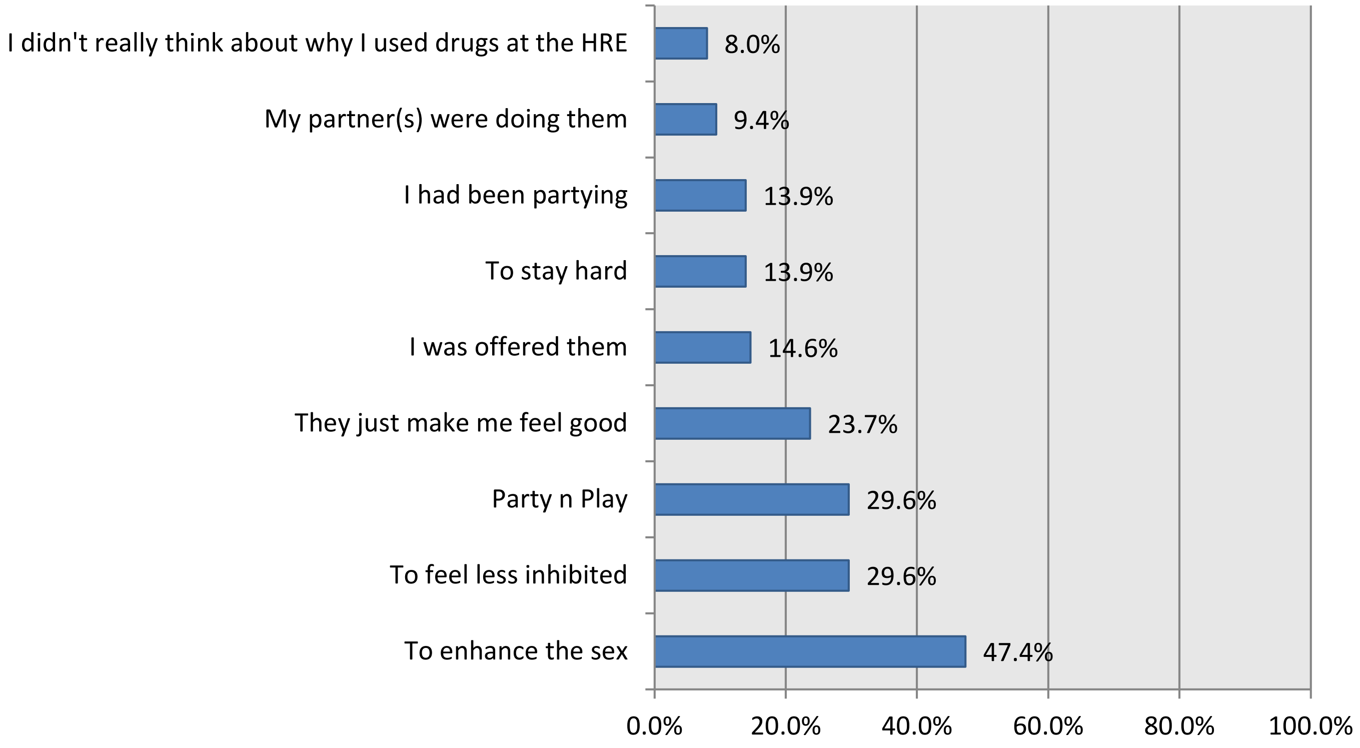
Table 66 Injecting drug use at the high-risk event.

	Frequency	Percent
No	384	89.1
Yes	47	10.9
Total	431	100.0

Note: Includes men who identified a high risk event at which they believe they acquired HIV infection and who responded to this question.

Each participant who reported using drugs at the high risk event was asked to indicate why they had used drugs at the time. Nearly half indicated that enhancing the sex was their reason for drug use. About a quarter used drugs as part of a “Party n Play” session. One quarter also indicated that they used drugs to feel less inhibited. Interestingly, only a small number of men indicated that they didn’t really think about their reasons for using drugs so it appears that drug use was quite a conscious choice (the opposite of what was found in condom use).

Figure 6 Reasons for drug use at the high-risk event



Note: Includes men who reported having used drugs during the high risk event at which they believe they acquired HIV infection.

STIs and other health conditions

Having open wounds and ulcerous conditions can exacerbate the likelihood of HIV transmission, even potentially during what might otherwise be a low risk sexual encounter. Some of the men in our sample indicated that they did not engage in condomless anal intercourse on the occasion that they believe resulted in their HIV infection. Among these men, some reported having a medical condition or infection that might have contributed to their infection.

Table 67 Site of medical problem or infection at the time of the high-risk event

N=260	Frequency	Percent
Anus	11	4.2
Mouth	13	5.0
Penis	8	3.1
Throat	8	3.1

An active STI has been shown to increase the risk of acquiring HIV so each participant was asked if they had any active STIs at the time of the high-risk event. One in twenty reported having syphilis at the time, and slightly more said they had anal chlamydia.

Table 68 Active sexually transmitted infections at the time of the high-risk event

N=232	Frequency	Percent
Anal chlamydia	15	6.5
Syphilis	13	5.6
Anal herpes	8	3.4
Anal warts	7	3.0
Genital herpes	7	3.0
Oral herpes (cold sores)	5	2.2
Anal gonorrhoea	4	1.7

The high risk event: Reflections from the interviews

Most interviewees were able to identify either one or several high risk events that they believe led to their HIV infection. Similar to the online survey a majority of the men interviewed identify receptive condomless sex as the sexual behaviour in which they engaged. However, the narrative accounts of newly diagnosed gay men reveal a range of other factors that shaped the high risk event/s. These factors include relationships, emotions, communication around HIV status, drug use, sexual pleasure, spaces, and travel. While these factors should not be interpreted as causal they do nonetheless provide insights into the circumstances and contexts in which HIV transmission can occur.

The following extract from an interview with a 49-year-old gay man from Queensland shows how factors such as being away from home, drugs, sexual pleasure, and being in a space which enabled casual sex were part of the context in which he believes he contracted HIV:

> ***Tell me about the circumstances through which you believe you acquired your HIV.***
>
> *I was with my partner at the time and we were in Sydney, and we'd gone to Sydney specifically for a dance party. We were staying with friends and our practice at the time was to partake in a little bit of, I, well we took pills and then we'd go to the dance party and dance. And this particular dance party has a reputation for having a dark corner where casual sex takes place and, yeah, that's where I was and my partner had been in there, and we would go in separately or together. And, yeah, at the end of the night, I guess I had taken more substances than I had realised and I had engaged in some sexual practices that I had not normally, that I would not normally engage in. I had been in the dark corner and I had, basically, I was fucked without, without condoms and I don't think, well I, I know I didn't have the wherewithal to stop it. It was … But, having said that, it wasn't without consent… I let it happen (SS1060-B, 49, Qld, 2014***)***.*

While this was not the only time he had ever had condomless anal sex with casual partners, it was nonetheless his usual practice to use condoms with casual partners, and it was also usually the case that he would discuss HIV status with partners, but this also did not happen at the high risk event:

> **And I wonder if, because you mentioned, … using condoms, I mean that was a way of… *protecting yourself, avoiding HIV but did you discuss HIV with, with the guys you had sex with insofar as asking about their status?***
>
> *Generally, we'd, yeah, generally, I did, yeah. [Yep] On the particular event, no. In some cases during that particular event, I didn't even know who was in there. I just know there were people there. So …it really highlighted to me that, you know, I, I really, I really dropped the ball for, you know, responsible self-care. It just disappeared completely. It … I allowed myself to fall into that. It's it's a trade-off of intimacy against self-care and that's what it was for me. And it was a … and maybe that, maybe it wasn't intimacy: maybe it was just, just sheer basic pleasure, that sort of sexual pleasure that's just not, that there's a level of intimacy in it but it's, the intimacy is a, is a chemistry between two individuals. You don't necessarily have to know each other. Just, they're, sexually they just, they click at that moment and that's probably more than anything because of the drug. But there's a, it just happens right then. It's that sort of spontaneous thing. But it's the, what you go through afterwards that's the, the drama. It's a big price to pay (SS1060-B, 49, Qld, 2014***)***.*

This account illustrates the tensions that can arise for some gay men when trying to negotiate the kind of sex they want, the spatial and sexual context and avoiding HIV. It was only once he returned home, that he consciously recognised the potential HIV risk. He believed it was too late to access PEP and about two weeks later he became ill, had an HIV test and was diagnosed with HIV:

> *Got home to my friend's place where we were staying. We slept. The next day slept all day. I think we got up at lunch time and went for lunch somewhere. Did not even think about what happened the night before. Didn't even remember. Really, it hadn't even struck me. It wasn't until probably the Tuesday or the Wednesday when we got home and I thought, "No, it'll be fine. It's too late now anyway. I'll be fine." And then probably two weeks later the flu hit. 'Cause I got my diagnosis… it was exactly a month. So I guess between my, my infection and my diagnosis, it was 30 days or something. Not many people have that sort of narrow window. So I guess I got caught early but, you know, on treatment early, which is good (SS1060-B, 49, Qld, 2014).*

For other men, the end of a long term relationship and re-emergence as a single gay man formed part of the context in which the high risk event occurred. This was the case for a 29 year old gay man who had ended an eight year monogamous relationship 12 months prior to his HIV diagnosis:

> *…We split up…life was pretty normal. It was pretty good. I was living by myself. I was working full-time. Still working full-time…lots of casual sex, basically. That is pretty much where I'd gotten to. I had come out of a relationship and I was trying to make up for lost time (ss1140-B, 29, QLD, 2015).*

Making up for lost time for him involved having receptive condomless sex:

> *A large portion of sexual activity that I was engaging in was condomless sex. There was only a handful of times where a condom was used. I, I, I'm a bottom so I'm always the receiver; I'm never the giver. I never, I just never enjoyed the, the, the feeling of sex with a condom on. I always felt like there was some kind of barrier. I guess there is. But, yeah, the, yeah, the connection wasn't, wasn't really there if there was a condom being used. But it was also in relation to the end result of the climax, the ejaculation. I didn't, didn't appreciate that being inside a condom; I preferred that to be either inside me or on me.*

He did not wish to use condoms and only ever used them if one of his partner/s proposed using condoms:

> ***And, so, when condoms were used, was that, was that because the other person suggested condoms being used? Or -***
>
> *Yep. [Yeah] Yeah. I never made the suggestion. It was always, I always left it up to the other person to say whether they wanted to or not. If they did suggest it, then my usual response was, "You don't have to but, if you want to, we can." So, yeah, I tried to avoid it where possible.*

Here his reasons for not using condoms relate to his own sexual desires around ejaculation, being the receptive partner and finding condoms a physical and emotional barrier to achieving sexual connection. While he appears to have tried to avoid deliberately having condomless sex with someone who was HIV positive, his practice around establishing the serostatus of his partners was inconsistent:

> ***And would you ask guys about, about, about their HIV status?***
>
> *That's a tricky one. Sometimes. It depends in what forum I was meeting people. If I was meeting someone in person, I wouldn't ask the question. If I was talking to somebody on-line, then it was always a question that I would ask, yeah. [Okay] Yeah.*

> ***Why do you think that was?***
>
> *It's a hard question to ask people, especially if, if, if the question was asked in person and they responded they were positive; it meant either no sex or sex with a condom. And, given my aversion to condoms, it pretty much meant no sex. So it was just, the question was too hard to ask, given the end result and how that might make the other person feel in the situation (SS1140-B, age 29, QLD, 2015).*

His account highlights some of the complexities of serosorting and status disclosure, particularly in face-to-face encounters where both partners already have an expectation that sex is going to occur. There is no suggestion in this account that he was seeking HIV, but he was aware that his sexual practices increased the possibility that he would contract HIV and with this in mind was testing every two or three months:

> *It was a very real possibility of contracting. But I wanted to make sure that, if it happened, I was at least on top of it straight away, basically...Just, if, if I had, if I had contracted it that I wasn't spreading it unknowingly, basically (SS1140-B, age 29, QLD, 2015).*

Not all of the men interviewed were easily able to identify a high risk event/s, either because they had not had condomless anal sex, or all their condomless sex was with a HIV-negative partner. For some this inability to identify a high risk event was frustrating:

> ***I wonder if we might move on now then to the occasion where, that you believe was the occasion that you were exposed to HIV? Are you able to identify an event that -***
>
> *No, I'm not able to identify an event. I can identify potential risk but out of, you know, three potential risks, you know, one person who I was having condomless sex with he was very worried after diagnosis and he wouldn't even meet me again unless he'd been tested multiple times negative after months. So, as far as I know, I don't think he was ever positive. One, the other person was outside the window period that I had referred to previously so that was months before and I had tested negative I think around Christmas before returning to Russia, so the previous Christmas. So I don't think it was from him. So there was only one other brief exposure with one other person. So, with that in mind, I don't know how it occurred, essentially. So whether it could have been potentially some condom breakage or something slipping off that I didn't know about, or something else. But, yeah, that frustrates me that I don't actually know who. (SS1130-B, 32, Qld, 2015***).***

It should be noted that there is little evidence in the interviews of men who were deliberately misled or of participants holding other men responsible for their infection. Most men took responsibility for their own situation and did not blame their infection on others.

The interviews produce valuable data about the high risk event including the ways in which gay men negotiate sex and HIV status and how they understand risk reduction. They also provide important information about sexual risk and HIV transmission, and the contexts in which these occur. However, the interviews also enable newly diagnosed men to reflect and make sense of their own HIV infection. The minority of men who are not readily able to identify a high risk event may particularly take the opportunity of participating in the research in order to make sense of their HIV infection.

The Source Person

> “Of the respondents that believed they knew who the source person was for their HIV infection, 64 per cent indicated that it was a casual partner. Contact tracing continues to be a key public health response, providing opportunities for people from high risk groups to engage with the healthcare system and increase HIV and STI testing frequency.”
>
> Lea Narciso
> *SA Health*

The Source Person

The separate face-to-face in-depth interviews clearly tell us that most participants had a firm belief about who the person was from whom they believed they acquired HIV (the ‘source person’). When asked about this in the online questionnaire, all but a handful of those who were able to identify a high risk event during which they believe they had become infected with HIV were also able to identify the person from whom they believe they had acquired HIV (the ‘source person’).

Relationship to the source person

About half believed they acquired HIV from a casual partner, almost one in five believed it was from a fuckbuddy and fewer than one in ten believed it was from their primary partner (or boyfriend). Given that two fifths of men indicated elsewhere in the questionnaire that they were in a relationship at the time, this means that about three quarters of those in a relationship believed they acquired HIV from a partner other than their regular partner.

Table 69 Relationship to the source person

	Frequency	Percent
Casual partner	356	63.5
Fuckbuddy	127	22.6
Regular partner/boyfriend	58	10.3
Sex worker	4	0.7
Other	16	2.9
Total	561	100.0

Note: Does not include men who could not identify a person from they believe they acquired HIV infection.

The participants were asked how well they knew the source person at the time of the high risk event. Over half had never previously met this person, or knew nothing about him. Only one in five was someone who was previously well known to the participant.

Table 70 Level of knowledge of the source person

	Total	Percent
Previously well known to you	121	21.7
Someone you had met recently	139	25.0
Someone you had met for the first time at the high-risk event	142	25.5
Completely anonymous/unknown to you	155	27.8
Total	557	100.0

Note: Includes only those men able to identify a ‘source person’ and answered this question.

In addition to how well they knew the source person, participants were asked about prior sexual contact with him. For the most part, prior sex with the source person reflected prior acquaintance. The majority had not previously had sex with the source person, prior to the high risk event. Interestingly, one in ten men (10.5%) who indicated the source person was their primary partner, or boyfriend, reported that the high risk event was actually the first time they had sex. This was also true of a third of men (33.9%) who indicated that the source person was a fuckbuddy.

Table 71 Prior sex with the source person

	Total	Percent
No	351	63.0
Yes	206	37.0
	557	100.0

Note: Includes only those men able to identify a 'source person'.

Nearly two thirds (60.9%) of those who reported having previously had sex with the source person prior to the high risk event, indicated that the first time they had had sex was less than six months previously. This included about a quarter who had first had sex within the month prior to the risk event. So, even among those who had a prior sexual relationship with the source person, this was usually a relatively recent relationship. This appeared to apply equally to boyfriend relationships as well. When the source person was a boyfriend with whom they had already commenced a sexual relationship at the time of the high risk event, two thirds (68.6%) indicated that they had first had sex within the previous six months (indicating the relationship was new at the time of HIV acquisition).

Table 72 Length of time before the high-risk event since first sex with source person

	Total	Percent
Less than one month	48	23.4
1-3 months	48	23.4
3-6 months	29	14.1
6-12 months	30	14.6
1-2 years	29	14.1
More than two years	21	10.2
Total	205	100.0

Note: Includes only those men who had previously had sex with the 'source person'.

So, overall, the source person tended to be either a new partner – one with whom they had never previously had sex – or someone with whom they had only recently begun a sexual relationship.

Characteristics of the source person

Participants were asked to estimate the age of the source person. The source person's mean age was 33.9 years (SD=7.93) and median age was 35 years. The youngest source person reported was 19 years old and the oldest was 58 years old. We calculated the difference in age between participants and the source person: about two thirds indicated they were of similar age (within 10 years). One in five indicated that the source person was younger by more than 10 years and one in seven indicated that the source person was more than 10 years older. So, while the source person was somewhat more likely to be perceived as being younger than older than the participant, the majority were approximately similar in age.

Table 73 Age difference between participant and source person

	Frequency	Percent
Source person was more than 10 years older than participant	49	14.0
Source person and participant were same ages (within 10 years)	230	65.9
Source person was more than 10 years younger than participant	70	20.1
Total	581	100.0

Note: Includes only respondents who were able to identify a 'source person' and responded to this question.

Most participants (83.1%) described the source person as being gay, although 6.9% of men were unsure or unable to say how the source person identified sexually. Just 7.3% men described the source person as being bisexual or heterosexual.

It is often suggested that men are more likely to take risks when they consider their partner to be particularly attractive ('hot'). This claim appears not to be particularly supported in these data. Participants between 2010 and 2013 were also asked to rate their own sexual attractiveness and that of the source person. While nearly half (46.6%) rated themselves as being more attractive, just a third (34.7%) considered the source person to have been more attractive than themselves. One in six (18.8%) rated themselves and the source person to be equally attractive.

Meeting the source person

Participants who responded to questionnaire 1 (prior to June 2010) were asked how they met their partner, or partners, from this high-risk event. One third met these partners on the internet and one in four (25.9%) met these partners at a sauna or sex club. Relatively few men met the source person through friends or in non-gay settings.

Table 74 Where met the sex partner/s who were present at the highest risk event

N=232	Frequency	Percent
On the internet	82	35.3
At a sauna	35	15.1
At a sex club	25	10.8
Through friends	22	9.5
Gay bar/club	22	9.5
At a beat	15	6.5
On an overseas trip	13	5.6
Gay dance party	12	5.2
At a sex party	6	2.6
At a gym	3	1.3

Note: Includes only respondents to questionnaires 1 and who were able to identify a 'source person'.

Participants who responded to later versions of the study questionnaire (2013-2015) were asked specifically about where they met the partner they believed to be the source person. Also, more detailed information was obtained about how partners were met online. Over a quarter met the source person through mobile phone hook-up apps, and nearly as many met him through online dating sites. Taken all together, a third (35.0%) had met the source person at a physical gay venue, either a social venue (gay bar/club, dance party; 12.1%) or a sex venue (sauna, sex club, or sex party; 22.9%) but no one type of physical venue was particularly common. Again, relatively few men met the source person through friends or in non-gay settings.

Table 75 Where met the source person

	Frequency	Percent
Using a mobile phone application (Grindr, Scruff, etc.)	41	27.7
Over the internet/online dating site (Manhunt, Gaydar, etc.)	33	22.3
At a gay bar/club	16	10.8
At a gay dance party	2	1.3
Through friends	4	2.7
At a sauna	16	10.8
At a sex club	15	10.1
At a sex party	3	2.0
At a beat	12	8.1
Other (please specify)	6	5.0
Total	148	100.0

Note: Includes only respondents to questionnaires 2-4 who were able to identify a 'source person' and responded to this question.

HIV status of the source person

The majority of men did not know the HIV status of the source person on the occasion of the high risk event. Among those who believed they did know his HIV status, most (68.3%) nonetheless believed that he was HIV-negative at the time. In the end, only about one in seven were aware that the source person was HIV-positive at the time of the high risk event. Even among men who reported that the source person was their primary partner, or boyfriend, one in twelve (8.9%) did not know his HIV status at the time, and only a third (30.4%) were aware at the time that he was HIV-positive.

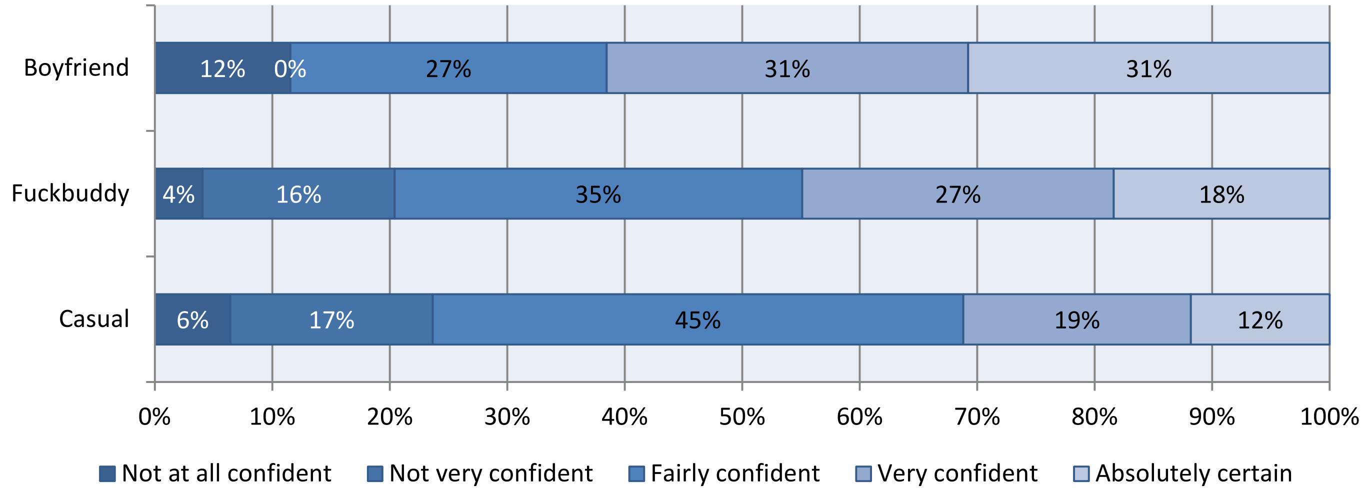
Table 76 Perception of source person's HIV status immediately before the high risk event

	Total	Percentage
I thought he was HIV-positive	85	15.9
I thought he was HIV-negative	183	34.3
I did not know his HIV status	266	49.8
Total	534	100.0

Note: Includes only respondents who were able to identify a 'source person'.

The participants who believed the source person was HIV-negative were also asked how confident they were in their knowledge of the source person's HIV status. Only a minority (39.9%) indicated being very confident or certain. The more established their relationship was to the source person, the more confident they were in this knowledge.

Figure 7 Confidence in knowledge of 'HIV-negative' Source Person's HIV status



Note: Includes only those men recruited since July 2010, who believed the source person to be HIV-negative, and who provided a response to this question.

Participants who were aware of the HIV status of the source person were asked how they knew his HIV status. Proactive disclosure, either by the source person himself offering this information or by disclosure having been requested by the participant were the two most frequently cited sources of this knowledge. However, proactive disclosure accounted for less than half of the cases with many men having indicated that they both asked and were told the source person's HIV status. In most other cases, participants tended to make some sort of assumption about the source person's HIV status.

Table 77 How the HIV status of the source person was 'known'

N=268	Frequency	Percent
He told me before the event	85	31.7
I asked him before the event	67	25.0
I just assumed	51	19.0
His attitude to condoms	25	9.3
His appearance	22	8.2
The sort of sex he wanted	16	6.0
The place we met	12	4.5
Someone else told me	11	4.1
The people he was with	6	2.2
Where I have seen him before	5	1.9

Note: Includes only respondents who believed they were aware of the source person's HIV status. Items were not mutually exclusive.

When asked whether the source person had directly told them of their HIV status, the majority of participants indicated that this had never occurred. Of those who had been directly informed by the source person of his HIV status, nearly a third had only been told on the occasion of the high risk event and one in five had actually been told after the event. Even among those who reported that the source person was their primary partner, or boyfriend, one third (36.4%) had not actually verbally disclosed their HIV status at the time of the high risk event. So, the reported knowledge of the source person's HIV status, when such 'knowledge' existed, may have often been based on indirect information and assumptions that would have been less reliable than might have been the case with direct, verbal disclosure by both partners.

Table 78 Verbal disclosure of HIV status by the source person

	Frequency	Percent
No, NEVER	345	66.1
Yes, BEFORE we had sex on a previous occasion	91	17.4
Yes, JUST BEFORE we had sex at the high risk event	52	10.0
Yes, AFTER we had sex at the high risk event	34	6.5
TOTAL	522	100.0

A question about participants' own disclosure of their HIV status to the source person was included in questionnaire 2. Over half did not disclose their status at all. One quarter disclosed on a previous sexual encounter and about one in seven disclosed just before sex at the high-risk event.

Table 79 Verbal disclosure by participant to the source person

	Frequency	Percent
No, NEVER	99	51.3
Yes, BEFORE we had sex on a previous occasion	54	28.0
Yes, JUST BEFORE we had sex at the high risk event	29	15.0
Yes, AFTER we had sex at the high risk event	11	5.7
Total	193	100.0

Note: Includes only respondents to questionnaire 2 who were able to identify a 'source person' and responded to this question.

HIV-positive source person

The minority of participants who were aware that the source person was HIV positive were asked about the detectability of the source person's viral load. Two in five did not know the viral load of the source person. However, one in six of those who indicated the source person was HIV-positive did not answer this question; it is very likely that many of these men were also unaware of his viral load and so simply skipped this question. So, the majority of those who were aware the source person was HIV-positive likely did not know his viral load status. Among the 37 men who believed they knew the source person's viral load, 20 men (54.1%) indicated that he had undetectable viral load.

Table 80 Known HIV-positive source person's viral load at the time of the high risk event

	Frequency	Percent
Undetectable	20	23.3
Detectable	17	19.8
I don't know	35	40.7
Not provided	14	16.3
Total	86	100.0

Note: Includes only respondents who indicated that the 'source person' was HIV-positive.

Diagnosis and Clinical Markers

"The impact of telling someone they are HIV positive has really changed over the years. Whilst many people are understandably still devastated we can now offer so much in the way of effective, well tolerated treatments that I think that optimism now prevails"

Anna McNulty
Sydney Sexual Health Centre

Diagnosis

The participants who responded to questionnaire 1 were asked about the specifics of their HIV diagnosis. When asked whether the participant had experienced a seroconversion illness, the responses were evenly divided with half indicating yes and half indicating no.

Table 81 Experience of seroconversion illness

	Frequency	Percent
No	114	49.1
Yes	109	47.0
I don’t know	9	3.9
Total	232	100.0

Note: Includes only respondents to questionnaire 1.

Participants were asked why they decided to have the test that returned their HIV-positive result. About a third indicated they had symptoms that made them worry, a quarter indicated it was part of their regular testing pattern. Only one in six said they had decided to get tested because they believed they had done something risky. One in ten men indicated that a doctor asked him to be tested and one in twelve indicated they had had sex with someone who is HIV positive. So, despite their own high risk behaviour, few men felt that this behaviour had been sufficiently risky to warrant being tested; they had eventually decided to have a test for other reasons than perceived risk.

Table 82 Reasons for having the test that returned the HIV-positive result

N=716	Frequency	Percent
I had symptoms that made me worry	243	33.9
It was part of my regular testing pattern	189	26.4
I did something risky	132	18.4
Doctor asked	73	10.2
I had sex with someone I knew to be positive	59	8.2
I wanted to know my status	40	5.6
A partner told me they tested positive	33	4.6
My partner did something risky	26	3.6
My partner asked me to	25	3.5
Condom slippage/breakage	20	2.8
I changed partners	19	2.7
As part of a negotiated safety agreement	13	1.8

Most men were diagnosed in Australia.

Table 83 Country where diagnosed

	Frequency	Percent
Australia	629	89.0
Elsewhere	42	5.9
Subtotal	671	94.9
Not provided	36	5.1
Total	707	100.0

Those participants who were diagnosed in Australia were asked in which state they were diagnosed. These data broadly accord with HIV notification data with two thirds (64%) of people having been diagnosed in either New South Wales or Victoria.

Table 84 State in which diagnosis occurred

	Frequency	Percent
New South Wales	223	35.5
Victoria	171	27.2
Queensland	129	20.5
Western Australia	40	6.4
South Australia	26	4.1
Australian Capital Territory	12	1.9
Tasmania	8	1.3
Northern Territory	7	1.1
Not provided	13	2.1
Total	629	100.0

Participants were asked what service they were using for testing when the diagnosis occurred. Over a third were diagnosed at a sexual health clinic and one third (35.3%) by a general practitioner (GP). The number self-testing or availing themselves of testing at community events or organisations was very small. With a larger number of rapid HIV testing sites operating outside of traditional clinical settings, and the existence of home testing trials, these numbers may change.

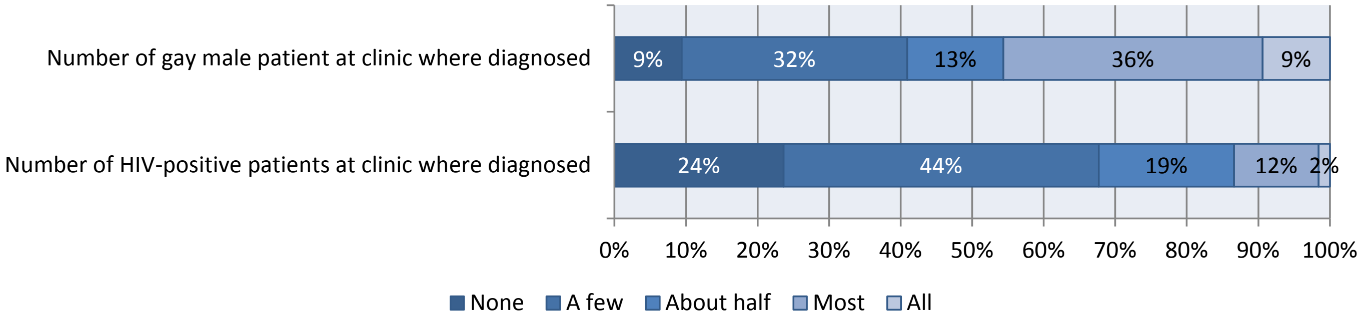
Table 85 Service where diagnosed

	Frequency	Percent
My regular doctor	59	27.4
First available doctor	17	7.9
Sexual health clinic	78	36.3
Community organisation	2	0.9
Community event	2	0.9
I was tested interstate or overseas	5	2.3
I did it myself, at home	4	1.9
Some other location	17	7.9
Not provided	31	14.4
Total	215	100.0

Note: Includes only respondents enrolled since 2013.

Participants were asked about their perceptions of the clinic where they were diagnosed. Only a minority of men believed that substantial numbers of the patients attending the clinic where they were diagnosed were HIV-positive, although quite a few more men (nearly half) believed that the clinic's clientele was mainly gay.

Figure 8 Clientele of diagnosing clinic

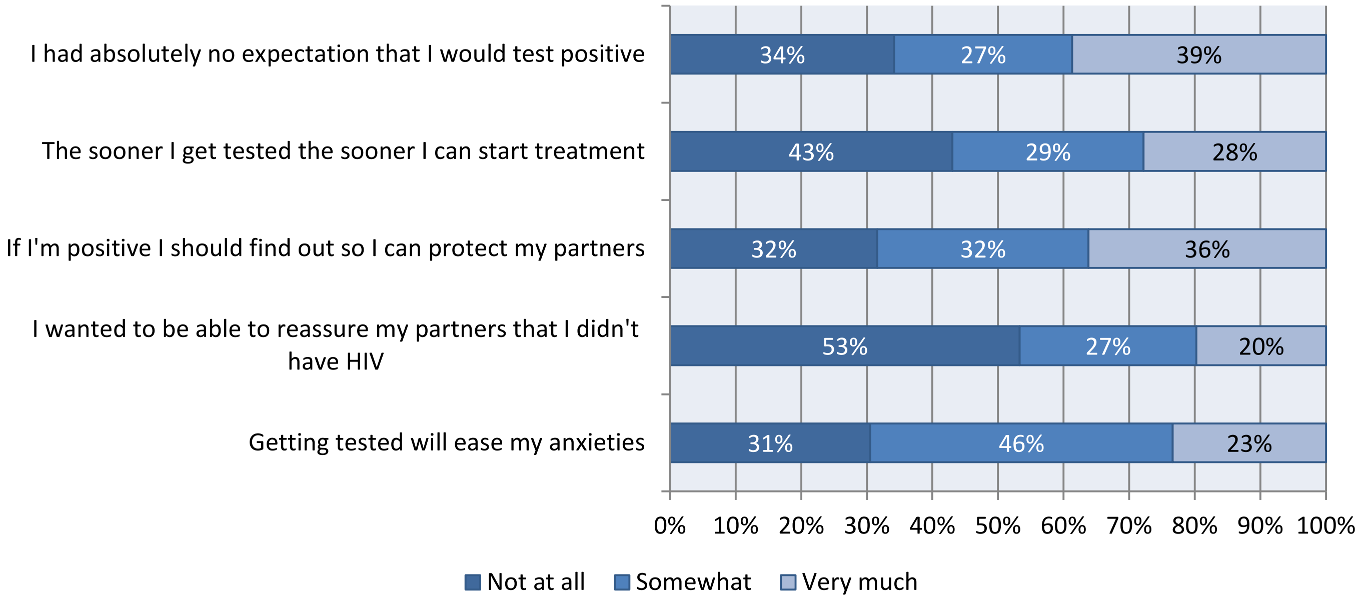


Participants appeared to have limited awareness of their own HIV risk. Those who had enrolled since March 2013 were asked whether they had expected to test HIV-positive. Of those who responded to these questions, one in six (17.4%) had thought it very likely and another quarter (26.6%) thought it was at least somewhat likely, with well over half indicating that they did not expect to test positive.

The participants were asked for their thoughts about being tested on that occasion. The majority of men indicated that starting treatment early was either "somewhat" or "very much" a factor in getting tested sooner. For the most part, these data were collected prior to the clear evidence from the SMART trial on the health benefits of early treatment, so it may well be that this proportion who believe there is value in early detection to enable earlier treatment has been increasing.

When asked about their expectations from being tested on that occasion, altruism appeared to be one factor in their motivation: over two thirds of men said they were "somewhat" or "very much" getting tested to protect their partners. When asked about whether men wanted to be tested to reassure their partner that they did not have HIV, this was "somewhat" or "very much" a consideration for just under half of the men. Over half the men indicated that getting tested would "somewhat" or "very much" ease their own anxieties.

Figure 9 Expectations about HIV test at time of diagnosis



Participants responding to questionnaires 3 and 4 were asked how the test results were conveyed to them. Two thirds of men returned to the clinic a number of days after the test to get the result from their doctor. Around one in ten received their results 30 minutes after the test (presumably using a rapid test), and one in ten received their results over the phone.

Table 86 How test results were conveyed

	Frequency	Percent
I went back at a later date to see the doctor/nurse	125	64.8
I got the results over the phone	18	9.3
They sent me a text message	1	0.5
They emailed me	1	0.5
They gave me the results about 30 minutes later, after the test	23	11.9
I did the test myself	4	2.1
Some other way	15	7.8
Not provided	6	3.1
Total	193	100.0

Note: Includes only respondents enrolled since 2013

Participants responding to questionnaires 3 and 4 were also asked how they felt getting the test results in the way they had indicated. One third (20.5%) of those who responded reported that “it was OK” and a further 20.5% reported they felt “supported”, “reassured” or “relieved” – resulting in over half (56.2%) reporting a generally positive experience. Nonetheless, one third (34.6%) of men who responded reported feeling “alone”, “frightened” or “confused”.

When asked whether they would have preferred to have received their positive HIV diagnosis a different way, two thirds of men who responded said they would not. Few men expressed a preference to have been given their diagnosis a different way.

Table 87 Preference for results being given another way

	Frequency	Percent
No	128	66.3
Yes	28	14.5
I don’t know	29	15.0
Not provided	8	4.1
Total	193	100.0

Note: Includes only respondents enrolled since 2013.

Those men who expressed a preference for receiving their HIV test a different way or who were unsure about it were asked their preferred way to receive a HIV-positive test. Of these men, two fifths (42.9%) expressed a preference for rapid testing and one quarter (26.8%) expressed a preference for a repeat visit with a clinician.

Table 88 Preferred way to receive HIV-positive result

	Frequency	Percent
From a repeat visit with the doctor/nurse	15	26.3
Over the phone	1	1.8
Via text message	1	1.8
Via email	2	3.5
Straight away, or about 30 minutes after the test	24	42.1
At home, by myself	5	8.8
Some other way	8	14.0
Not provided	1	1.8
Total	57	100.0

Note: Includes only respondents who wanted to receive their diagnosis in some other way.

Participants were asked how they felt the doctor handled telling them they had acquired HIV. Of those who responded, three quarters indicated either “very well” or “well” whereas one quarter indicated “poorly” or “very poorly”.

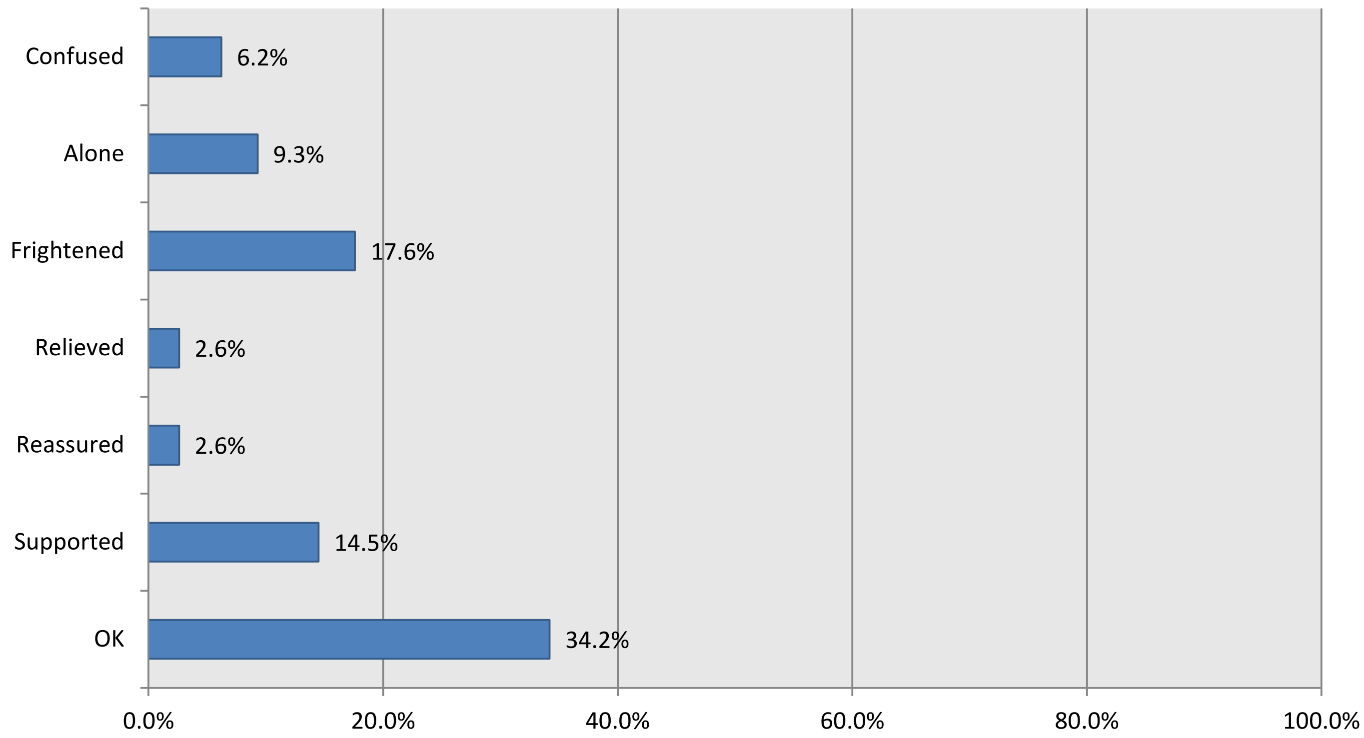
Table 89 How the diagnosis was handled

	Frequency	Percent
Very well	192	40.4
Well	114	24.0
Poorly	61	12.8
Very poorly	27	5.7
Not provided	81	17.1
Total	475	100.0

Note: Includes only respondents enrolled since 2013.

The respondents who had enrolled since March 2013 were asked how they felt on the occasion of their diagnosis. While the majority did not report feeling particularly discomforted or reported having been reassured by their doctor, about a third nonetheless reported feeling confused, alone, or frightened.

Figure 10 Feelings on the occasion of diagnosis



Note: Question added March 2013. Only includes men who responded to this question.

They were also asked what they had discussed with their doctor on the occasion of their diagnosis. The most frequently reported topics they had discussed with their doctor were contacting regular sex partners, sources of counselling and support, disclosure and advice on HIV support organisations (each of which were reported by about three fifths of men). Discussing treatment options, viral load meaning and CD4 meaning were each reported by about half of the men.

Table 90 Topics discussed by the doctor at diagnosis

N=177	Frequency	Percent
Contacting recent sex partners	114	64.4
Advice about where to go for counselling and support	107	60.5
Disclosure	105	59.3
Advice about what organisations are able to help you	103	58.2
What treatment options might be available for you	88	49.7
What viral load means	86	48.6
What CD4 means	85	48.0
About any legal requirements for you to tell sex partners your HIV status	81	45.8
What this would mean for having safe sex	79	44.6

Note: Includes only respondents enrolled since 2013.

Diagnosis: Reflections from the interviews

Treatment has changed the meaning and experience of HIV in countries such as Australia where there is access to ART. Nonetheless HIV is still a serious chronic illness that can have multiple medical and social implications and therefore it is not surprising that the majority of men in the interview sample were initially shocked and uncertain about what having HIV would mean to their lives:

> *… So I had the test and then a week later I went to get the results. And I remember that, I mean like I remember I went into the room and he told me that I was positive. And then my first reaction was, "This can't be right." Like first I couldn't believe that it was, that I was tested positive. And I tried to think like how did it happen, who did I get it from, when did it happen. And I kind of just went into like a shock and my whole body just went really numb. And my thought was, "Oh my God! I'm gonna die! I'm gonna die really early! I'm gonna die before my parents!" You know. "And how am I gonna tell people about this," kind of thing. So I went into, basically I think my body just went kind of really numb and into a state of shock, not really being able to think about anything else or think properly about anything else (SS0270-M, age 34, Victoria, 2010)*

Another participant had severe flu like symptoms and when they did not pass after nearly a week he rang a sexual health clinic and spoke with a nurse who encouraged him to come in for an HIV test. Even though the nurse mentioned that the symptoms were consistent with the symptoms of seroconversion he did not expect the result to be positive:

> ***And did the Rapid test show a reactive?***
>
> *Yeah, it did. Within 10 minutes. Yeah. That was, that was weird. Basically, she, she'd done the test and we were just sitting there. We were just chatting. She was just making conversation, trying to make me feel good, basically. I guess she kind of knew or, or had suspected that it was going to come out positive anyway. But, when she went back over to the trolley after about 10, 12 minutes, she just turned around and said, "I'm really sorry to tell you this but this test looks like it's going to come back positive." And that's when I went into freak-out mode. That's when I had no idea what was going on or what was going happen, or what it meant for me. She did what she could to keep me calm. I guess I was probably in more of a state of shock now that I think about it. She was trying to make conversation with me but I wasn't really conversing back very much (SS1140-B, age 29, OLD, 2015).*

The initial sense of shock was present even for men that recognised that their sexual behaviours placed them at risk of HIV transmission, as illustrated in the following quote:

> ***So, so you just, so you went for, you know, just a regular test and then you went back for your result.***
>
> *Yeah, I went back for the result. It wasn't my usual doctor; it was somebody else who, 'cause I phoned, just called up to make the appointment and they said, "Oh no, your doctor isn't available but this one …" And it's like, "Yeah, that's alright, that's fine. I'm just getting the results. That's all good, you know. They all, all know the same thing," so to speak. Yeah. And the poor bugger. Hasn't seen me before and he gets to give me that sort of news. It was a shock, as one would expect. It wasn't a surprise I suppose given, given what I'd been doing. It's sort of like it isn't really much of a surprise, sort of thing. It's, was a matter of time. But yeah, it was still a bit of a shock (SS0700-M, age 29, Victoria, 2012).*

Here a distinction is made between shock and surprise. In a similar vein another man described having felt simultaneously a sense of disbelief and a sense of knowing the result would be positive:

> *… one of your results has detected HIV." Immediately, he said that. And it was, I almost didn't hear it. It's almost a moment where your mind and body is sort of paralysed for a second, frozen. And it's like, I think, "Can you repeat that?" And I think that that's the shock hitting you. And it's a sense of disbelief and shock at the, but at the same time there was a strange sense of I knew it. I knew it would come to this in a sense, in a way. Which I can't really describe why but I think in, in knowing my risky behaviour that I engaged in, it was almost a sense of foreboding that I knew something like this might have been coming. So, in a sense, it almost wasn't a surprise I think, considering my risky behaviour and what I'd just experienced, my symptoms and everything over the weekend (SSO530-S, age 31, NSW, 2011).*

While most men were initially shocked by their diagnosis the majority of the men interviewed were satisfied with the way their diagnosis was handled:

> ***Did he handle, in a manner that was, made it, made it as easy for you as it could be?***
>
> *I don't think giving news like that can be easy for anybody. Despite what some people say about it, "Oh yeah, it's alright …" I'm, I'm prepared to … No, you're not. You're never prepared to get that news. So, and I think he was actually quite good. Yeah, he was, he said, "Look, I'm sorry to tell you that your HIV test has come back positive." And, you know, he said, "Look, we will do another test, a confirmation test just, just in case," but he asked me, "What are you going to do now?" sort of thing. He asked me what I was going to do and I said, "Gonna keep going with my day." So … and he's actually now my, my permanent doctor (SS0700-M, age 29, Victoria, 2012).*

In another example the direct, calm and non-judgmental approach taken by the nurse giving the result was seen by the participant as making his situation better:

> *She, she was great. And I'll be forever indebted to her for, for the way that she handled the situation because I think, if it, it could have very, very, very easily have turned out completely differently, if, if it had have been someone in that situation who didn't know what they were doing. Just the way that she spoke to me she was calm the entire time. She was really quite soothing and caring as well. So I didn't feel like I was in trouble. You know what I mean? Like it didn't feel like I had done something that was so very, very naughty. I didn't feel like I was going to get sent to detention. She, she, basically, just explained the process to me from there in regards to taking more blood and then sending that off for the Western Blot test, to have full confirmation and that there … she didn't, she didn't lie to me at any stage. …I didn't feel pressured to leave. I felt like I could sit there all day and talk to her if I wanted to so there was no sort of like, "Oh I've got another appointment. (SS1140-B, age 29, OLD,).*

While there is unlikely to be a single right way to approach giving an HIV-positive result, the interview data suggest that being direct, avoiding judgement and giving the person space and time to digest the news are beneficial to the person receiving the result.

Men in the sample had a range of different information and supports needs at their initial diagnosis, some wanted immediate answers about what HIV was likely to mean in their life:

> ***So can you recall what your initial reaction was?***

> *Being informed of the diagnosis? [Yes, the diagnosis, sorry] … so that was at the [name of sexual health clinic] with my specialist, I didn't know, I didn't know what it meant and I wanted, I just wanted a lot of information about how it affects my body, how it, how I get treated. Can I have children? And, yeah, I ended up becoming very, very shut-down, yeah, and just, and shocked. [Shocked?] Yeah. Yeah, very devastated not because I knew how bad it was or anything; it's just there was so much that I didn't know. Yeah. Yeah. Not fun (SS1100-S, age 23, NSW, 2014).*

In contrast others found receiving information at the point of diagnosis unhelpful:

> *I mean I was piled up with heaps and heaps, and heaps of pamphlets and booklets, and pieces of paper. And I remember just looking at it all, going, "I don't know why you're giving this to me. I could just start a fire with it right now. I think there's, there's no point in giving this to me (SS1140-B, age 29, OLD, 2015).*

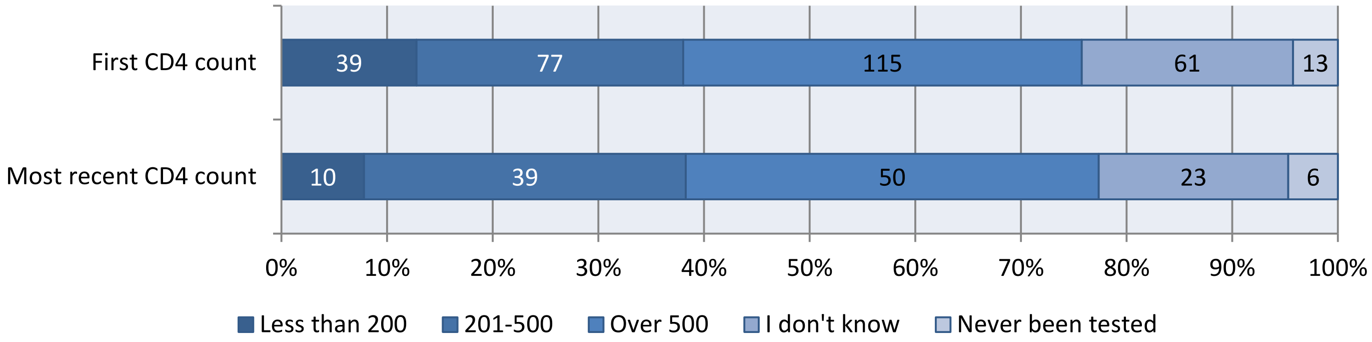
The interviews show that being diagnosed with HIV is a process and individual PLHIV have different information and support needs during minutes, hours, days and months after diagnosis. Therefore, it may be useful for clinicians seeing newly diagnosed people to explore information and support needs at multiple appointments and periodically re-offer patients pamphlets, contacts for peer support programmes and counselling.

The shock and uncertainty experienced at the point of diagnosis may to some extent reflect the way in which HIV is currently understood among HIV negative gay men in Australia. While the HIV sector in Australia has rightly rejected the use of prevention messages that exaggerate the side-effects of treatment and represent HIV as debilitating, this has not necessarily meant that HIV negative men have a better understanding of what it means to have HIV now. There is potential for this to change with the recent promotion of the benefits of early initiation of treatment on the individual health of PLHIV and in reducing transmission and overtime this may reduce some of the uncertainty associated with receiving an HIV-positive result.

Clinical Markers

Seroconversion Study questionnaires 3 and 4 included questions about the details of the two key clinical markers CD4 count and viral load both at the time of diagnosis and their most recent test when they completed the questionnaire. Looking first at CD4 count, about a quarter believed they had never been tested or did not know their test results. The majority of those tested, and who knew their results, had a CD4 count above 500. There was only minimal change between their test results at diagnosis and their most recent test.

Figure 11 CD4 count at diagnosis and at most recent test



Note: First CD4 count question added in July 2011, includes only responses from men enrolled since then. Most recent CD4 question added in March 2013, includes only responses from men enrolled since then.

One in six believed they had never been tested for viral load or did not know their test results. However, an additional quarter of men did not respond, some of whom may simply not have known their test results and so skipped the question. Half (51.2%) of the men who responded indicated their viral load at diagnosis was greater than 10,000, and one fifth (22.2%) indicated their viral load was 10,000 or less.

Table 91 Viral load at diagnosis

	Frequency	Percent
Less than 400	10	4.7
400-10,000	26	12.1
Over 10,000	83	38.6
I don’t know	36	16.7
I’ve never had a test for my viral load count	7	3.3
Not provided	53	24.7
Total	215	100.0

Note: Includes only respondents enrolled since 2013.

When asked the result of their most recent HIV viral load test, the findings were fairly similar as those regarding their viral load test results at diagnosis. Two fifths (40.9%) of those participants who responded indicated they had an undetectable viral load and another two fifths (39.4%) indicated they had a detectable viral load. The remaining one fifth (19.7%) indicated they either didn't know or had never had a viral load test.

Table 92 Most recent viral load test result

	Frequency	Percent
Undetectable	52	24.2
Detectable	50	23.3
I don't know	19	8.8
I've never had a test for my viral load count	6	2.8
Not provided	88	40.9
Total	215	100.0

Note: Includes only respondents enrolled since 2013.

Sexual behaviour since diagnosis

> “The Seroconversion Study shows that men change their sexual behaviour after diagnosis in ways that help reduce onward transmission of HIV, and that contact with peers seems to support these kinds of changes. Peer support is essential for people when they are newly diagnosed.”
>
> Brent Allan
> *Living Positive Victoria*

Sexual behaviour since diagnosis

Participants responding to questionnaires 3 and 4 were asked about their sexual behaviour since receiving their HIV diagnosis. When asked whether they had engaged in sex with any casual partners, most of those who responded indicated that they had done so.

Table 93 Casual sex partners since diagnosis

	Frequency	Percent
No	11	11.6
Yes	84	88.4
Total	95	100.0

Note: Includes only respondents enrolled since 2013 and who responded to these questions.

Half of the men who had engaged in any casual sex since diagnosis reported that at least one of their casual partners was HIV-negative. Three fifths had at least one HIV-positive casual partner, and three quarters had engaged in any casual sex since diagnosis with at least one partner whose HIV status they did not know.

Table 94 HIV status of casual partners since diagnosis

	Frequency	Percent
HIV-negative	42	50.0
HIV-positive	50	59.5
Unknown status	63	75.0
Total	84	100.0

Note: includes only those who were enrolled since March 2013 and who reported having had sex with casual partners since their HIV diagnosis.

Participants were also asked to reflect on some of the changes they had made in their sexual behaviours since receiving their HIV diagnosis. When those who responded to questionnaire 1 were asked whether they had engaged in sex with any casual partners in the four weeks prior to diagnosis, nearly half indicated that they had. In the four weeks after their diagnosis, however, less than a third reported having done so, and generally with fewer partners.

Table 95 Casual sex partners prior to and since diagnosis

n (%)	4 weeks before diagnosis	4 weeks following diagnosis
No casual partners	122 (54.0)	157 (69.5)
One	13 (5.8)	21 (9.3)
2-3	41 (18.1)	18 (8.0)
4-5	27 (12.0)	19 (8.4)
More than 5	22 (9.7)	6 (2.6)
Not provided	1 (0.4)	5 (2.2)

Note: includes only those who were enrolled prior to 2010.

Since 2010, participants were asked a simpler, more direct question about how they had changed their behaviour since their HIV diagnosis. Over half (55.8%) indicated that they had reduced the number of men with whom they had sex and 47.2% said they had stopped having sex altogether, at least for some time, since their diagnosis: in total 74.1% had either reduced their partner number or ceased having sex.

When those who responded to questionnaire 1 were asked whether they had specifically engaged in condomless sex with any casual partners in the four weeks prior to diagnosis, over a quarter indicated that they had. In the four weeks after their diagnosis, however, less than one in six reported having done so, and they generally restricted this to HIV-positive partners only.

Table 96 CLAI with any casual sex partners prior to and since diagnosis

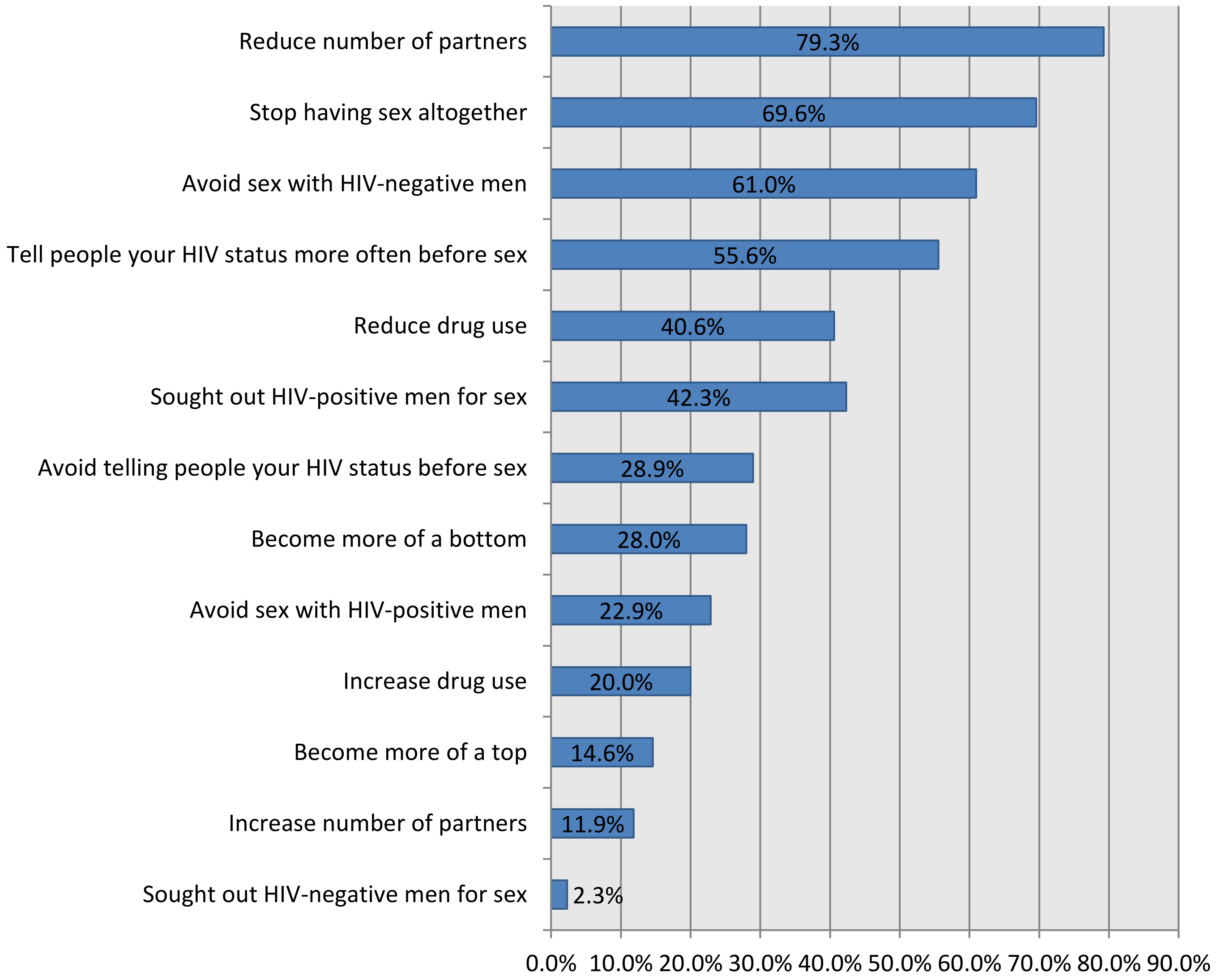
n (%)	4 weeks before diagnosis	4 weeks following diagnosis
No casual partners	122 (54.0)	157 (69.5)
No CLAI	42 (18.6)	33 (14.6)
CLAI with known HIV-positive only	2 (0.9)	14 (6.2)
CLAI with partners not known to be HIV-positive	60 (26.6)	22 (9.7)

Note: includes only those who were enrolled prior to 2010.

Interestingly, men who sought, and found, peer support, either through other HIV-positive friends and acquaintances or through peer-support programs run by community organisations, also tended to be the same men who changed their sexual behaviours after diagnosis in ways they would minimise the risk of onward transmission to others (Prestage et al., 2016). They were also more inclined to disclose their HIV status to sexual partners.

In responding to questions about changes in behaviour since diagnosis, four fifths of men said they had reduced their number of partners, two thirds had stopped having sex altogether, and three fifths had begun to avoid sex with HIV-negative men. Half of the men disclosed their HIV status more often before sex than had been the case prior to their HIV diagnosis.

Figure 12 Changes in sexual behaviour since diagnosis



Changes in personal circumstances

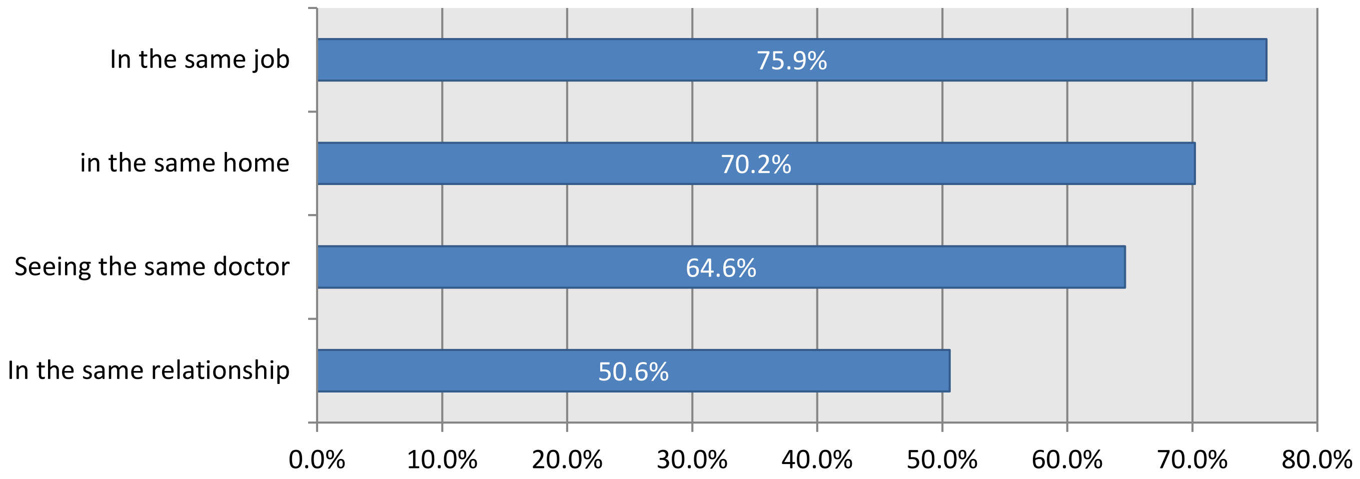
> “While many people’s broader personal circumstances change very little as a result of their HIV diagnosis, it is important for the community to know that AIDS Councils, peer led HIV organisations and other peer groups can provide support to those who need it.”

Harry McAnulty
Victorian AIDS Council (VAC)

Changes in personal circumstances since diagnosis

Men were also asked about any changes in their personal circumstances post-diagnosis and most men reported minimal change with three quarters still in the same job since before diagnosis, over two thirds in the same home and two thirds in the same home. Only half of respondents who had been in a relationship prior to their HIV diagnosis were still in the same relationship. Note that when further analysis was conducted, it was found that three fifths (59.2%) of men who were in a relationship at the time of the high-risk event were still in that relationship at the time of completing the survey.

Figure 13 Changes in circumstances since diagnosis



Disclosure of HIV status

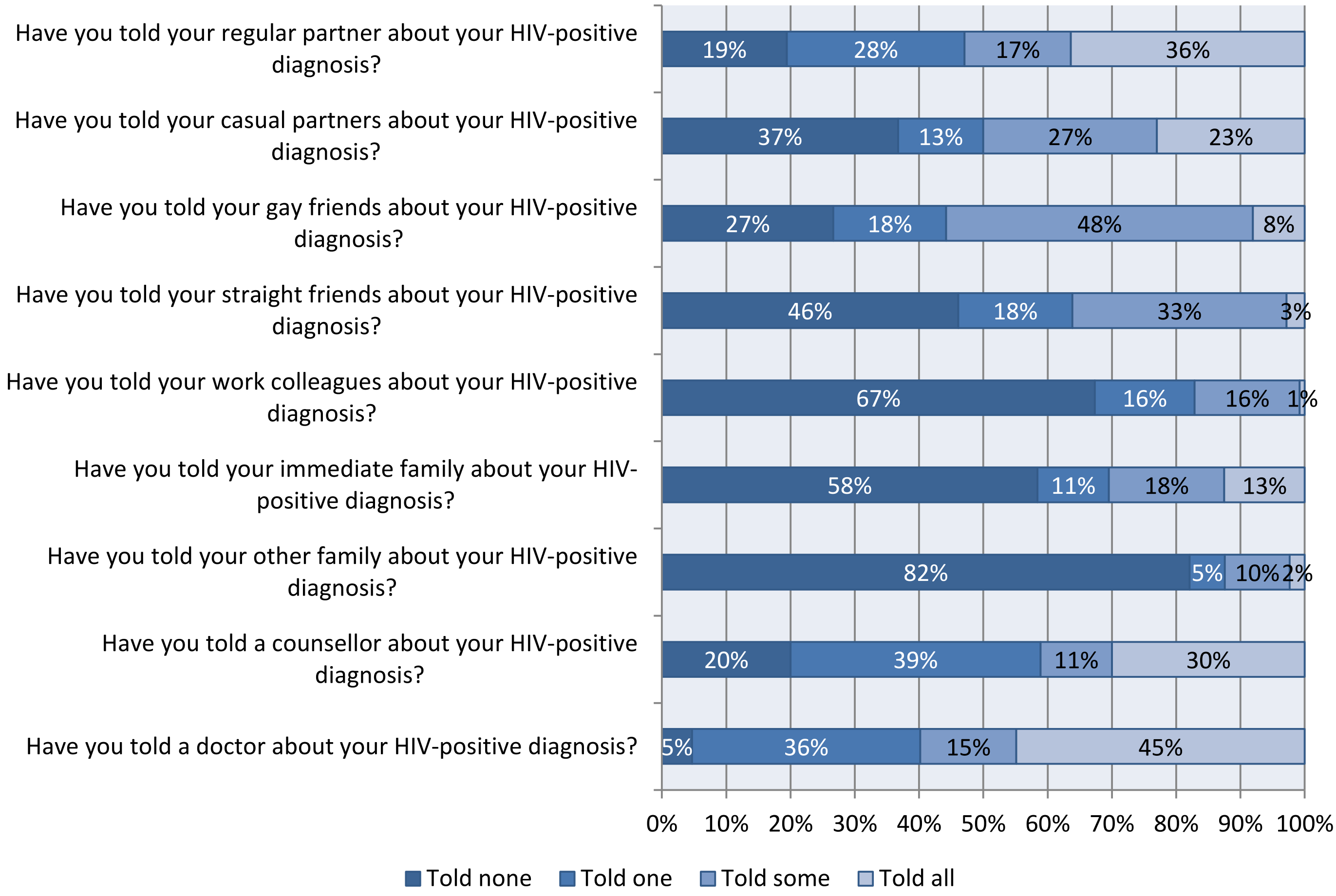
> "HIV ignorance, stigma and discrimination remain challenges to overcome when communicating your HIV status.
>
> Navigating the disclosure maze is easier when you're accepting of yourself and have the solid backing of people who matter in your life."

Cipri Martinez
National Association for People with HIV Australia (NAPWHA)

Disclosure of HIV status

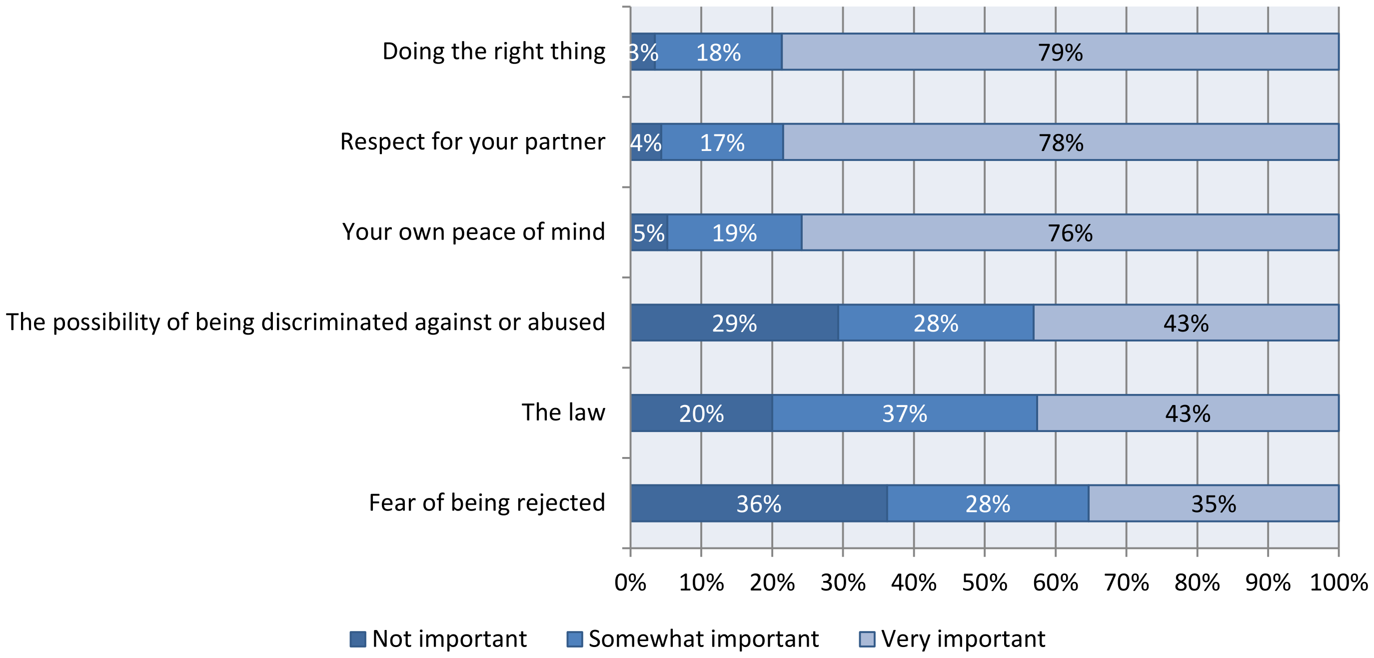
Participants were asked to whom they had disclosed their HIV status since diagnosis. Participants responding to questionnaires 1-4 were asked about disclosure to partners, friends, colleagues and family members. Those responding to questionnaires 3-4 were also asked about disclosure to counsellors and doctors. Four fifths (80.6%) of men had told a regular partner about their HIV diagnosis, while three fifths (63.3%) had disclosed to at least one casual partner. Men were more likely to have disclosed to gay friends rather than straight friends with three quarters (73.3%) of respondents having told at least one gay friend and about half (53.9%) having told at least one straight friend. Men tended not to disclose to work colleagues with two thirds (67.3%) reporting that they had not told any of them. There was also limited disclosure to biological family members with three fifths (58.4%) reporting that they had not told any immediate family and four fifths (82.1%) had not disclosed to any "other" family. There were high levels of disclosure to health professionals, with four fifths (80.0%) having told at least one counsellor and almost all participants (95.3%) having disclosed to their doctor.

Figure 14 Disclosure since diagnosis



Participants were asked to describe their motivations in their decisions to disclose their HIV status. Doing the right thing, respect for their partner, and their own peace of mind were all rated as very important by most men. Discrimination, abuse and the law were at least somewhat important for the majority of men. Fear of being rejected, while also considered important by many men, was not as common a consideration in men's decisions about disclosure.

Figure 15 Considerations around disclosure



Given the legal implications for HIV-positive men's disclosure to sex partners, participants responding to questionnaires 3 and 4 were asked what they believed were the current legal requirements. Almost half believed they were required to disclose to all sex partners and a third believed they were only required to disclose to condomless sex partners. Only one in twelve men believed they were under no legal requirement to disclose to anyone and another one in nine did not know.

Table 97 Legal requirements to disclose

N=119	Frequency	Percentage
I must disclose to all sex partners	54	45.4
I am only required to disclose to any condomless sex partners	44	37.0
I am under no legal requirement to disclose to anyone	10	8.4
I don't know	14	11.8

Note: includes only those who were enrolled since March 2013 and responded to these questions.

HIV status on online profiles

Participants responding to questionnaires 3 and 4 were asked how their HIV diagnosis had influenced how they designed their online dating profiles and their behaviours. When asked how they described themselves online before their diagnosis, most men indicated that they were HIV-negative and one third left all or some of the questions pertaining to HIV status blank. A small proportion of men said “ask me” and very small proportion did not have any online or mobile app profiles.

Table 98 Online profiles and HIV status prior to diagnosis

N=130	Frequency	Percentage
Some or all said ‘HIV-negative’	78	60.0
I didn’t have any online or mobile app profiles	5	3.8
Some or all said ‘Ask me’	21	16.2
I left all or some of them blank	38	29.2

Note: includes only those who were enrolled since March 2013 and responded to these questions.

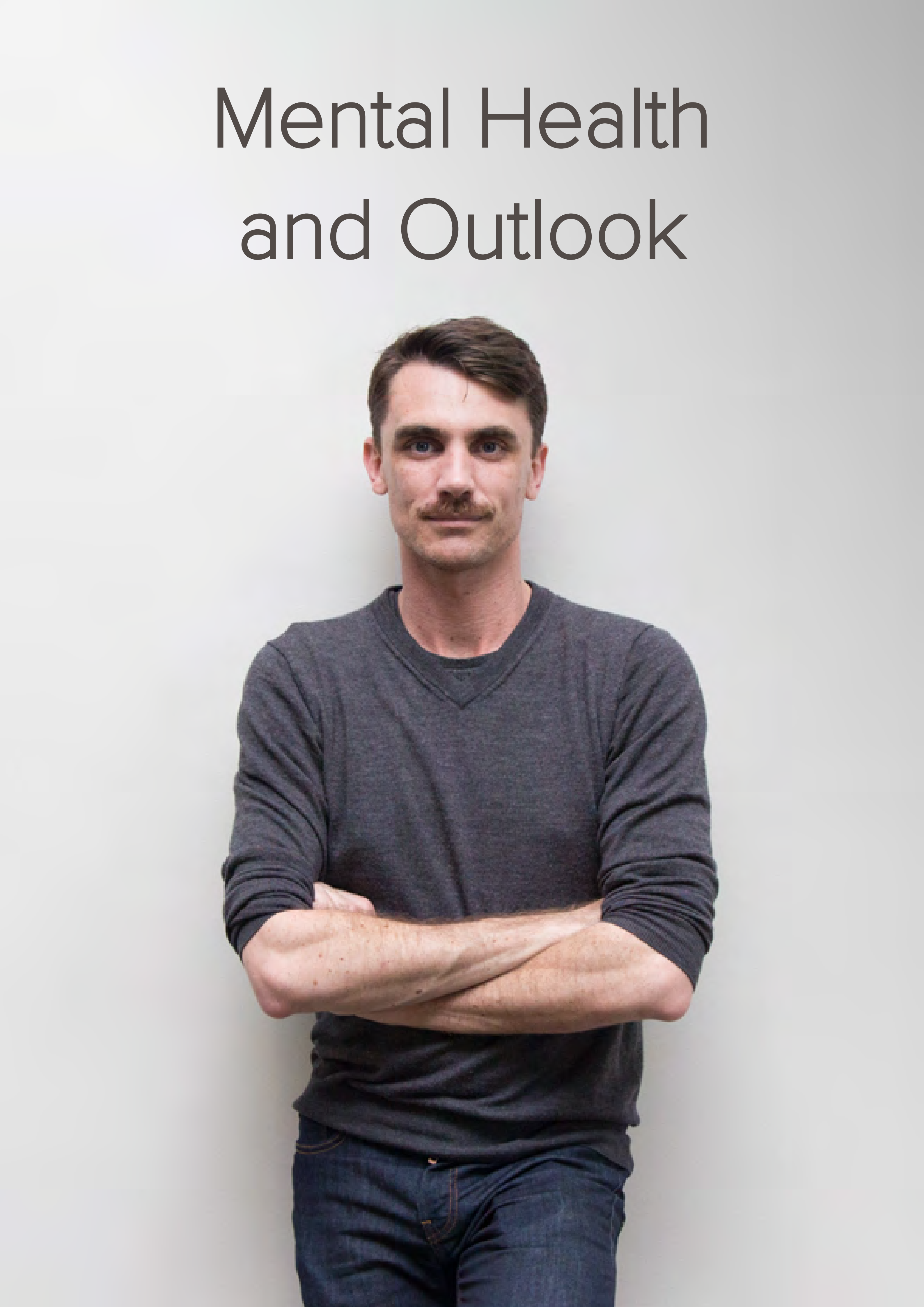
Men responding to questionnaires 3 and 4 were also asked if, and how, they had changed their online dating profiles since diagnosis. One third of men removed their profile from at least one site. One quarter changed their HIV status on their profile to “ask me”, while another quarter changed it to HIV-positive, but one quarter did not make any changes. One in five removed any reference to HIV status. One in ten men set up a new profile on a different site and one in twenty men set up a new profile on the same site.

Table 99 Changes to online profiles since diagnosis

N=130	Frequency	Percentage
Removed my profile from a particular site	39	30.0
Changed my status to ‘ask me’	33	25.4
Changed my status to ‘HIV-positive’	33	25.4
Kept it the same as it was before	30	23.1
Removed any reference to HIV status	26	20.0
Set up a new profile on a different site	14	10.8
Set up a new profile on same site	9	6.9

Note: includes only those who were enrolled since March 2013 and responded to these questions.

Mental Health and Outlook



> ‘HIV needn’t be a lonely, isolating experience. One of the reasons we started TIM was because we saw people place their emotional, sexual, and social lives on hold because of an HIV diagnosis. We wanted to make a place to combat that unnecessary loneliness.’
>
> Nic Holas
> *The Institute of Many (TIM)*

Mental Health and Outlook

Participants were asked about their mental health and their feelings about the future.

Depression and self-esteem

The PHQ-9 depression scale was administered to participants to determine their level of self-reported symptoms of depression. Two thirds of men provided responses consistent with no or minimal depression. One quarter had evidence of a major depressive disorder and a small proportion appeared to have some depressive disorder less severe than major depressive disorder.

Table 100 PHQ-9 depression assessment

	Frequency	Percentage
No/minimal depression	306	67.0
Other depressive disorder	32	7.0
Major depressive disorder	119	26.0
Total	457	100.0

Note: includes only those who responded to the PHQ-9 items.

Men also completed the Rosenberg self-esteem scale and three quarters (73.7%) had either normal or high self-esteem. About a quarter of the men were classed as having low self-esteem.

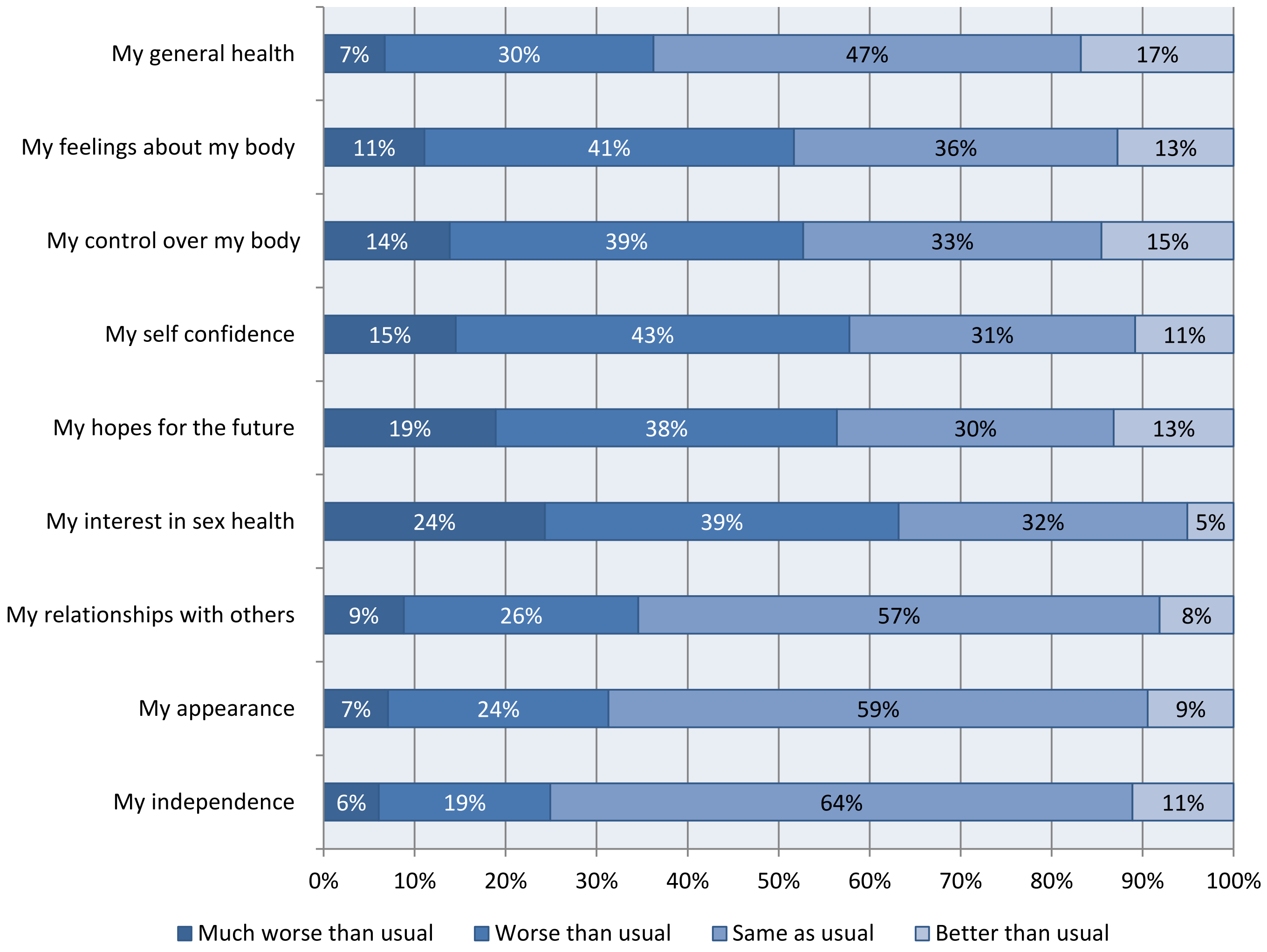
Table 101 Rosenberg self-esteem assessment

	Frequency	Percent
Low self-esteem	30	26.3
Normal self-esteem	62	54.4
High self-esteem	22	19.3
Total	114	100.0

Note: includes only those who responded to the Rosenberg self-esteem items

Looking more broadly at participants' general outlook, they were asked about their physical, mental, and social health. A majority of men reported being the "same as usual" or "better than usual" with regard to their general health (63.8%), relationships with others (65.4%), appearance (68.7%), and independence (75.1%). However, a majority reported being "worse than usual" or "much worse than usual" regarding their body (51.7%), their control over their body (52.7%), their self-confidence (57.8%), and their hopes for the future (56.4%). Men were most negative about their interest in sex with two thirds (63.2%) reporting feeling "worse than usual" or "much worse than usual".

Figure 16 General outlook since diagnosis



Peer Support

> “ACON’s peer support programs provide a space for newly-diagnosed guys to come together, share experiences and gain confidence and knowledge. This study provides the guys with a welcome opportunity to tell their story. The insights from this study are really valuable for HIV education and support programs.”
>
> Brent Clifton
> *ACON*

Peer Support

Participants were asked where they had sought support from other HIV-positive men post-diagnosis. Two fifths of men contacted HIV organisations and one third looked for HIV-positive support groups. One quarter of men used online dating sites and one fifth reached out to other HIV-positive men through online forums.

Table 102 Sources of support post-diagnosis

N=119	Frequency	Percentage
Contacting HIV organisations	47	39.5
Looking for HIV-positive support groups	41	34.5
Online dating sites	33	27.7
Through online forums	24	20.2
Other	13	10.9

Note: includes only those who were enrolled since March 2013 and responded to these questions.

Most men who acquire HIV in Australia reside in jurisdictions where they have access to workshops for people who have recently seroconverted. These workshops provide information on medical, social and legal issues relating to an HIV diagnosis and support to newly diagnosed men by their peers. When asked whether they had heard of these workshops, approximately one in five had heard of Genesis (36.2%) and slightly less had heard of Phoenix.

Table 103 Awareness of the Genesis/Phoenix workshops

	Frequency	Percent
Heard of Genesis	42	19.5
Heard of Phoenix	33	15.3
Total	215	100.0

Note: includes only those who were enrolled since March 2013.

Participants responding to questionnaire 4 were asked whether they had participated in one of the workshops. About two fifths indicated they had.

Table 104 Participation in workshops

	Frequency	Percent
No	31	53.4
Yes	25	43.1
I don’t know	2	3.4
Total	58	100.0

Note: includes only those who were enrolled since February 2014 and responded to these questions.

Of the 25 men who had participated in a workshop, virtually all of them rated the experience as good (7 men) or very good (17 men). No participants rated the experience badly. The 31 men who had not yet participated in a workshop were asked if they intended to do so in the future. Thirteen of these 31 men indicated a desire to do so.

Reflections from the interviews: Peer support

In this sample peer support emerges as an important factor in working through becoming HIV positive. Many of the men interviewed highlighted the benefits of peer support in terms of gathering knowledge about living with HIV, making sense of their diagnosis, managing their emotional and physical wellbeing, preventing onward transmission and making decisions about treatment. Participants engaged with a range of different types of peer support including formal newly diagnosed programs, one-on-one discussions with peer workers from PLHIV organisations and AIDS Councils and interactions with HIV positive friends and with HIV positive men they met online. While most men valued the advice provided by their doctor or clinic nurses, particularly in relation to decisions around treatment, they also valued the perspectives and experiences of peers. In the following example the participant actively reached out to a local PLHIV organisation in search of a non-clinical perspective on his recent HIV diagnosis:

> *I get a very clinical response from her rather than an emotional or a connecting response from her. So that's why I've reached out to [name of PLHIV organisation] to be able to talk to other people who've been through the experience that can relate to me.*
>
> ***And how's that been?***
>
> *… it was actually, it was actually really, really, … good to be able to sit down with [name of peer worker. I think I'm lucky in that [name of peer worker] and I have very, … similar experiences and we've got very, very similar personalities. And that's just from, you know, like an hour and a half of sitting down and talking to each other. We're like two peas in a pod, basically. I found that really beneficial but it also really cemented into my head that this doesn't necessarily need to be a bad thing in my life. I can use it for, for, to have a, a good, positive influence in other peoples' lives as well. And I can do that with organisations like [name of PLHIV organisation]. So it's something, it's not something that I'm looking at doing right now - I'm still not completely, still not completely me just yet - but, yeah, it's, it's, it's shown me more hope than what I had beforehand anyway, yeah (SS1140-B, 29, QLD. 2015).*

For this participant talking with a peer had reinforced his own emerging sense that living with HIV did not necessarily have to be a barrier to him having a good life. He could potentially use it as a catalyst for being a constructive influence in other people's lives. He was comfortable with one-on-one peer support, interested in becoming more involved with the PLHIV organisation, but he was reluctant to participate in any group situation involving other newly diagnosed men:

> *No. No. No. I still have, I was saying this to the psychologist today as well, I still have this trepidation of walking into a room full of people whom I don't know and, automatically, the first thing they know about me is my HIV status just because of where I am. I find that really, really hard to comprehend in my head so, like I said to my psychologist, it seems a little bit silly but, yeah, I'd prefer to walk in and, you know, basically, whisper, "HIV positive," rather than walk into a room and, and just, automatically, everybody knows just because I'm there, if you know what I mean. Yeah. So … yeah. [Yep] Not something I plan on doing, although I've had a couple of people ask if I'll come with them. I've not said yes but I've not said no (SS1140-B, 29, OLD, 2015).*

His reservations about attending a peer support group targeting newly diagnosed men centred on the way in which is very attendance at such a group would involve a public declaration of his HIV positive status, a prospect which he found confronting and for that reason he had a preference for one-on-one peer support. Another man described being initially reluctant to attend a newly diagnosed program because of fears about the nature of HIV disease grounded in outmoded understandings of what it was like to have HIV in contemporary Australia, ‘I perceived everybody to be gaunt, thin, dying, and I just didn’t want to meet people like that at the time’ (SSO300-s, 39, NSW, 2010), but as time passed his perceptions changed:

> ***So you went to [name of newly diagnosed peer program] just recently?***
>
> *Yeah… at that stage and I wanted to go because … I don’t know. Whether it’s the accepting that I’ve actually got it, I don’t know. Maybe that was what I was doing: trying to move forward. I don’t see too many people who’ve, who’ve got it and, you know, I see people on medication and who aren’t on medication. I learn about it a bit more. Because I’ve, all I’ve got are these boxes at home – you know the leaflets you get. I’ve not read them.*
>
> ***What did you do with it?***
>
> *Stuck it in a drawer. [laughs] … I felt that was the right time for me to go to Genesis and try to meet other people. I know it sounds stupid – maybe I’m contradicting myself there but in the past my, my friend, his first boyfriend died of AIDS. His second boyfriend had HIV. But he’s fine. He’s on medication. And one of M’s friends or friend of a friend, he’s got HIV. But he, he doesn’t look gaunt and he’s had it for quite a while…It’s, it’s weird, isn’t it? Your mind works … [Yep] I met most people before I knew I had it. So maybe it’s just the … the exceptions now, that I should go too. And that’s when I went to Genesis.*
>
> ***And how was Genesis for you?***
>
> *It was good, yeah. Met some really nice people. Friends. Yep…well I keep in touch with a couple… (SSO300-s, 39, NSW, 2010),*

One of the strengths of peer support is that it is able to challenge some of the misconceptions newly diagnosed men may have about what living with HIV will mean to their life. Nonetheless finding ways to encourage newly diagnosed men to engage with peer support can be challenging and therefore continuing to have a range of peer support models is essential.

Although a small number of men in the sample may have been reticent about attending group programs who did attend newly diagnosed group programs spoke highly of the experience:

> ***I might ask then specifically about the [name of newly diagnosed group] workshop.***
>
> *That’s the one I went to. And first of all not long after I was diagnosed, I went to the first one which is for an introduction to people who have just been diagnosed with HIV, and that was fantastic doing that.*
>
> ***Can you tell me a bit about it? Like how did you feel about the, the prospect of even going to a group like that.***
>
> *No, it wasn’t daunting at all. I think I, I’d seen it advertised somewhere. I think I’d gone off and I think it was through the MSV or whatever it is…The, the gay newspaper…And I saw it advertised there, and I thought, “Okay, I’m going to go.” … And so that, when I came in, I think there was about 11 of us, 11 of us at the [name] workshop.*
>
> ***That’s quite a big group.***
>
> *So it was quite a big group [Yeah] at that time [Yep] and [0:28:54] I think virtually on a yearly basis has a dinner in a little Vietnamese restaurant in Richmond just for people who have been to the workshop to come along and see each other and meet each other, and*

> *all that sort of thing. So that's been really good. [Yep] So I've gone along to quite a few of those (SS1050-M, 65, Victoria, 2014).*

As this participant observed peer support can also create opportunities for building new social connections and forms of community and ensure that the gay community and in particular HIV-positive people continue to be strong voices in the Australian response to HIV.

For some men peer support provided a way to process the volumes of information they were receiving in the early stages of diagnosis:

> ***…did you receive a referral to any other doctors or services?***
>
> *Oddly enough, so he offered, he asked me if I wanted to see a counsellor at the time. And I was like, "No, I, you know, I don't need, feel like I need to see. I just want to go outside, tell my partner and then figure out what we're going to do." So actually my partner did, 'cause I was kind of like, "What the fuck do I do?" I was just in, like just reading and reading, and reading. I'm like, "Okay, all this reading and what do I do?" So he got me in touch with somebody from … If I say his name, you may know where he's from. [name of treatments officer] [Oh yes, PLHIV organisation] … So my partner got in touch with him and then gave him my information, then told me to call him. And then he actually was like a lifesaver. Like he told me, okay, so he put me in touch … so basically just had a chat and he said, based on how I was behaving and my answers, he's like, "Oh you're probably going to be fine in terms of …" he's like, "emotionally and psychologically. It's the most, that's the most important part of dealing with it." So he said I was gonna be fine and that, but he put me in touch with the [name of newly diagnosed group program] (SS1120-S, 36, NSW, 2014)*

The interviewer asked him if he followed up on getting in touch with the newly diagnosed group and he responded in the following way:

> *Yes. I came and attended [name of newly diagnosed group program] here. It, I missed the June one so I came for the August one and that was really good too. That was the first time sitting in front of a group of others that was outside my house, that we were, you know, we were in a room. We knew all, we were all positive, so it's the first time that happened. So it was, it was good. [Okay] (SS1120-S, 36, NSW, 2014).*

The interviews show that peer support can play an essential role in negotiating treatments, sex and stigma, by providing opportunities for newly diagnosed men to share knowledge and experience:

> ***What were the take-away messages for you?***
>
> *There were some things about risk which was, there was something about the risks. Some things that I thought were not that risky that are, actually are with the opposite. … And then about access to the medication and the possible side effects then about stigma… everybody's experience is different. Everybody's HIV, not the so much the conversion but the way their body adapts to it. And it was just really interesting to see all that. And it was different types of people from, there were older, younger…It was a mix. And it was a, like the group had a, a nice flow, a nice energy. We got along well… you feel comfortable talking about … since we're all positive, I think it was easier to talk, to be more specific about things like…we know we're not gonna judge each other and, [Yeah] you know, they set some house rules which helped too. (SS1120-S, 36, NSW, 2014).*

Peer support provides a safe and non-judgemental context for newly diagnosed men to explore all aspects of HIV.

Treatments

> “Over the last five years there have been major changes in what we know about HIV treatments, including recent research that demonstrates early treatment is unambiguously good for the individual, as well as reducing transmission risk. Almost half of men who aren’t on treatment have not yet made a decision and QPP plays a critical role in supporting all PLHIV around treatment decisions..”

Simon O’Connor
Queensland Positive People (QPP)

Treatments

Participants responding to questionnaires 3 and 4 were asked about their use of anti-retroviral treatment. The majority indicated that they were on treatment at the time of completing the questionnaire.

Table 105 Current antiretroviral treatment

	Frequency	Percent
No	49	38.0
Yes	78	60.5
No response provided	2	1.6
Total	129	100.0

Note: includes only those who were enrolled since March 2013 and responded to these questions.

Men not yet on treatment

For people living with HIV, their treating doctor is a key source of medical knowledge, advice and guidance with respect to HIV treatments. Among those responding to questionnaires 3 and 4, men who were not already on treatment were asked about their doctor's most recent advice. Few doctors had suggested immediate commencement of treatment. Findings from recent large clinical trials (most notably the START trial; INSIGHT START Study Group (2015)) have shown the clear benefits of immediate commencement of treatment. As this evidence has become more available, doctors may be more inclined to advise early commencement of treatment.

Table 106 Doctor's most recent advice about treatment to men not on treatment

	Frequency	Percent
I should be on antiretroviral treatments	6	12.2
I should wait until the clinical signs show that it is necessary before I start treatments	12	24.5
It's too soon for me to decide	14	28.6
Something else	16	32.7
No response provided	1	2.0
Total	49	100.0

Note: includes only those who were enrolled since March 2013 and indicated they were not yet on treatment.

Those participants not yet on treatment were also asked whether they agreed with their doctor's advice and almost three quarters (73.5%) of those who answered either agreed or strongly agreed.

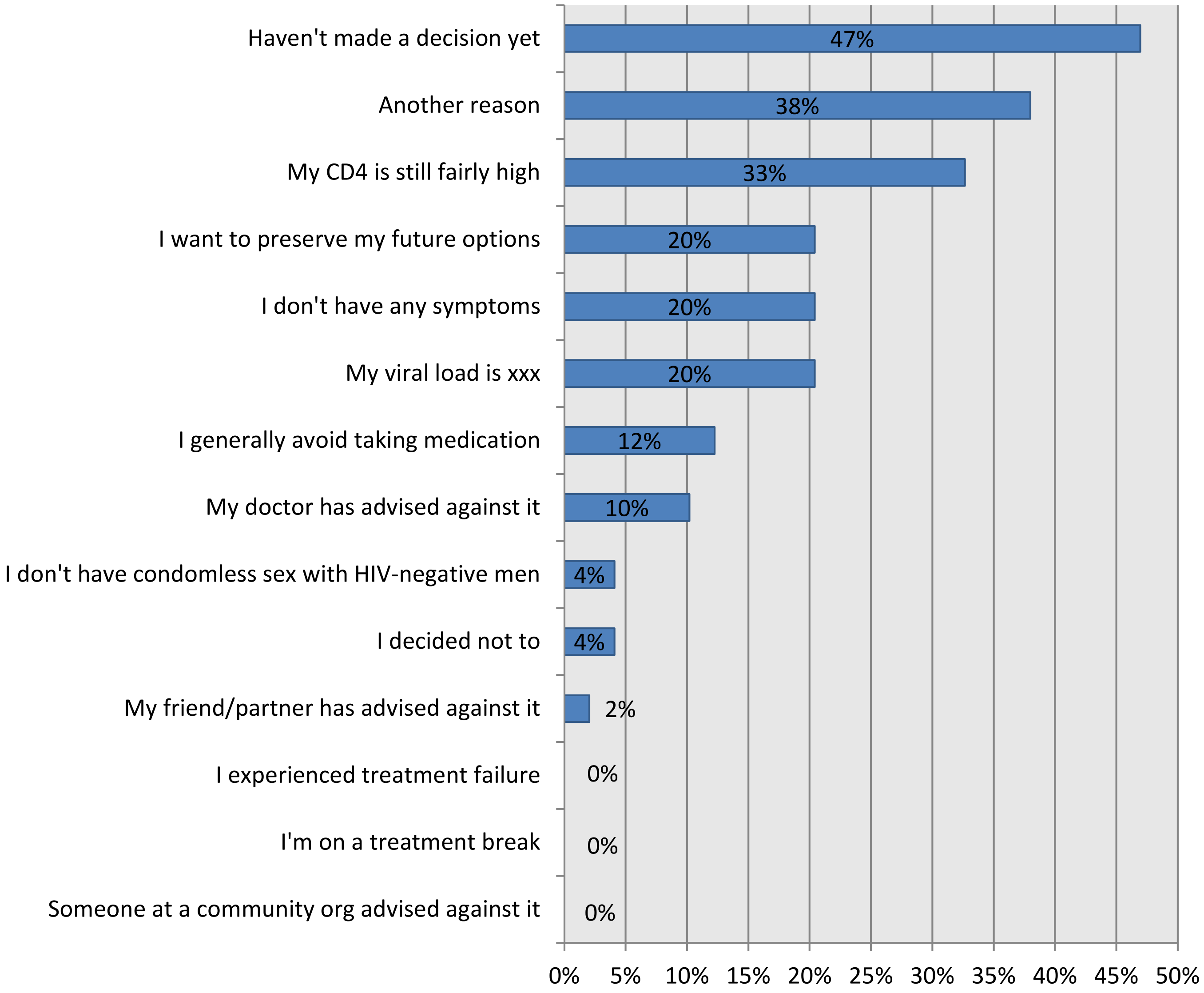
Table 107 Agreement with doctor's most recent advice about treatment (not on treatment)

	Frequency	Percent
Strongly disagree	4	8.2
Disagree	7	14.3
Agree	23	46.9
Strongly agree	9	18.4
No response provided	6	12.2
Total	49	100.0

Note: includes only those who were enrolled since March 2013 and indicated they were not yet on treatment.

They were also asked why they had not yet commenced antiretroviral therapy. Just under half (46.9%) indicated that they had not yet made a decision and one third of men (32.7%) said their CD4 count was still high. Viral load, being asymptomatic, and preservation of future options were each cited as reasons for not having commenced treatment by about one in four men.

Figure 17 Reasons for not yet being on treatment



Men on treatment

Among men responding to questionnaires 3 and 4, those who were on treatment were asked about the advice provided to them by their doctor. Nearly all men (90.9%) indicated that their doctor had specified that they should be on antiretroviral or should stay on treatment (either on their current or an alternate treatment regime).

Table 108 Doctor's most recent advice about being on treatment to men on treatment

	Frequency	Percent
I should be on antiretroviral treatments	18	23.4
I should stay on my current antiretroviral treatments	49	63.6
I should switch treatments	3	3.9
I should wait until the clinical signs show that it is necessary before I start treatments	1	1.3
Something else	6	7.8
Total	77	100.0

Note: includes only those who were enrolled since March 2013 and indicated they were already on treatment.

Although almost all men (90.9%) either agreed or strongly agreed with their doctor, a small number of men on treatment nonetheless strongly disagreed with their doctor's advice.

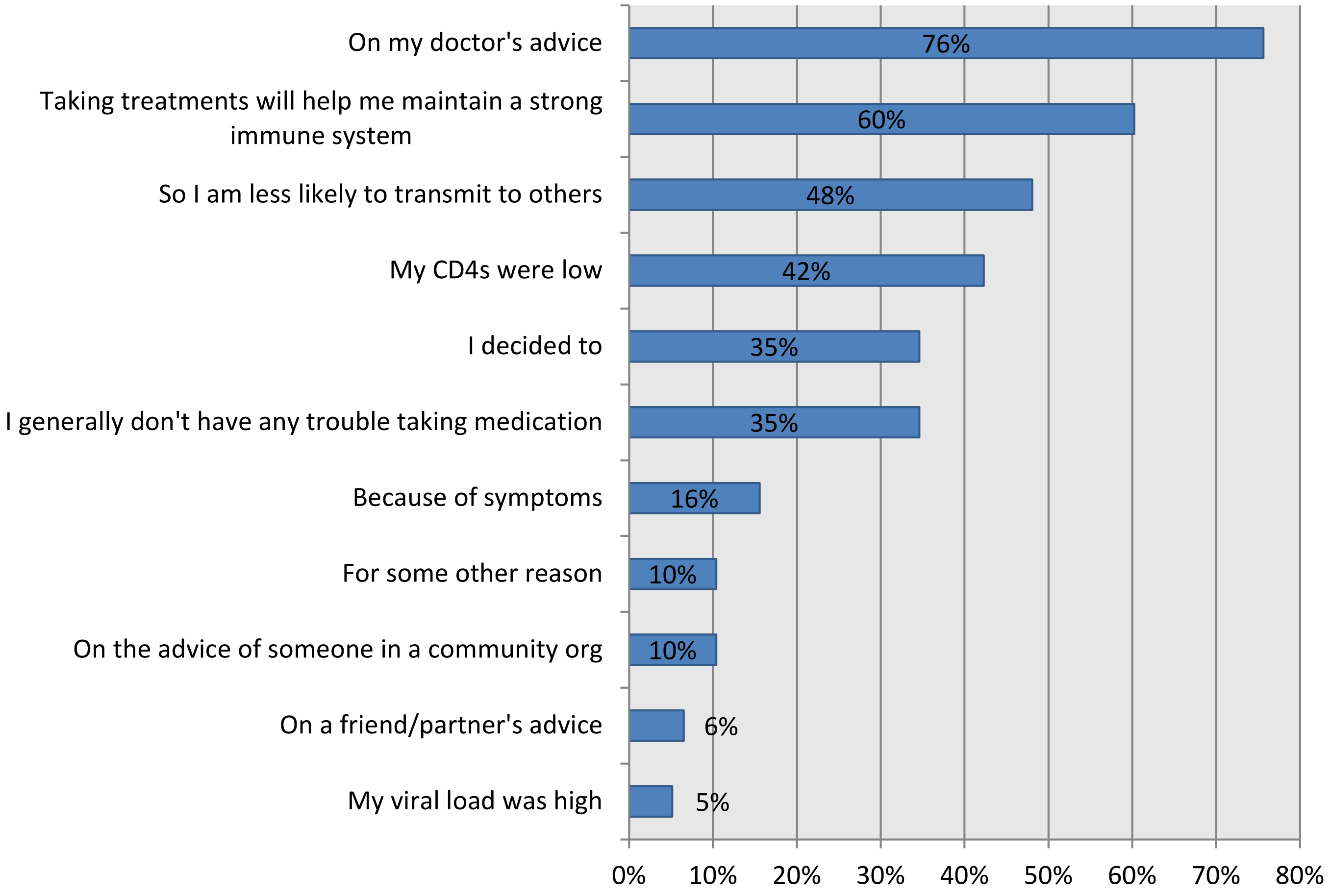
Table 109 Agreement with doctor's most recent advice about treatment (on treatment)

	Frequency	Percent
Strongly disagree	7	9.1
Disagree	0	0
Agree	14	18.2
Strongly agree	56	72.7
Total	77	100.0

Note: includes only those who were enrolled since March 2013 and indicated they were already on treatment.

Three quarters (75.6%) of men indicated that their doctors' advice was key to their decision to commence treatments, and nearly two thirds (60.3%) said that keeping their immune system strong was also a factor. Half (48.1%) reported that reducing transmission risk was a reason for commencing treatment. Two fifths (42.3%) of men cited a low CD4 count as a reason for commencing treatment. High viral load, symptoms and advice from friends/partners or a community organisation were not often cited as reasons for commencing treatment.

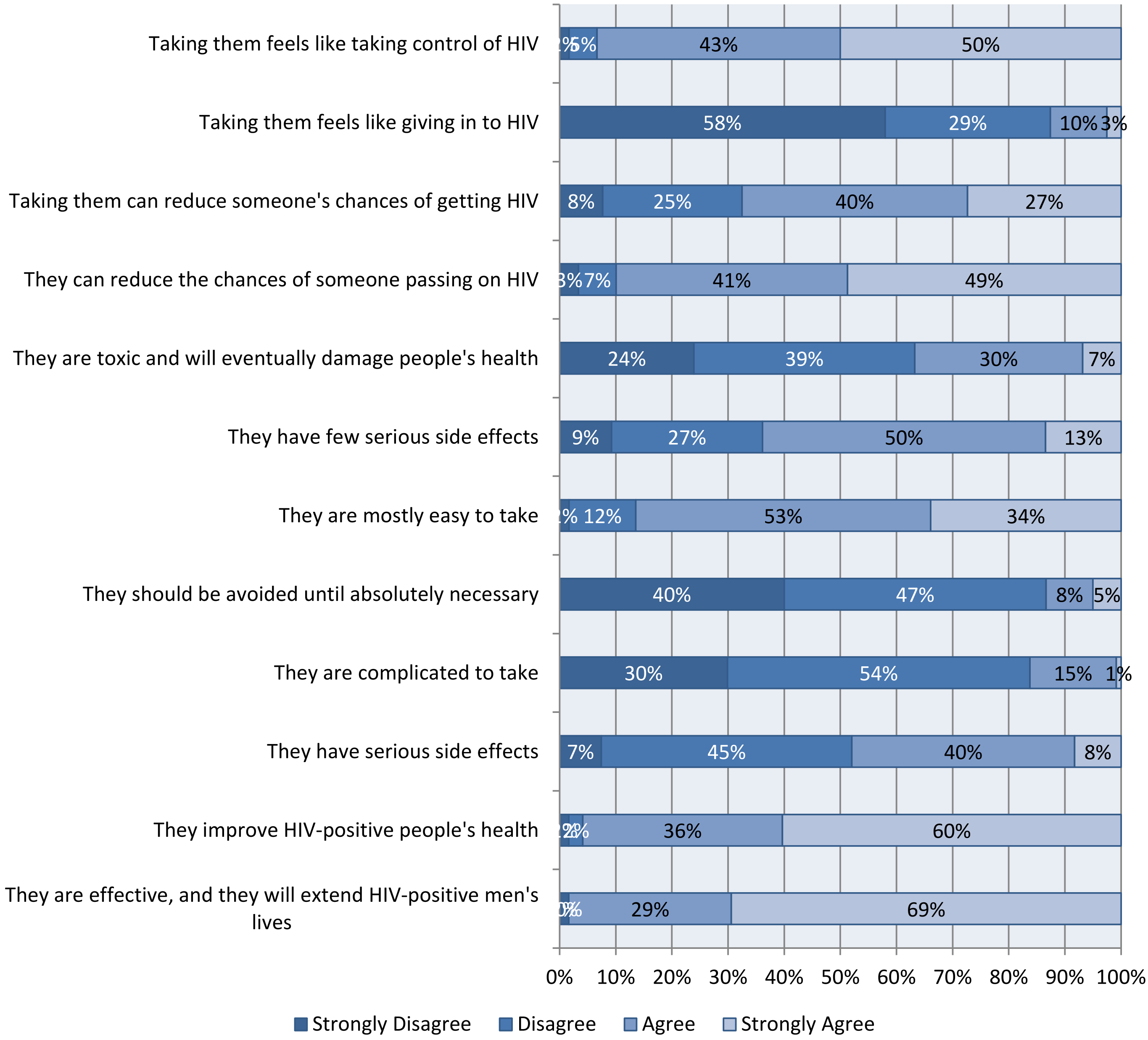
Figure 18 Reasons for starting treatment



Beliefs about treatment

When asked about their beliefs about treatments, the majority of all participants were generally very positive about them. Almost all participants agreed or strongly agreed antiretroviral drugs were effective in extending HIV-positive people’s lives (98.3%), and that they would improve HIV-positive people’s health (95.8%). A clear majority of participants agreed that HIV treatments had few serious side effects (64.4%) and are mostly easy to take (86.3%). Similarly, a clear majority agreed that being on treatment made them feel like they were taking control of HIV (93.3%). Most disagreed that taking treatment felt like giving in to HIV (87.3%). Looking at transmission risk, the majority agreed or strongly agreed that antiretroviral drugs can reduce the chance of someone getting HIV (68.1%) or reduce the chance of them passing on HIV (89.8%). Participants were evenly split on whether antiretroviral drugs had serious side effects with 52.5% disagreeing and 47.5% agreeing. Finally, most participants either strongly disagreed or disagreed that drugs are toxic and damaging (63.8%), that they should be avoided until absolutely necessary (86.6%), and that they are complicated to take (83.6%).

Figure 19 Beliefs about treatments



Participants responding to questionnaires 3 and 4 were asked under what circumstances treatment should be commenced with the intent of reducing transmission risk. Two fifths (40.3%) indicated that HIV-positive men should commence treatment but only if it is good for their health while another two fifths (41.9%) thought that everyone should be on treatment.

Table 110 Treatment commencement to reduce the chances of passing HIV on to others

	Frequency	Percent
No, HIV treatments make no difference to the risk of passing on HIV	11	8.5
They should NOT commence treatments, unless it is also good for their health	10	7.8
They SHOULD commence treatments, BUT ONLY IF it is also good for their health	52	40.3
Yes, always	54	41.9
No response provided	2	1.6
Total	129	100.0

Note: includes only those who were enrolled since March 2013 and responded to these questions.

Participants responding to questionnaires 3 and 4 were also asked how likely they thought it was that an HIV-positive man on treatment could still pass on HIV to an HIV-negative partner. Half (48.8%) thought it was either very unlikely or unlikely. Two fifths (39.7) thought it was likely or very likely. One in ten did not know.

Table 111 Transmission likelihood when on treatment

	Frequency	Percent
Very unlikely	23	17.8
Unlikely	40	31.0
Likely	41	31.8
Very likely	10	7.8
I don’t know	13	10.1
No response provided	2	1.6
Total	129	100.0

Note: includes only those who were enrolled since March 2013 and responded to these questions.

Given the accumulating evidence of successful antiretroviral treatment dramatically reducing HIV transmission risk, participants responding to questionnaires 3 and 4 were asked about their knowledge of what research had demonstrated in this regard. About half (51.2%) of the respondents thought that risk was reduced in both hetero- and homosexual sex and less than one in ten (7.8%) believed treatment had not been shown to reduce transmission risk at all. About a quarter (23.3%) did not know and the remainder were evenly divided between believing there was protection demonstrated in heterosexual sex only (8.5%) and in homosexual sex only (7.8%).

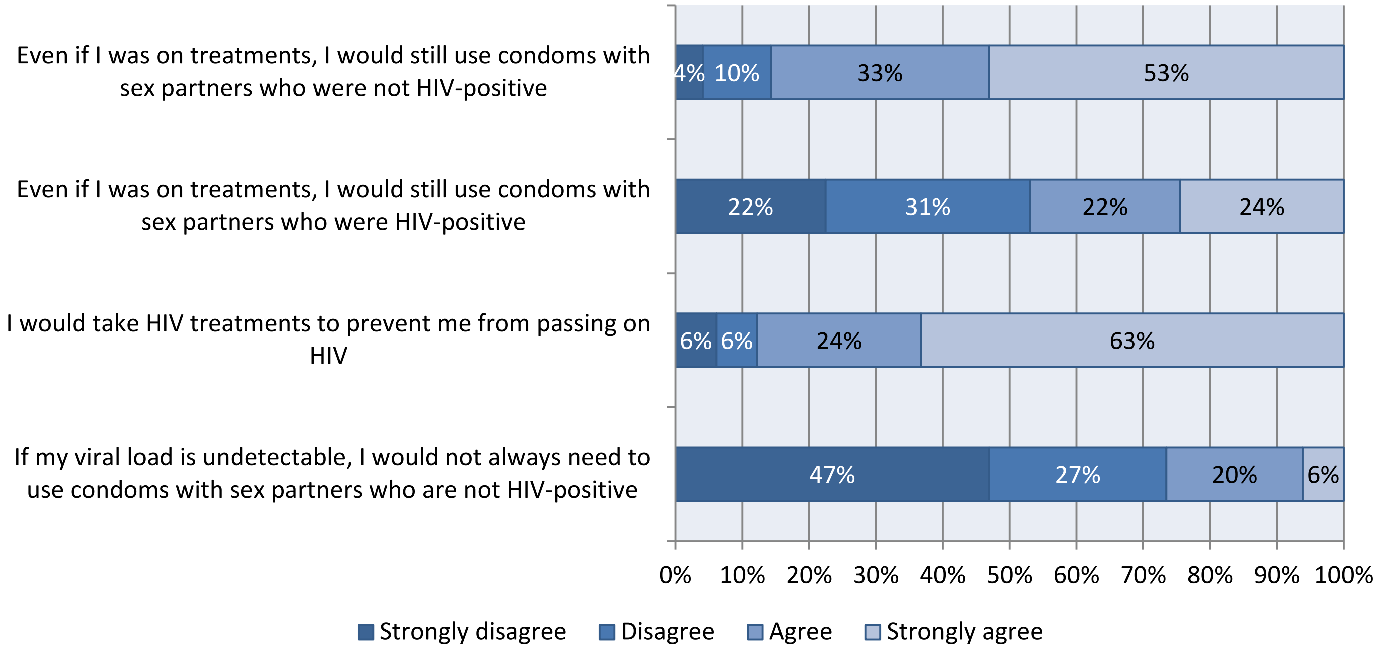
Table 112 Evidence of efficacy of Treatment as Prevention

	Frequency	Percent
Yes - in heterosexual sex	11	8.5
Yes - in male homosexual sex	10	7.8
Yes - in any sexual situation, homosexual or heterosexual	66	51.2
No - this has not been shown for any type of sex	10	7.8
I don’t know	30	23.3
No response provided	2	1.6
Total	129	100.0

Note: includes only those who were enrolled since March 2013 and responded to these questions.

Finally, men on treatment were asked about their practices and beliefs around HIV transmission risk. Participants tended to be risk-averse with a large majority (85.7%) agreeing that even if they were on treatments, they would still use condoms with partners who are not HIV-positive. If participants were on treatment, they were evenly divided between whether they would still use condoms with sex partners who were HIV-positive. A large majority (87.8%) of men agreed that they would take HIV treatments to prevent them from passing on HIV. However, a quarter (26.5%) of participants agreed that if their viral load was undetectable, they would not always need to use condoms with sex partners who are not HIV-positive.

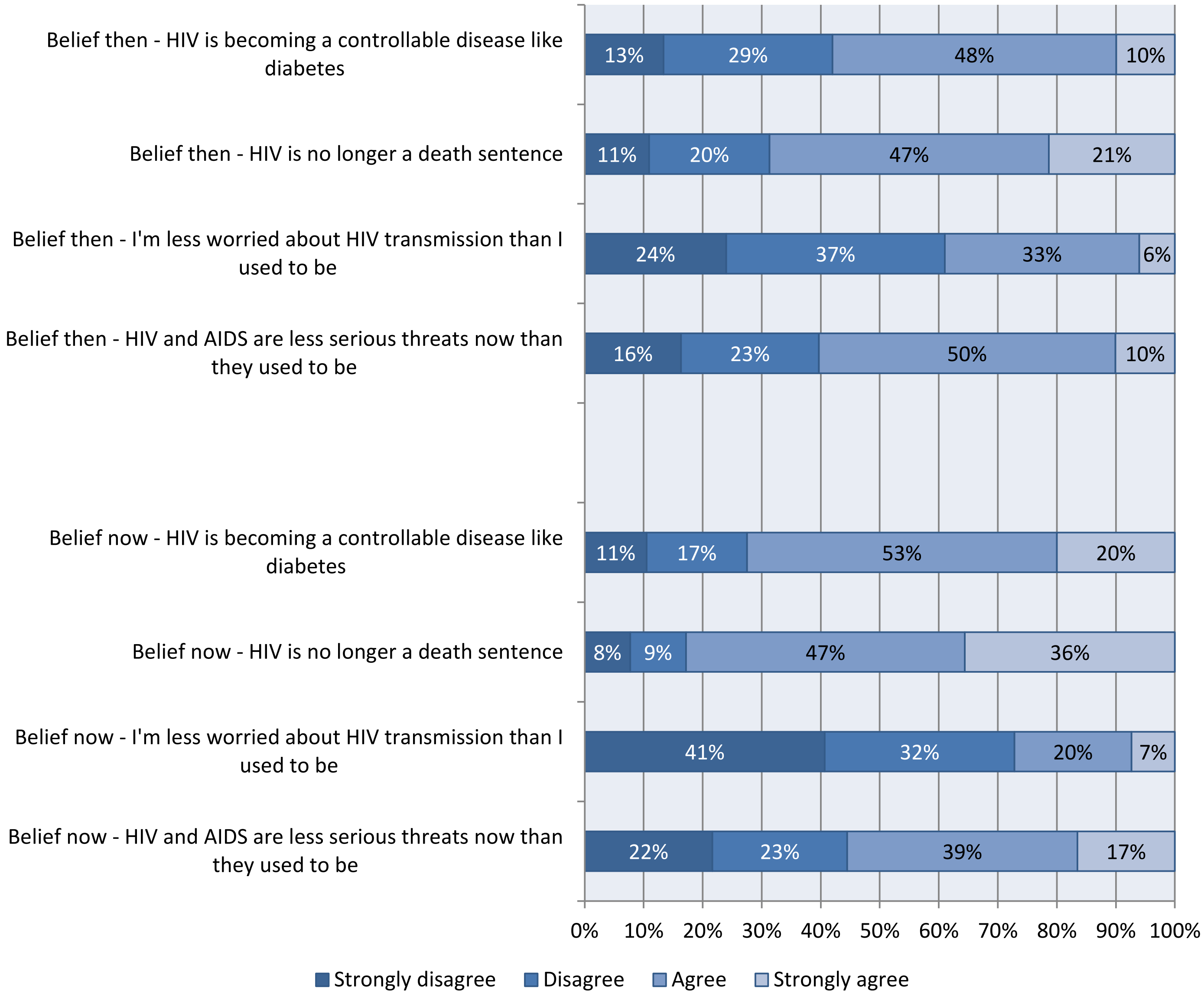
Figure 20 Beliefs about transmission risk



Knowledge and Beliefs

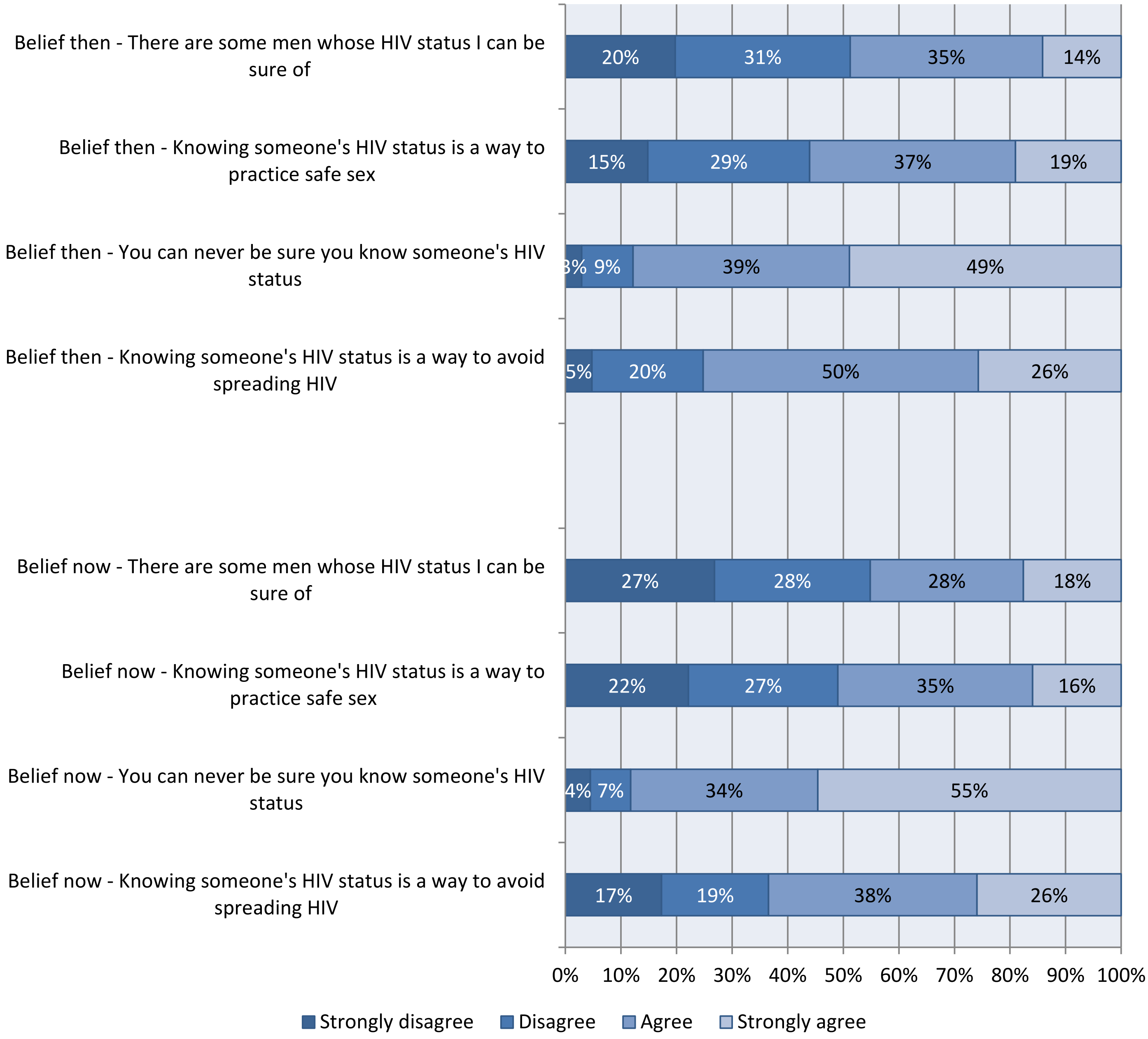
Participants were asked how their knowledge and beliefs have changed since their HIV diagnosis. Looking firstly at the consequences of infection, participants tended to become more optimistic after their diagnosis, with more agreeing that HIV is becoming a controllable disease and that HIV is no longer a death sentence. Nonetheless, fewer men felt less worried about HIV transmission after diagnosis.

Figure 21 Beliefs about consequences of infection



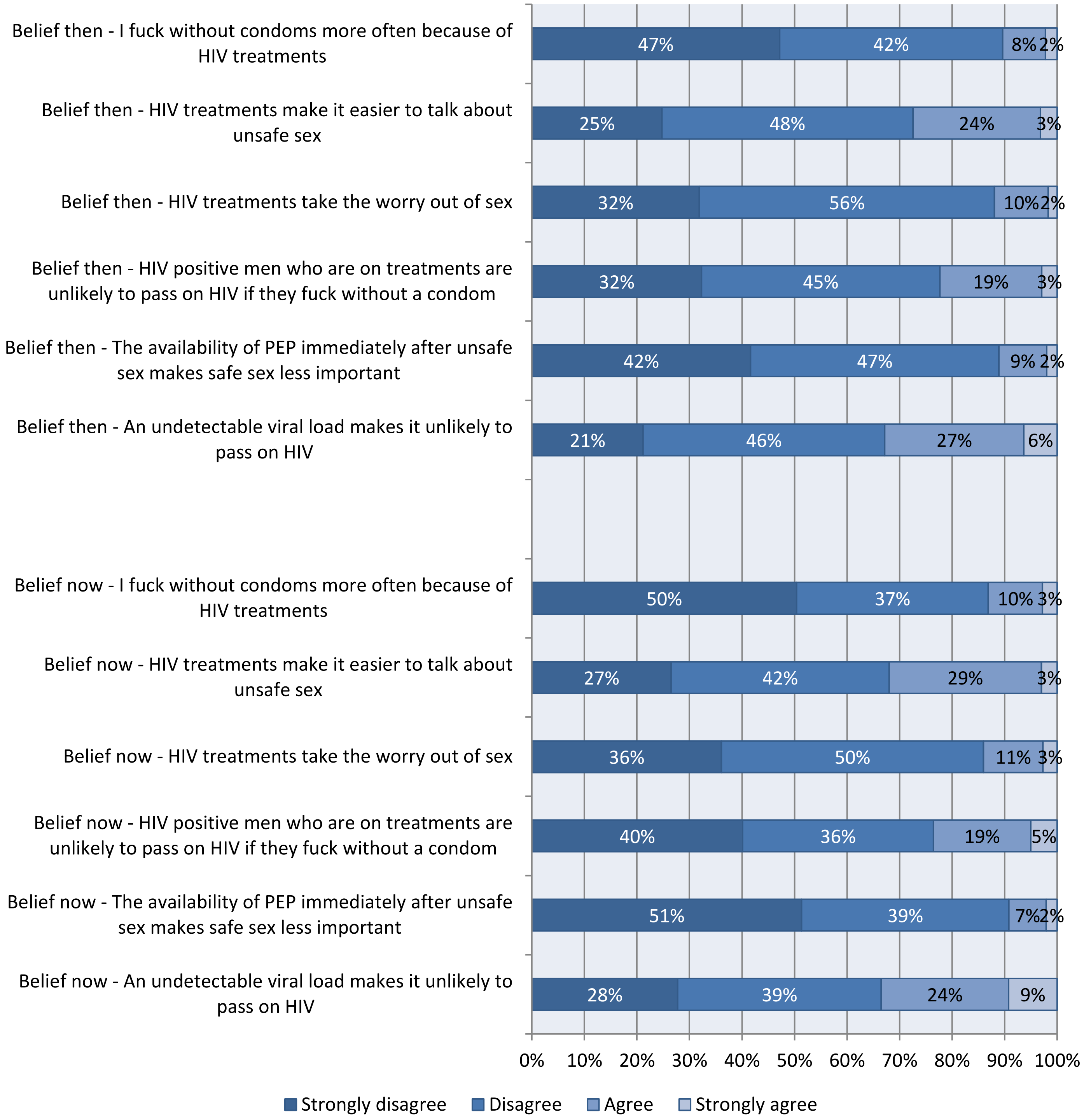
Men were also asked what they believed about using their HIV status to negotiate sex. There was little change since diagnosis in what they believed. Similar numbers of men agreed before and after diagnosis that knowing someone's HIV status is a way to practice safe sex and that knowing someone's HIV status is a way to avoid spreading HIV.

Figure 22 Beliefs about using HIV status to negotiate sex



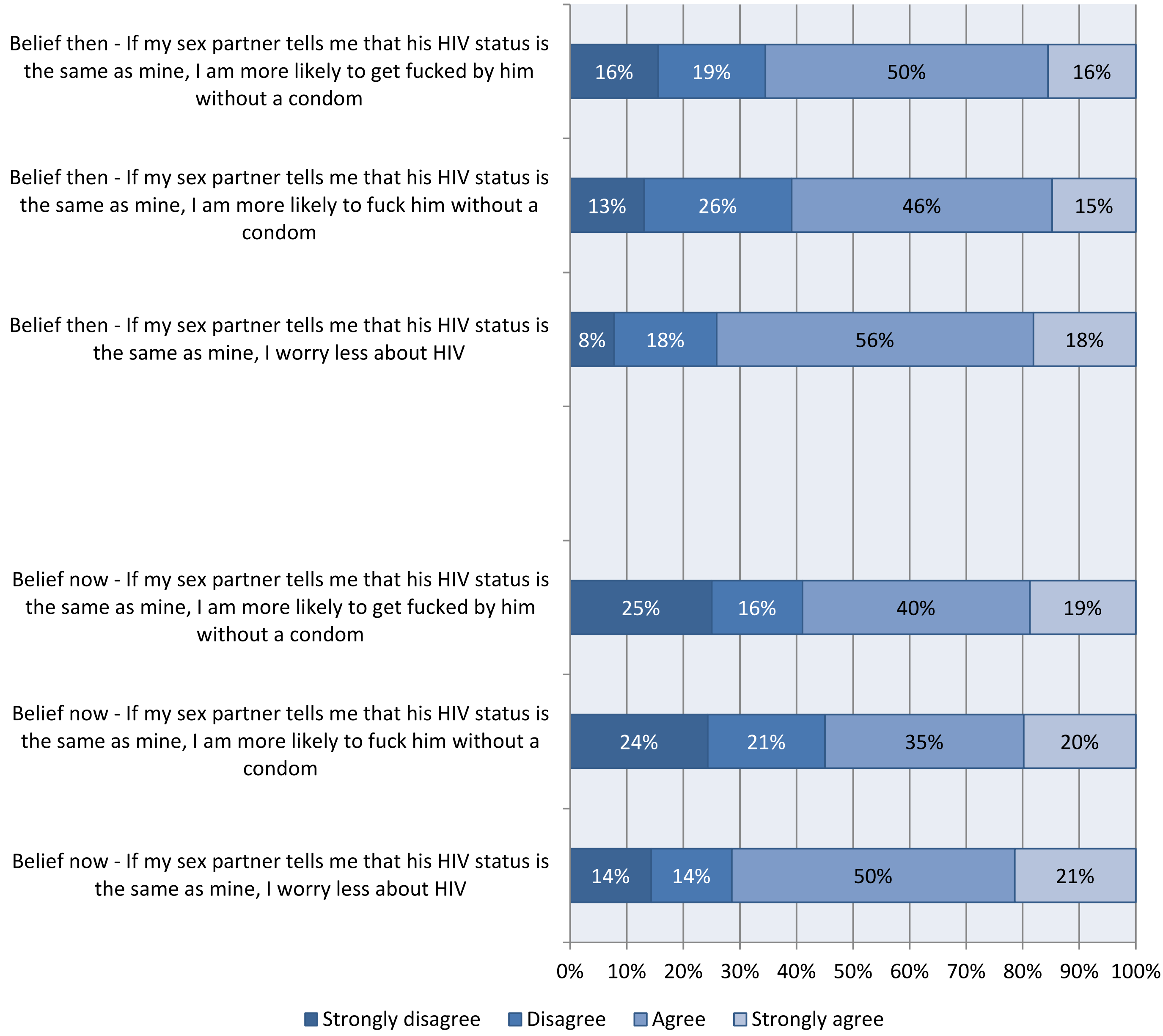
Regarding their beliefs about HIV transmission, there was also little change since diagnosis. Men tended to disagree both before and after diagnosis that they are less likely to use condoms because of HIV treatments. They also tended to disagree, both prior to and since HIV diagnosis, that HIV-positive men on treatment are unlikely to pass on HIV during condomless anal intercourse and that the availability of PEP makes safe sex less important. Finally, before and after diagnosis the majority of men disagreed that an undetectable viral load makes it unlikely to pass on HIV.

Figure 23 Beliefs about HIV treatments



Participants were also asked what they believed regarding risk reduction, specifically strategic positioning (whereby the HIV-negative partner takes the insertive position during condomless anal intercourse). There was little change since their diagnosis in what they believed about the relative risk of using this strategy to reduce risk.

Figure 24 Beliefs about risk of reduction



Treatment: Reflections from the interviews

There has been significant change in the guidance around when PLHIV should start treatment. In the period 2009-2012 initiation of treatment was recommended for those PLHIV with a CD4 count below 500. More recently the guidance has been that all PLHIV start treatment irrespective of CD4 count, this shift reflects the strong evidence that early initiation of treatment reduces the risk of disease progression. In addition, there has also been increasing evidence that ART reduces the risk of onward transmission and in recent years TasP has been promoted in Australia. While the guidelines around treatment have changed over the course of the study, the key role played by treating doctors in guiding decisions about treatment has remained constant. Men in the interview sample typically valued and followed the advice of their doctor. However, this did not mean they were not active participants in decisions about treatment and nor did it mean they were always comfortable with decisions:

> ***How did you feel about going on treatments?***
>
> *So, ultimately, proactive, empowered, empowered, you know, like, yeah, proactive and shit scared.*
>
> ***Can you talk about the shit scared?***
>
> *[Laughs] Well, you know, like, once you see the pill bottle every morning and every night, you know, that's, you know, and once you start, you can't stop, a bit like chocolate. So, you know, there is that constant reminder. Ultimately, I think you have to think of what the bigger picture is. Yes, it's perhaps a mild inconvenience to be taking a pill every day or a series of pills - six it is at the moment - but the alternatives I think are probably less desirable. But yeah I felt empowered to do it but then also, you know, the human side was kind of like jeepers creepers (SS0960-S, age 41, NSW, 2013).*

The concept of control was a common theme in the interviews including in relation to treatment:

> *I suppose going on medication in a way will help me control it. Because at the moment I've got no control over what my body's doing. And it's out of control. By going on medication in some aspects will help me think mentally that, hey, it's getting under control. You know, the doctors are controlling what's happening to me SS0040-M, age 32, Victoria, 2009).*

Here treatment is perceived as something that he and his doctors can use to regain control over his body.

While most participants valued the advice of their treating doctor, some men wanted their doctor's to be more directive, particularly when they were faced with differing and sometimes contradictory information about when to start treatment:

> ***What's your feeling about treatments or, you know, I guess your future health?***
>
> *… for me at the moment it's one of the biggest dilemmas because my GP made it very clear that the, there are, you know, many schools of thought about when to go on treatment and the trend at the moment is, happens to be that not to go on treatment until, you know, your T cells are 350. And all that, all that sort of stuff. But he said, "You will encounter other people that say otherwise" (SS0480-S, age 40, NSW, 2011).*

This man felt that he needed more direction from his GP or another medical expert:

> *I know if I went to my GP and said, "I'd like to start treatment," he'd have no problem… if there's anything that I feel that I don't know, that's, that's the area that I'm kind of most in the dark about. When, when to start treatment. And it's all very well kind of equipping us non-medical people with all the facts but there's a sense so I just kind of, I want a recommendation from somebody who, you know, who, who does know. You know what I mean? It's like, I don't know, you know, going to have your car fixed and the mechanic saying, "It could be this, could be that, you know, whichever, however you want me to …" It's just kind of like, "I don't know. I don't know." And whilst I know, I recognise the need to own the disease, I recognise the need to not, not let it define me. But, for, it's part of me but it doesn't define me. I know, I know all of that and I can deal with all of that but there comes a technical side which just overwhelms (SS0480-S, age 40, NSW, 2011).*

This quote illustrates some of the challenges around PLHIV being active participants in treatment decisions and capacity to navigate the medical field. It is likely that some of the difficulties around when to start treatment will be reduced now that the guidelines recommend initiation of ART irrespective of CD4 count.

For many men starting treatment was perceived as a way to reduce the negative impacts of HIV on their daily life:

> *…knowing the option of treatment was there from sort of the very start was sort of a helpful sort of, yeah, mind like thing to keep in mind, to sort of deal with it mentally, yeah. So … like that, it definitely helped I think, of … I guess there's always that, I, I know it's bad but I, when I told Mum, it was, "Yeah, there'll be a cure soon," which everybody does and we all know that it's not. But I guess it's that same sort of thing of, "Yeah, I've got it but I can deal with it, so it's not a problem. I can manage it." And that's probably how it all sort of ticked in my head of … if I go, if I get onto medication straight away, then it, I can, I can cover it up. I can sort of push it away and I don't have to worry about it every day… (SS1110-S, age 31, NSW, 2014)*

Here treatment acts as a form of reassurance, and as a way to minimise the impact of HIV on his everyday life. He goes to explain that starting treatment also allowed him to stop feeling like he was infectious:

> *Not in the forefront of my mind. Not in every step that I take of you've got to think of it, which, in that first four-week period from diagnosis 'til I was on medication, I sort of was doing that a lot. It was always like, "Oh, I cut myself. I've … I've got to look (after) … I, I …" like be self-conscious of what I do because potentially I'm a bio-hazard, which is a weird headspace to be. Like it's a weird thing to think of. Like having studied science and stuff, and it's rather odd having that sort of constant medical caution of other people… (SS1110-S, age 31, NSW, 2014).*

Although it was rare for men in the interview sample to reject medical advice about starting treatment this did not mean that they had no reservations or concerns about treatment. Most men understood the health benefits of treatment, but unsurprisingly some were also daunted by the life-long nature of current HIV treatment:

> *Yeah. I was away from home… I picked up the drugs, picked up my car and then drove down to [regional town in NSW] to work. And I'd planned to start taking them that night. I had a bit of a realisation that night though. 'Cause I was away from home, I mean I live by myself but I have a cat at home so I was by myself in a hotel room… And, you know, I just kind of had this, this realisation that, once I take that first pill, that's it: I have to keep taking them every single day for the rest of my life. And I just thought to myself, "I'll, I'll just give myself one more night of freedom and I'll do it when I'm back at home in an environment*

> *that I'm comfortable in." … I gave myself the one more night. I enjoyed my night… I came home and started taking them the next day (SS1140-B, age 29, QLD, 2015).*

Some men also had concerns about the long-term side effects of treatment:

> *The idea was to try and start at the start of the year where there mightn't be as much work because then it's easier to manage side effects as, as opposed to being, you know, very busy, possibly involved in full-time work and then trying to deal with it, which is a little bit harder I think. So, and I was weighing up in my mind being able to reduce the possibility of damage, you know. So, that was occurring to the system from the virus and stuff like that. So I know that, in the long-term, the medications across a lifespan could, obviously, cause problems because it's a foreign substance that's going into your body. So, and, with limited amounts of research done, even if it's five-year clinical trials or however long they do it, it's still you're taking these drugs for a much longer period of time than what they've researched. But either, which way, what do you do? You, you don't take a medication, you'll be fine for X amount of years, unless you get an AIDS-defined illness or something like that prior where you're just stuffed anyway. Or you begin medication where you at least feel more confident that you're trying to control something (SS1130-B, age 32, QLD, 2015).*

This quote indicates that people newly diagnosed with HIV may need further information about the long-term effects of treatment and some assistance in interpreting the 'science', including the results of clinical trials.

Decisions about when to start treatment were primarily influenced by health issues, for some men however the potential prevention benefits of treatment were also a factor:

> *…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" (SS0700-M, age 29, Victoria, 2012).*

He went on to explain that concerns about being infectious had sometimes acted as barrier to sex:

> *… I was actually thinking, "Do you know, I'd rather not be a risk to people," you know. 'Cause there, there was that feeling straight after: I felt a bit toxic. You know, I was sort of feeling like, you know, I'd look at someone and go, "Oh they're cute. no, hang on …" And I'd immediately feel like no, I was a danger to them. So it's just like … but now on medication, undetectable viral load and, and good CD4 counts (SS0700-M, age 29, Victoria, 2012).*

This quote illustrates that treatment for prevention is not necessarily at odds with individual health needs. Further, there may be significant health and wellbeing benefits for newly diagnosed people 'feeling' less infectious in their social and sexual lives.

Differences across jurisdictions

> “Australian gay men are geographically and culturally diverse, yet there is risk from HIV around the country. We need to maintain a national approach to prevention, while also sharing knowledge and experience across jurisdictions.”
>
> Darryl O’Donnell
> Australian Federation of AIDS Organisatins (AFAO)

Differences across jurisdictions

We examined differences across the jurisdictions to determine if there were any particular issues that applied more or less in any of the states and territories. For the most part, there were few significant differences across jurisdictions, other than those that would necessarily apply due to differences in locally available services, facilities, or opportunities.

Demographically, there was very little difference across the jurisdictions. The men enrolled in Tasmania tended to be somewhat younger, but this may be simply due to small numbers of participants from that state. Social engagement with other gay men, and therefore, likely engagement in aspects of gay community life, was unsurprisingly strongest in NSW and Victoria and somewhat lower in the less populous jurisdictions. The higher social engagement among men in Tasmania may also be a product of small participant numbers, although it is possible that in this small jurisdiction gay men may be more closely interconnected.

The PHQ-9 measure of depression indicates that men in less populous states tend to have higher rates of depression. Given that depression among gay and bisexual men tends to be highest among those who are least socially connected to other gay and bisexual men, or to some form of gay community, this is perhaps not surprising. Of course, it is also possible that these higher rates of depression reflect differences in stigma about HIV outside Sydney and Melbourne, or differences in access to services and peer support in the less populous jurisdictions.

There is little difference in the measures of optimism about HIV treatments and transmission across the jurisdictions. Nonetheless, the relatively lower scores among the men in Tasmania, while small in number, are nonetheless worth considering.

Given the apparent importance of (lack of) prior acquaintance with the person from whom participants believed they acquired their HIV, it is interesting to note that for the most part this appears to apply across jurisdictions. Nonetheless, men in Western Australia and, especially, Tasmania do appear to have been more likely to have previously had sex with the source person prior to the high risk event at which they believe they had acquired HIV. This also applied somewhat to men in Canberra. These trends may simply be due to small numbers, but they might equally represent some differences in sexual patterns among high risk men in those jurisdictions. Equally notable, none of the small number of respondents from the Northern Territory indicated having previously had sex with the source person. Given they also reported relatively low levels of social engagement with other gay men, this may also represent a difference in patterns of sexual connection, but the numbers involved are very small and therefore any possible implications should be treated with caution.

Knowledge of PEP appeared to differ substantially across jurisdictions. Men in NSW appear to have been more aware of PEP prior to their diagnosis than was the case among men in other jurisdictions, except perhaps in the Northern Territory (but, again, the small numbers may be the reason for this and so any implications should be considered with caution). The low proportions in most jurisdictions who were aware of PEP prior to their diagnosis, and, indeed, the fact that only two thirds of these very high risk men in NSW had been aware of PEP, is concerning. This is perhaps an important consideration as the implementation of PrEP is undertaken.

HIV testing prior to diagnosis also seems to have differed somewhat across jurisdictions. All jurisdictions had lower rates of previous testing than was the case among men in NSW. Even in Victoria, there were about a third more men who had never been previously tested than among men in NSW. The rates of no previous testing among men in South Australia, Tasmania, and the Northern Territory were particularly concerning, although small numbers need to again be considered as a potential explanation.

Rates of commencement of treatment did not differ greatly across jurisdictions (note: these questions were not asked of men in the Northern Territory). Nonetheless, the relatively high rate of treatment uptake in Queensland is notable, as is the very low rate of uptake among men in Canberra.

Table 113 Comparison by jurisdiction

	NSW	VIC	QLD	WA	SA	ACT	NT	TAS	Total
Age (mean)	34.7	34.8	35.0	36.4	36.1	33.0	34.0	26.3	
Social engagement with other gay men	6.2	6.3	5.7	5.6	5.4	5.1	4.8	6.2	
Severity of depression	8.8	8.9	9.7	8.6	9.7	11.7	12.0	12.3	
HIV health optimism	10.0	10.4	10.0	10.5	9.2	10.3	11.0	8.8	
HIV treatment optimism	11.6	11.6	11.3	12.0	9.9	11.8	14.3	9.3	
No prior sex with source person	66.2%	66.7%	63.6%	42.2%	70.8%	56.3%	100%	20.0%	63.8%
Knew source person's viral load	19.6%	21.7%	12.9%	4.5%	18.2%	33.3%	100%	0%	18.6%
Had heard of PEP at time of HRE	67.1%	58.3%	49.6%	44.7%	28.6%	53.3%	66.7%	50.0%	57.6%
No previous HIV test	9.5%	12.4%	13.3%	14.6%	21.1%	0%	40.0%	20.0%	11.9%
Had commenced ART	58.3%	60.6%	66.7%	54.5%	100%	25.0%	-	100%	60/8%

Differences over time

> “A lot has changed in eight years but HIV hasn’t! Treating HIV early lets me lead a healthy, happy life. HIV treatments are now less complex and we know more about viral load and sexual risk. I take one pill a day and I couldn’t be healthier.”
>
> Tobin Saunders

Differences over time

We also examined differences over time (i.e., since the commencement of this version of the Seroconversion Study in late 2007) to determine if there were any particular changes that had occurred during the period of data collection for this latest version of the Seroconversion Study. For the most part, there were few significant changes over time. There has been little change in the profile of the men recruited into the study over time, nor in their patterns of sexual behaviour. There has also been no change, and therefore no improvement, in men's knowledge of PEP prior to diagnosis.

There does appear to have been some increasing optimism about HIV health and treatment since the study commenced enrolment. This may also be reflected in the suggestion of some recent slight increases in the proportion of men who had commenced treatment. On the other hand though, in more recent years, men appeared to have been more likely to believe they had known the viral load of HIV-positive source persons at the time of the high-risk event. This is a somewhat contradictory finding. It suggests that there may be more communication about viral load occurring, but the quality of that communication may be inadequate. Equally though, it may also be that with greater awareness of viral load, these high risk men may have been more inclined to assume knowledge at the time of the high risk event that was later proven to be incorrect.

There is also some suggestion of an increase in the proportion of men reporting no previous HIV test prior to their HIV diagnosis. This is also somewhat contradictory insofar as recent surveillance data have suggested an increase in HIV testing among gay and bisexual men generally. It may just be that these data simply precede those recent improvements in testing rates, but it may also be that while gay and bisexual men may be testing more often in general, this may not be as strongly reflected among these very high risk men.

Table 114 Comparison over time

	Q1 2007-2010	Q2 2011-2013	Q3 2014	Q4 2015	Total
Age (mean)	34.8	33.9	37.3	35.1	
Social engagement with other gay men	-	6	5.8	6.1	
Severity of depression	9.6	9.9	10.9	10.8	
HIV health optimism	9.6	9.9	10.9	10.8	
HIV treatment optimism	10.7	11	12	12.9	
No prior sex with source person	66.7%	56.0%	72.6%	68.3%	63.5%
Knew HIV-positive source person’s viral load	24.3%	13.3%	31.3%	36.4%	18.6%
Had heard of PEP at time of HRE	57.1%	56.3%	65.6%	57.5%	57.8%
No previous HIV test	12.6%	6.9%	14.6%	16.4%	11.8%
Had commenced ART	-	-	59.3%	62.7%	61.1%

Non-homosexually acquired HIV

> “Whilst there is a relatively established culture of HIV testing within the gay community, this is not the case for women and heterosexual men. Heterosexuals are still not regarded as an ‘at risk’ population which feeds stigma and discrimination, and this has major implications for public health policy.”
>
> Jane Costello
> *Positive Life NSW*

Non-homosexually acquired HIV

By Asha Persson, Centre for Social Research in Health

The numbers of HIV diagnoses in Australia that are attributed to modes of transmission other than through sex between men remains at about one quarter of new diagnoses each year. This has varied little during the past decade. Most of these ‘non-homosexual’ diagnoses have been attributed to heterosexual contact, although many of these were among individuals from high-prevalence countries or their partners (The Kirby Institute, 2015).

Table 115 Newly diagnosed HIV infections by exposure category 2005-2014

Year	Injecting drug use	Heterosexual sex	Receipt of blood/tissue	Mother with/ at risk of HIV infection	Other/ undetermined
2005	31	167	1	5	81
2006	27	224	0	6	59
2007	25	200	1	4	63
2008	32	207	0	5	39
2009	23	231	1	8	45
2010	23	208	0	5	61
2011	20	192	0	7	44
2012	25	207	4	1	52
2013	26	217	3	4	56
2014	31	201	0	3	38
Total	263	2054	10	48	538

Source: HIV, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report 2015

The experiences of women and heterosexual men

This section reports on the experiences of the women who responded to the survey, and also the men who acquired HIV through sex with a woman. Since July 2010, 13 women and 14 men have provided sufficiently complete responses to the survey questionnaire to be included. However, the sample is too small to identify any significant or reliable patterns and therefore this section should not be assumed to be representative of women and heterosexual men diagnosed with HIV in Australia. Despite these limitations, their inclusion in this report is important, given the dearth of research on this population. In addition to the survey questions, this section also draws on the free-text responses and qualitative interviews. It should be noted that the majority of free-text responses in the survey were provided by women and that the three respondents who elected to participate in a qualitative interview were all women (one of these women did not complete the survey, but information drawn from her interview has been incorporated into the data reported below). Therefore, this section is substantially biased towards the experiences of women. For more detailed accounts of the experiences of both men and women living heterosexually with HIV, see the *Straightpoz*[2] reports (Persson et al., 2006, Persson et al., 2009).

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[2] The Straightpoz study was a qualitative longitudinal cohort study (2004-2010) that explored the experiences of heterosexual men and women with HIV and their sero-negative partners in New South Wales.
https://csrh.arts.unsw.edu.au/media/CSRHFile/Straightpoz1.pdf
https://csrh.arts.unsw.edu.au/media/CSRHFile/12_Straightpoz2.pdf

About the sample

This section describes some of the demographic and other characteristics of the heterosexual identified men and women in the study

Geographic distribution

The distribution of this sample differs slightly from that of the gay men (Table 7), in that there were fewer respondents from Victoria and South Australia. The majority came from NSW, QLD and Western Australia, which were also the states where the majority of diagnoses attributed to a transmission route other than homosexual contact in Australia occurred. Three diagnoses reported here occurred overseas.

Table 116 Geographic distribution

N=28	Recruited		Residence		Diagnosis		High Risk Event	
	Women	Men	Women	Men	Women	Men	Women	Men
NSW	2	5	2	4	2	2	3	3
QLD	5	1	5	1	5	1	5	
WA	5	2	5	4	5	2	2	1
VIC		3		3		3		1
ACT	1	1	1		1	1		2
SA		1						
Overseas					1	2	1	3
Not known	1	1	1	2		3	3	4

At the time of their diagnosis, the women in this sample ranged in age from 21 to 59 years old, with a mean age of 38.4 years, while the men's ages ranged from 23 to 58 years old, with a mean of 35.8 years at diagnosis. Thus, the women are slightly older at diagnosis than the heterosexual and gay men in the sample, who are similar in age at diagnosis.

Table 117 Age at diagnosis

N=28	Women	Men
Under 25 years	2	1
25 – 29 years	2	2
30 – 39 years	2	5
40 – 49 years	5	2
Over 50 years	2	1
Not provided	1	3

Ethnicity

Sixteen were born in Australia, nine were born overseas, while three did not provide a response to this question. Of those born overseas, seven were born in Western Europe, one in Northern Africa and one in sub-Saharan Africa. Seventeen identified as Anglo-Australian.

Education

For nine, their highest level of education was equivalent of high school; 16 had university qualifications, including seven at post-graduate level. These rates are similar to those of the gay men in the sample; education levels were high among the sample overall.

Employment status

Nineteen were employed, half of these in professional or managerial roles, one participant had retired, one was a student and one was unemployed.

Sex work

Most of the respondents had never done sex work; 20 clearly stated they had not. Three had, while five did not answer this question. Of the three that had, two were female and one was male. For the man and one of the women, they had last been paid for sex within the month of completing the survey. In the case of the other woman, it had been two years since she had last been paid for sex.

Contact with the epidemic

Participants were asked, in the 12 months before their diagnosis, how many people they knew who had HIV, were diagnosed that year, or had died from AIDS.

Table 118 Contact with the epidemic

N=28	People with HIV		People who tested positive in that year		People who died of AIDS	
	Women	Men	Women	Men	Women	Men
None	7	6	10	7	8	7
One	3		1		2	
Two	1					
3-10						
More than ten		1		1	1	1
No response	3	7	3	6	3	6

Fewer than a quarter of those who responded to these questions said they knew any people with HIV prior to their own diagnosis, compared to a third of the gay men in the sample. This is consistent with findings from the qualitative *Straightpoz study*, which showed that heterosexual men and women had little or no contact with the epidemic prior to their diagnosis, as well as limited contact after their diagnosis (Persson et al., 2006).

Six months before diagnosis

This section describes the sexuality, relationships, and HIV testing patterns of these men and women in the six months prior to their HIV diagnosis.

Sexuality and relationships

Women

One woman identified as bisexual, the others as heterosexual. Three had ever had sex with another woman. Six women were in a relationship with a man at the time they believe they contracted HIV. One of these relationships was between three and six months' duration, while the other five had been for more than two years. Two of these longer relationships were with men the women knew to be HIV-positive. In the other cases the women believed their regular partner to be HIV-negative.

Men

Three men identified as bisexual, and reported having had sex with another man, while the other men identified as heterosexual and reported never having had sex with another man. Six men were in a relationship with a woman at the time of the high-risk event they believe led to their infection with HIV. Three of these relationships had been of more than two years' duration, while one was between six and twelve months. Two men did not specify the length of their relationship.

HIV/STI testing & diagnosis

Respondents were asked about their previous HIV and STI testing in the six- and twelve-month period before their diagnosis.

Women

Three women had never tested for HIV prior to their diagnosis. Five women had not been tested in the previous four years. Five women had not had a sexual health check in the 12 months prior to diagnosis, while five women reported that they had.

Men

Three men reported never having tested for HIV prior to their diagnosis. Two of the men had last tested for HIV within one month of their diagnosis, for one it had been between 7-12 months.

Table 119 Reasons for not having tested in previous twelve months

N=28	Female	Male
I had not had sex with anyone I knew or thought was infected	4	1
I had no illness which made me worry	3	3
I did not do anything risky	3	3
I don’t get tested regularly	4	1
I had not changed partners	2	
I had not experienced a condom slipping or breaking	2	
I was unaware testing was available	2	
I was afraid to get tested	1	1
My doctor did not suggest it	1	1
None of my partners asked me to	1	1
I didn’t have time	1	
My partner and I had not had sex with anyone outside the relationship	1	
I had not had sex with anyone	1	1

Note: Items not mutually exclusive

The most common reasons given by the respondents for not having tested for HIV in the previous twelve months indicate a perception of low or no risk, including not having had sex with anyone believed to be HIV positive, not having done anything perceived as risky, and not testing regularly for HIV. A few were unaware that testing was available, or assumed that it was automatically included in sexual health check-ups:

> *“I have always asked my doctor for STD checks every year when I have my Pap smear and annual check-up. I presumed HIV would have been one of those tests, but apparently not. I have now been told you have to specifically ask for HIV.” [free text response: woman]*

Post-exposure prophylaxis

None of these women or men had heard of PEP before the time of their HIV diagnosis, in stark contrast to the 47.9% of gay men who had knowledge of PEP at the time of exposure to HIV:

> *“I didn’t know about it and by the time I visited the clinic to have my initial test, the opportunity to take it had gone (i.e. too long after the event).” [free text response: woman].*

Another woman, noted that she was unaware of PEP, but she was also unaware of her need for a prevention strategy such as PEP:

> *“I hadn’t heard of PEP. I also didn’t believe I had reason to worry too much as we had both had negative HIV tests for the Immigration medicals before moving to Australia … I just wasn’t aware of his history.” [free text response: woman]*

The high-risk event[3]

Participants were asked to describe the event they believe was most likely to have led to their HIV infection, as well as the person they believe infected them. Twelve men and fourteen women were able to identify an event that they believe resulted in their HIV infection. The majority of these events occurred in Australia, while six occurred overseas. Among the men, three believe they were infected while in Thailand, one in Sweden and one in Zimbabwe. One of the women was infected in Indonesia. In addition, another woman mentioned in the free text responses that she had been infected in Peru. Eleven of the women and twelve of the men responded that the event involved sex.

Women

Ten women reported sex with a man, and one woman reported sex with two men. Five of these men are described as a casual partner, although in one case the participant had met this man and had sex with him previously. These male partners were all described as heterosexual except for one who was bisexual.

In three cases the partner was their regular partner, and in one case the partner was a long-term lover. Two women did not provide an answer. The sex event that resulted in their HIV infection occurred in a home. In all but two of cases, they occurred in the home of the participant's sex partner, as opposed to the participant's own home.

Men

Twelve men reported sex at the high-risk event that resulted in their HIV infection. In ten cases the partner is a women, in two cases a male-to-female transgender. Five of these women are described as casual partners, three as regular partners and two as sex workers. Five reported the high-risk event as occurring in a hotel room, three at home, one at a beat and one at a sex club. Two men did not describe the partner or the location of the event.

Knowledge of HIV status of source person

Most of these men and women either believed the partner to be HIV-negative or did not know the HIV status of the partner at the time of the high-risk sex event that resulted in their HIV infection, compared to just under half (46.6%) of the gay men in the sample. One woman believed the man who she contracted HIV from was unaware of this status, and thought it likely that he was inadvertently continuing to place sexual partners at risk of HIV:

> *"I don't like to think that he knew he had it. I don't think he would have been that malicious … [A]s far as I know, he, now, he is positive and doesn't know that he's got it, and he's still doing exactly what he was doing. So he's a potential high risk to people where he's living now, and his wife, obviously, that doesn't know." [interview: woman]*

Another woman said that HIV did not enter her mind when she had sex with a man from her past:

> *"[I] sort of knew him from the past – and caught up with him that night. Had sex and didn't wear a condom. And I suppose, in a sense, because I felt I knew him as a friend and, you know—there certainly was the question asked; did he have any STD, but I guess, in my mind, I wasn't even thinking HIV. And looking at him, he was such a fit, healthy [person].*

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[3] For the purpose of reporting, the event that participants believe to be the event that led to their infection with HIV is described here as the high-risk event. It is important to acknowledge that, at the time of the event, the participant may not have considered that particular event to be 'high-risk'.

> *And I suppose growing up in the eighties where, you know, all the messages of HIV I got were, you know, skinny." [interview: woman]*

Drug use at the high-risk event

Alcohol

Similarly to the gay men in the sample, alcohol consumption at the high-risk event was quite common. More than a third of the women and more than half of the men reported drinking alcohol at the high-risk event. Half of the men who had consumed alcohol reported that they felt drunk at the time. This was true for three of the women and one woman indicated that alcohol had played a part in the sex, she believed led to her HIV infection:

> *"I think, you know, certainly, certainly alcohol had a lot to do with the night that I met [casual partner] that night, yeah. Carried away, feeling good, music concert, ra, ra." [interview: woman]*

Table 120 Alcohol use at the high-risk event

N=28	Women	Men
No alcohol	4	3
Alcohol	6	8
Fewer than five drinks	5	2
More than five drinks	1	6
Felt drunk at high-risk event	3	4
No response	4	3

Drug use

Illicit drug use at the high-risk event was far less common among these men and women compared to the gay men in the sample. Drug use was also low in the six months prior to testing HIV positive.

Table 121 Drug use at the high-risk event

N=28	Women	Men
Erectile dysfunction medication		3
Crystal Meth		2
Ecstasy	2	1
Amyl/Poppers		1
Cocaine		1
Marijuana	1	

Note: Items not mutually exclusive

Injecting

None of these women or men injected any drugs at the time they believe they were infected with HIV.

Condom use at the transmission event

Most of these men and women did not respond to questions about condom use at the transmission event, or answered only some of the questions. Most of those answers indicated a lack of condom use at the event. In some cases, the non-use of condoms was not mutual, as illustrated in the following quote from a woman who felt that gender issues made it difficult for her to insist on her casual male partner using a condom:

> *"I actually felt very pressured with [casual partner]: I wanted him to wear a condom that night as well. And I think, you know, it's very difficult for a woman sometimes when you're faced with that attitude from men. So I don't know what we have to do to—yeah. But I think there's still a really big gap there." [interview: woman]*

In another case the woman believed the casual partner was using a condom, but post sex realised he had not:

> *"[S]o the incident where it was anal, unprotected sex, both, all of us were in the room together. And he went to put a condom on. He couldn't get it on so [husband] got another one out of the drawer to give to him. And I was sort of facing [husband] and [husband] was sort of facing [casual sex partner] thinking he's putting the condom on. But, and thought he'd got it on when he entered me and he, and he didn't." [interview: woman]*

Perception of risk at the high-risk transmission event

We asked how these men and women perceived any level of risk of HIV infection during the event that led to their infection. Of those who responded, none believed they had been at high or very high risk. Most commonly, they had not thought about risk, or else believed the risk was low or very low. This is consistent with the *Straightpoz study,* which found that thoughts about HIV risk rarely figured in heterosexual encounters, or else that such risk was perceived as being very low (Persson et al., 2006, 2009).

Table 122 Perception of risk at the transmission event

N=28	Women	Men
Didn't think about it	5	5
Very low	2	1
Low	2	1
No response	5	7

> *"Becoming far too drunk on the night, I had unprotected sex with the women. [I] didn't have a thorough understanding of HIV or not enough awareness of its potential to harm myself. [I] trusted someone I didn't know. [There is] not enough public alertness, advertising on the HIV/ aids epidemic in Australia." [free text response: man]*

> *"I was probably more fearful of pregnancy than STDs to be quite honest, yeah. As a woman, that was probably my number one fear. Although, you know, sort of wise enough to sort of look at the person and check them out, physically, with your own eyes. But yeah, probably I have to admit I was probably not as educated as I probably should have been or could have been yeah." [interview: woman]*

> *"Stupidity, lack of presence of thinking about HIV, was more worried at the time of pregnancy, other STIs. HIV did not even cross my mind. My partner looked too healthy to have HIV - how ignorant was I." [free text response: woman]*

> *"I thought I knew him and I thought he was honest, and I thought he was a low risk: that's the only reason why I had unprotected sex." [interview: woman]*

> *"If it was somebody that, that you just met in the street, it wouldn't have happened and it certainly wouldn't have been unprotected. But because it, because it was a friend, because you kind of, I knew him, it was a risk I was prepared to take … you see what you think is a safe bet … If I'd have known that he'd had unprotected sex or, with hundreds of people, then I would have thought differently of (a) him and I probably would have never gone that far anyway, 'cause I would have just realised what a pig he was. But it was like it was a risk assessment I suppose. Given the information, going by the information I had, not knowing the information I had wasn't all the information that I needed. Yeah. I mean again, you know, you can't stop a person from lying as well." [interview: woman]*

> *You know, we don't live a rock'n'roll lifestyle. We don't do drugs, don't, you know, drink. Not a massive amount. We don't go around, you know, at sex parties or, you know, we just, you know, I had an affair which hundreds of people do, thousands of people do. We had a threesome, again which people do. In our own home. It wasn't like a big—it was a real kind of non-event. I suppose for some people that would be classed as way out there but – we're just, you know, a couple in suburbia." [interview: woman]*

Diagnosis

Participants were asked about their experiences at the time of their diagnosis with HIV and subsequently.

When diagnosis occurred

For both the women and the men in this sample, half of them completed the survey questionnaire within three months of receiving their diagnosis, which might suggest that they were looking for opportunities to participate in this type of research and were willing to engage with it.

Table 123 Period between diagnosis and date of interview

N=28	Women	Men
Three months or less	6	6
4-6 months	2	1
7-12 months	2	3
13-18 months		1
19-24 months	1	1
More than two years	1	
Not known	2	1

Reasons for test at the time of diagnosis

Participants were asked what had led them to get tested for HIV, at the time when they received the HIV-positive test result. Their responses indicate that testing for HIV was not a regular practice among this sample. Compared to 25% of the gay men in the sample, only one of these respondents stated that the reason for having tested for HIV at the time of her diagnosis was because it was part of her regular testing pattern.

Women

For women, the most commonly stated reasons for testing for HIV at the time of the diagnosis included having an illness that was worrying them; having been told by a partner that the partner had tested HIV-positive; and having changed partners.

Men

The most common reason given by the men for having tested for HIV at the time of their diagnosis was that they experienced an illness that made them worry, although four stated that they tested because they had done something risky, even if their perception of HIV risk might have been low at the time of the actual event, as indicated previously in Table 122.

Table 124 Reasons for having the test that returned the HIV-positive result

N=28	Women	Men
I had an illness which made me worry	4	7
A partner told me they had tested HIV positive	2	
I changed partners	2	
I did something risky	1	4
I had sex with someone I knew or thought was HIV positive	1	2
My doctor suggested it	1	1
It was part of my regular testing pattern	1	
So my partner and I could make an agreement not to use condoms in our relationship	1	

Note: Items not mutually exclusive

Experience of diagnosis

Participants were asked how they felt the diagnosing clinic handled providing the diagnosis. Similarly, to the gay men in the sample, the majority felt that the diagnosis had been handled well or very well, especially the women; however, three women felt it had been handled very poorly.

Table 125 How the diagnosis was handled

N=28	Women	Men
Very well	7	3
Well	2	2
Poorly	1	1
Very poorly	3	1
No response	1	7

The free text responses and qualitative interviews provided additional comments about the experiences of being diagnosed with HIV.

> *"Contracting HIV has been an experience to say the least - I am the least likely person who would have it if you look at perceived stereotypes. Professional, educated, not promiscuous and had sex with a person I have known for years - and he fits that same bill. It just goes to show that no-one is immune." [free text response: woman]*

> *“[M]y local GP, who I didn’t have a long-term relationship with but started seeing the same fellow all the time, and he kind of kept saying, “You’ve got stress” and I’m thinking, “I’ve had stress before and this doesn’t feel like stress,” but … then I started losing weight. I probably lost about eight kilos. And he was sending me away to get lots of blood tests done and, you know, x-rays. But, surprisingly, with all the blood tests, he must not have tested for HIV … Perhaps because I didn’t fit the, what my doctor thought would have been the, the HIV stereotype, maybe that’s why he didn’t test, you know, for it.” [interview: woman]*
>
> *“And [husband]’s just thinking, “That’s it. I’m dead. I’m gonna die.” It’s, you know, back to the days of Philadelphia and, you know, all that sort of thing. Tom Hanks … And that’s what I thought [too]; I didn’t know advancements in medication. I didn’t know people could live with HIV. I just thought, “That’s it. I’ve,” you know, “I’ve just killed us both. Our kids are gonna grow up without any parents and that’s it.” Yeah. “Yes, you’ve really fucked-up this time”.” [interview: woman]*
>
> *“[G]etting diagnosed was such a relief ‘cause I was just getting sicker and sicker, and you’re thinking, you know, “My body is falling apart. What’s wrong?”” [interview: woman]*
>
> *“It’s funny, like even though I got diagnosed only eight months ago, that period of time when you think, you know, you feel like you’re infectious and you’re a bio hazard. And the kids are like, “Oh, don’t touch the kids!” ‘cause, you know, you might give it to them. And you forget that. And it was a real intense, you know, really, really crap time. But because you’ve come so far, you kind of, you sort of forget that happened. But it definitely did happen. So it wasn’t all like, “You’re going to be well.” “Okay, great, let’s carry on.” It’s been a really, really, really intense, crap, horrible existence that we’re just kind of coming out, you know, coming out from now over the last sort of couple of months or so.” [interview: woman]*

Since diagnosis

Participants were asked about their experiences since being diagnosed with HIV, including of the services and information they had accessed, experiences related to sex and relationships, and disclosure to others.

Accessing services

Among this sample, services required since diagnosis were predominantly related to information about health, treatment, safe sex and relationships (Table 126). The women were more active than the men in seeking a range of information and services. It is noteworthy that very few had ever heard of available workshops for newly diagnosed people or of peer support programs and services specifically for heterosexual men and women with HIV.

Table 126 Services required

N=28	Women	Men
Information on viral load	8	3
Treatment advice	7	4
Emotional support/counselling	7	1
Information on safe sex	7	
Access to networks of other HIV positive people	4	1
Housing support	1	

N=28	Women	Men
Dietary information	4	1
Relationship advice	3	
Information about complementary therapies	2	1
Legal advice	2	1
Financial support	2	
Advice around parenting	2	
Migration assistance	1	1
Drug & alcohol counselling	1	
Housing support	1	

Note: Items not mutually exclusive

> *“I think, really, having the support there of, you know, [specialist] and [nurse] at the sexual health clinic, and meeting friends through [the local HIV organisation] and that, it just keeps you kind of sane and it just keeps … and I think also it helps being positive. Hey! There’s that word! … But I just think it really helps having that, you know, the sort of network of people, utilising what services there are. And yeah, [HIV orgs], they’re pretty good with their help. And just having places where you can go and just think, you know, you wanna get something off your chest.” [interview: woman]*

> *“I have learnt that stereotypes are key in HIV/AIDS public information. I have never encountered so much gender and sexual bias in my life. It has enraged me. I find that the United States is better at breaking these ideas that HIV is just about gay men, drug users and the odd, unfortunate hetero male who goes to Thailand then gives it to his wife/girlfriend/partner … My relationships with people have changed, and I think the presence of stereotypes in public messaging has had an effect on that. I’m a woman, who contracted HIV through medical treatment whilst traveling. Where is the public information and box to tick on that one? HIV affects people from all areas of society, all genders, ages and races. I had to do research to find that out.” [free text response: woman]*

Sex and relationships since diagnosis

Participants were asked if they had changed their sexual behaviour in any way since receiving their diagnosis. Similar to the gay men, almost a third reported that they had stopped having sex altogether. Free text responses and qualitative interviews provided some additional information, which revealed a more complex picture.

Table 127 Changes in sexual behaviour since diagnosis

N=28	Women	Men
Stop having sex altogether	4	4
Reduce the number of partners I have sex with	2	4
Reduce my drug use	1	4
Increased my drug use	1	
Avoid sex with HIV negative partners	1	
Avoid sex with HIV positive partners	1	

Note: Items not mutually exclusive

> *“I’m engaged and have one partner only. Since being diagnosed, I’m petrified of giving this to him. I love him and our sex life has changed. We are using condoms, and oral sex has*

> *not been happening. We are both getting our heads around this virus and we are both still uncomfortable." [free text response: woman]*

> *"Don't want to have sex so much anymore. Only with the girl who gave me HIV, no problem, but other people no." [free text response: man]*

> *"I continued my relationship with my long-life partner, who gave HIV to me, we now always have sex WITH a condom. So the only change is, we ALWAYS do it with a condom now." [free text response: woman]*

> *"I'm scared to have sex with my girlfriend and so is she. She knows my status and is being tested at the moment to see if she has it." [free text response: man]*

> *"Happy to have casual sex, but don't want any long term involvement (too risky)." [free text response: man]*

> *"My relationship with my husband is a work in progress; we have had a lot to deal with. We've had professional help and it has made us communicate better and strive for a happier more fulfilling relationship, we're being more open with our feelings, emotions and becoming closer again." [free text response: woman]*

> *"[T]he other thing that I have found really interesting is that once I was diagnosed, you know, I said to [partner], "Well that's it," you know. "Sex with condom: it's gonna have to be that way." And there was a lot of pressure in our relationship. I actually sort of went to a counsellor about it for a while because he didn't wanna wear a condom. So it sort of came down to "well, this relationship's gonna have to end". I felt enormous stress about that and, and even though it was his decision I thought, "I don't wanna be responsible for that" … But I suppose as time's gone past I've given way to that and sort of thought, "Well you, you know. You're aware"." [interview: woman]*

> *"Definitely my libido and my interest in sex and that whole thing has just—and I don't know as well if that's HIV or medication-related, or maybe just after 40, you know, it's just not a priority for me anymore. Unfortunately for [partner], because it is for him … I've sort of now just sort of felt it's not important to me anymore. Even if this relationship didn't last, I don't know if I would go out and find another partner. And it certainly, being HIV positive wouldn't stop me from doing that 'cause I don't really think it inhibits our relationship. And I'm sure, you know, if I felt that way and met somebody that we would work through that. So that doesn't, that doesn't bother me." [interview: woman]*

Disclosure of HIV status to others

The majority of those who responded to questions relating to disclosure had not disclosed their HIV status to relatives, work colleagues and friends, or had told only a few. About half had told one or more of their immediate family. Only one woman indicated that she was fairly open about her status more broadly and saw it as a way to educate other people.

> *"I have devastated some people. Some have been in shock when I told them. Mostly everyone I have told has dealt with it well and positively. I think in some ways more positively than I've been dealing with it. I find it hard to tell some people, so I've told them I have cervical cancer instead, as a reason for my strange behaviour and depressed outlook. My mother is a nurse. She has been the most incredible support for me. She knows a lot about the virus and this has helped me immensely. In general, it has bought me closer to those I love. Especially my partner, who is my key support right now. I also feel, that since I found out four weeks ago, I have cleared out the people who I feel like I can't*

> *tell. I have culled people in my life, because those who I have told, have been amazing. I would have killed myself by now if it wasn't for my partner, parents and close friends, who have given me so much support and love." [free text response: woman]*

> *"My husband and I have chosen to tell no one, it's just me, him and [the health department] that know. That may change, but for the foreseeable future that is what we feel comfortable with." [free text response: woman]*

> *"After I was diagnosed I called a number of my friends together and told them of my diagnosis. And one of the things I said, you know, "How many of you had had unprotected sex?" Because I think, you know, probably sometimes, and I think there's probably a lot of women about my age that do end up, you know, separated after a number of years, that haven't been in the dating scene or, you know, that we're probably a little bit naïve I guess maybe. So I wanted to, you know, just pass that message onto them." [interview: woman]*

> *"I'm open about it. I like them to see that, you know, you don't have to be a drug addict or a slut, or gay to get the disease. It can happen to, you know, it could be just like getting lots of things I suppose. I also like to remind people of that risk, you know. That it's there and it's real, and it is here in our community … I could see the shock on a couple of my students. Because I think that is the part of breaking it down. It's probably, I expected someone with HIV to be scrawny and skinny, and sick-looking." [interview: woman]*

> *"I know there's still this stigma surrounded by this and by what was, you know, presented in the eighties and nineties. And I said to [husband], "I'm not gonna help that; I mean I'm actually enabling that stigma by keeping quiet." And so part of me is thinking, "Get out there and tell people, and, if you lose friends from it, you lose friends. Were they really friends in the first place?" Just 'cause like, you know, to educate heterosexual people about HIV … The only way you can change it is by coming out and saying, "Look at me, I'm perfectly normal," in various parts … "Would you think I've got it? No. Well I have and yeah, so shoot me … So I say, "Go us heterosexuals! Bring it out into the, bring it out into the mainstream … [But] I don't know if I'm ready to yet. 'Cause this is the thing: once you, there's no going, you can't take it back once you've, once you've put it out there. You cannot take it back." [interview: woman]*

Knowledge and beliefs

Participants were asked about their prior and current knowledge and beliefs about the implications of an HIV infection. Three-quarters of those who responded to questions about their beliefs prior to the HIV diagnosis disagreed or strongly disagreed that "HIV and AIDS are less serious threats than they used to be". The majority also disagreed that an undetectable viral load makes it unlikely to pass on HIV. However more than half agreed with the proposition that "HIV is no longer a death sentence". When asked about their current beliefs, these were not very different. The majority of respondents still disagreed that HIV is a less serious threat than it used to be and that an undetectable viral load makes it unlikely to pass on HIV. Similarly, they continued to disagree with the proposition that "HIV treatment takes the worry out of sex". The only marked change in current beliefs was that more respondents now agreed that HIV is no longer a death sentence. This belief was echoed in the free text responses and the qualitative interviews.

> *"I just think that, you know what? It is an illness and it is a disease that can be controlled. And it's, it's no—well it is a biggie. But it's no different to being diagnosed with anything else other than the fact the way you catch it." [interview: woman]*

> *"I just thank the people that do these surveys, medical science and past, present and future research into this disease that enable people, myself and husband now included, to live hopefully long healthy and normal lives. I was not aware at the time that it had advanced so much, so I thought I was being handed a death sentence on my diagnosis." [free text response: woman]*

> *"I feel no different now, hardly, to prior HIV days. I'm not as fit. But, you know, that's got nothing to do with the HIV at the moment … But to be able to say to perhaps some people who are out there, you know, there is some normality on the other side of diagnosis. So that's not, you know, it's perhaps not the, all the doom and gloom that maybe when medications weren't so good." [interview: woman]*

> *"I think medications have improved as well so you don't see the sickly people around anymore. I mean thank God for medical research, you know." [interview: woman]*

> *"I don't see it as a death sentence, which is what I did before, definitely." [interview: woman]*

General outlook since diagnosis and expectations for the future

The participants were asked about the impact of diagnosis on how they felt about themselves. Among those who responded, the majority felt that the diagnosis had negatively affected how they felt about themselves and their lives, including their sense of independence, their appearance, their sense of control over their body, their self-confidence, their relationships with others, and their hopes for the future. Many also reported that they felt down, depressed and hopeless more often now than they had before their diagnosis. However, the free text responses and the qualitative interviews provided more detailed and in some cases more optimistic accounts, including in relation to their expectations for the future:

> *"I am worried that I will have to make changes for my future and that the things I had planned to do this year I will have to postpone until I am sure that the treatment I have started is working and that the medication I am taking will not have negative side effects. I don't think I will die anytime soon but since testing positive I will have to adapt my lifestyle." [free text response: woman]*

> *"I have no expectations for the future apart from trying to stay alive as long as possible for my wife and kids, to provide for them as long as I can." [free text response: man]*

> *"I didn't really think too much about the future, I was more about the now, but now I'm more concerned about not being here in the future and it's given me a real cause to make sure I am here especially for my children, by looking after myself better." [free text response: woman]*

> *"I guess, at the moment, because life's travelling around fairly normal, I feel normal and don't really think about it too much." [interview: woman]*

> *"I don't want this illness and I have shed many tears and had lots of down days. But I don't think it's the worst thing that will happen to me. I may be just playing mind games with myself, but I decided that I would try to turn every negative into a positive. So I hate having to do the blood tests, but I became friendly with the girl who does them and we have a great chat every time I go. My Doctor and nurse are amazing people and I love meeting with them, even though I hate what we have to talk about. I was very clear with my friend who I contracted it from that I am not angry and our friendship is stronger than ever. I don't want to get bogged down with bitterness or anger. This disease may be taking my body but I'm going to make it work for its money and it will never define who I am. So my*

> *expectations for the future are positive and I think I will see a cure in my lifetime." [free text: woman]*

> *"I would say everything is the same but ironically, I visited my friend overseas recently, and he told me I was different now. He thinks my values have changed, that I'm more relaxed and open to new ideas and experiences than I was before, and that it's a good change. I think he's probably right in some regards. I notice people get stressed about stuff that isn't important (including me) and I worry a lot less about work than I did before. I'm also more appreciative of friends - I don't hesitate to tell them I love them or say thank you whereas before I think I just assumed that they would know that." [free text response: woman]*

> *"I suppose now, after, it's probably been about 18 months since I've been diagnosed, yeah, life seems pretty normal. So, you know, as my doctor said, you know, I'd rather have HIV than cancer or anything else. So now it's really like, not "what's all the fuss about?" but it really hasn't, it hasn't really inhibited my life or I haven't felt like it has at all. I've always been open about it. I've never, I mean I don't go around telling everyone I've got HIV but, you know, my work colleagues know. Some of my students know. We were talking about discrimination and, you know, I shared that. So I don't, don't feel, I don't feel ashamed of it and I certainly think that perhaps talking to people about it creates normality about it. So I'm quite happy to do that. And to date I have never experienced any negative reactions from anybody or any, you know, prejudice or anything like that." [interview: woman]*

Discussion of findings for women and heterosexual men

Although the findings presented in this section should be read with caution, given the small sample, the data do point to some key issues in this population, which echo findings from the *Straightpoz study* (Persson et al., 2006, Persson et al., 2009). These key issues include low levels of perceived HIV risk among heterosexuals and, consequently, a lack of regular testing for HIV. They also include a lack of contact with the epidemic and generally poor knowledge and awareness of HIV prior to diagnosis. Furthermore, the qualitative interviews suggest that the perception of low HIV risk among heterosexuals might be shared to some degree by health professionals, as none of the three women who were interviewed were initially tested for HIV when they became very ill, two were subsequently diagnosed with seroconversion-related meningitis, and one because of low immunity caused by her undiagnosed HIV infection. She and another woman were not tested until many months later, by which time she had become seriously ill and the other woman had unknowingly infected her husband. Several women who completed the survey also indicated that they had a low CD4 count when diagnosed, which speaks to surveillance data that show a continued overrepresentation of heterosexual people among late presenters in Australia (The Kirby Institute, 2011, p11.). The fact that heterosexual HIV notifications have increased in the last five years, particularly in Western Australia, South Australia, and the Northern Territory, indicate that these key issues have significant effects and need to be urgently addressed.

Discussion

“The study provides rich data to support evidence-informed policy change and health promotion practice. Intervention and evaluation research to test (and scale up) effective policies and programs is critical alongside continued investment to advance HIV testing, treatment and prevention research.”

Roanna Lobo
Sexual Heath and Blood Borne Virus Applied
Research and Evaluation Network (SiREN)

Discussion

BY PAUL KIDD

The introduction to this report argues that the current 'moment' in the history of HIV is one in which seismic shifts are underway in our understanding of the relationship between risk, pleasure, and HIV. These changes are being driven by important scientific discoveries about the ways in which anti-HIV drugs can be used to reduce the risk of transmission – as pre-exposure prophylaxis (PrEP) in HIV-uninfected people, and as treatment-as-prevention (TasP) in people with HIV. It echoes the so-called 'protease moment' that followed the discovery of new HIV treatments in the mid-1990s, both in its impact and, arguably, in our ability to comprehend the enormity of the change we are going through.

The results of this third and likely final iteration of the Seroconversion Study support this view. The difference between the experiences and attitudes of the men who participated in this study, and those of the participants almost a quarter century ago, is stark. Where once they faced life-threatening illness, often with a gritty determination to survive against the odds, today they accept the necessity of treatment, and in many cases are enthusiastic about its role in preventing onward infection.

This section of the report discusses the findings of the current study as they relate to four key themes that have been constant throughout the history of the Seroconversion Study – understandings of risk, attitudes to treatment, dealing with stigma, and seeking support.

'How did this happen to me?'

A major focus of the Seroconversion Study has been to explore the ways that gay men balance the desire for sexual pleasure and intimacy with the risk of HIV in their lives. Participants have been asked to identify the high-risk event to which they attribute their infection, and to discuss their understanding of HIV prevention practices.

Inevitably, a study conducted among recent seroconverters will be limited in the way it can talk about HIV prevention. All of the men in this study became positive, so they represent the failings of, and gaps in, the HIV prevention paradigm. PrEP started to become widely used by gay men towards the end of the study, too late for these men to benefit from it, but is expected to have a dramatic impact on HIV notifications over the next few years.

The impact of TasP on the Australian epidemic is unknown, but it seems reasonable to assume that the relatively high uptake of treatment by Australian gay men over many years has prevented a considerable number of infections, even before the efficacy of TasP was established in clinical trials. But awareness of TasP, especially among HIV-negative gay men, appears to be poor, and this is reflected in the present study.

Overall, the impression is that gay men continue to respond to the risk of HIV in an informed and sophisticated way, integrating scientific knowledge and community-based educational messages into sexual practice with generally good results. But the men in this study, for whom that process has failed, may be evidence that in some quarters there is a lack of understanding or application of this new paradigm of HIV prevention.

Most were bottoms or versatile (Table 21) and a substantial majority had engaged in receptive or reciprocal anal sex with a casual partner (Table 34). Most identified an occasion of receptive anal intercourse, with ejaculation, as the high-risk event to which they attributed their seroconversion (Down et al., 2016). This suggests a good level of awareness of the risk associated with condomless anal intercourse among these men, at least by the time they participated in the study, so what is happening here? Undoubtedly for some men, they took a calculated gamble to engage in sex they knew was inherently risky, but for others, they did not believe they were at significant risk.

Most participants attributed their infection to a casual encounter, often with a person they had met for the first time. For those who believed they had been infected by a fuckbuddy or regular partner, in many cases the event to which the seroconversion was linked was early in the relationship. It appears that the shorter the duration over which the two partners knew each other, the greater the risk. Conversely, very few of these men attributed their infection to sex within an already established relationship of medium to long duration. Only eight percent of these men attributed their infection to their main or primary partner (Table 69), a stark decrease from the 42 percent who did so in the first iteration of the study (Kippax et al., 2003). Whether this represents an actual shift in where risk occurs, or reflects the changes in the way that the questions have been asked cannot be clearly determined. It is likely a mixture of both. Nonetheless, it is perhaps worth acknowledging the potential role played by the recognition of, and support for, negotiated safety that occurred after the commencement of the first version of the Seroconversion Study and the implementation of this most recent version.

A sizeable minority of participants nominated ‘adventurous’ or ‘esoteric’ sexual acts as the source of their infection, or attributed it to mediating factors such as the presence of sores or tears (Callander et al., 2016). This suggests some level of post-facto rationalisation of their infection as being due to extraordinary factors, not merely the fact they were engaging in a sexual practice (receptive condomless anal intercourse with ejaculation) that is responsible for the vast majority of HIV infections among gay men in Australia.

Many participants did not believe they were at risk due to beliefs or assumptions about the HIV status of their partner. More than 80 percent of men who attributed their infection to a casual partner either did not know the status of their partners or wrongly believed they were HIV-negative (Table 76). Serosorting between casual partners who believe or assume both to be HIV-negative is clearly did not work for these men.

A common theme in men’s own assessment of why they placed themselves at risk, was abandonment of safe practice due to being in the ‘heat of the moment’ or the other party being especially ‘hot’ – this is something that has been a common finding throughout the history of the Seroconversion Study.

Less than three-fifths of the men in this study were aware of PEP, and only about half of that subgroup had previously accessed it. Low awareness of PEP, together with a poor appreciation of the risk associated with this sexual practice (and perhaps an unwillingness to put themselves through the awkwardness and trauma of accessing it) meant these men missed the opportunity to avoid their infection using PEP. There’s a potential lesson here that should be incorporated into planning for PrEP: some men at high risk of HIV mistakenly believe themselves to be at relatively low risk, and may not see themselves as part of the ‘high-risk’ group to whom PrEP is being marketed, and may be less likely to access PrEP if doing so means submitting to intrusive questioning about their sex lives or undergoing difficult bureaucratic processes.

What these men needed were better mechanisms for HIV prevention – such as PrEP. They needed a better understanding of, and protocols for managing, the relative risk of various real-world sexual situations. In particular, they needed a much more sophisticated understanding of the risks associated with receptive condomless anal intercourse, especially where they did not know or merely assumed they knew their partner’s status. A more extensive dialogue about the role of TasP is one way the community could highlight the relatively higher risk of neg-neg serosorting, particularly among men who do not actually know each other.

Compounding the overreliance of these men on serosorting, few of the participants followed the guidelines for regular testing. While almost 90 percent had previously been tested for HIV, only 55 percent had done so in the twelve months before their positive test, and 37 percent in the previous six months (Table 44). The current recommendation for gay men with high numbers of partners is for three-monthly testing for both HIV and other STIs.

Many participants only tested for HIV if they felt they had been at risk; as discussed above, in many cases they underestimated the level of risk they were at. Some said they did not test because they had no symptoms, because they were afraid of getting a positive test result, or because they simply 'did not want to know' (Figure 2). These are troubling findings, given the elevated risk these men were at. The impact of HIV stigma is evident in this avoidance of testing due to fear of the result.

Men who were less socially engaged with other gay men and the gay community were less likely to have tested recently, suggesting a need for campaigns targeting these men. In recent years the nature of gay community has changed significantly as we move to a more diffuse, more decentralised and less homogenous conception of what being gay means, and it is essential that education programs targeting gay men are able to respond to these changes. That said though, some of the reasons for this relative disconnection to other gay men, and therefore to gay community, that underlies lower testing (and potentially, awareness of prevention options, such as PEP, and uptake of treatment), may be due to more structural reasons. Men in the less populous jurisdictions, for example, also tended to be somewhat less connected, and less aware of current options and trends.

While few participants nominated inconvenience as a reason for not testing, affordable, reliable home-based HIV testing could have a positive impact on the low testing rates in this group, and on the number of new infections in gay men generally. This may be particularly useful as a counter to the reluctance of some men to want to know out of concern for the consequences, and even discussing their circumstances. It may also assist some high-risk men to test more frequently, and more responsively to risks, particularly those whose access to services may be more restricted.

The men in this study were highly sexually active and more sexually adventurous than comparable cohorts of HIV-negative gay men; they also had higher rates of recreational drug use (Table 41). They were generally reluctant, however, to attribute their infection to loss of control or disinhibition under the influence of drugs. The association between drug use and infection is far from clear. Men who use drugs, and especially those drugs used specifically to enhance sexual experience, have been shown to be at increased risk of HIV infection (Prestage et al., 2011). These data reinforce that finding. However, it has also been found that among men who take risks sexually, drug use is not a factor in whether they choose to use condoms on a specific occasion or not (Prestage et al., 2005). That the men in this sample tend not to ascribe their decision to take a risk to their drug use, may reflect this fact: their relative adventurousness in regard to sex most likely also applied to drugs. So they were more inclined than other men to both use drugs and take risks. For some of them, their drug use would have made little difference, and indeed, almost half of them did not use drugs on the occasion they believe they acquired HIV. For others, however, their drug use combined with their own inclination to take risk may have been a key reason for why they seroconverted.

'Should I start treatment?'

The decision to start or defer treatment is one that every newly-diagnosed person must make, especially in the current era of earlier treatment initiation. Deciding to start treatment is a personal decision, and doctors tend to play a supportive and advisory role, respecting the individual autonomy of the patient. The men in this study had limited contact with other people with HIV prior to their diagnosis: 36 percent did not know anyone else with HIV (Table 25), and only 16 percent knew someone who had recently seroconverted (Table 26).

That observation is unsettling on two levels. First, it suggests a social divide between HIV-positive and HIV-negative men in the gay community, and a lack of dialogue that represents a missed opportunity for HIV-positive men to educate their peers on managing risk. Second, it suggests that the process of coming to terms with an HIV diagnosis is a lonely one for many men.

Some of the men in this study did not appreciate the extent to which HIV treatments have changed in the last decade, and were unreasonably fearful of treatment side effects (Down et al., 2014). They were fearful of the negative impact treatments would have on their lives, and less enthusiastic about the positives of starting treatment. Some described the difficulty of making sense of a barrage of new information about HIV treatments, and the uncertainty about whether to start that resulted from this.

Most participants relied heavily on their doctor's advice in making the decision about treatments, and most doctors seemed to be quite conservative in their advice. Medical practitioners are conservative in their attitudes to treatment by training, and good doctors always place a high regard on patient autonomy, so this reticence to encourage early treatment is perhaps understandable (also, much of the data was collected prior to the release of the findings of the START study, which forms the basis of the current recommendation for early treatment initiation; (INSIGHT START Study Group, 2015)). It is essential that treating doctors are aware of the impact of their advice, and the possibility that telling a patient 'the decision is up to you' might be heard as 'you don't need treatment yet'. The evidence for early treatment is unequivocal, and doctors and community organisations should not shy away from encouraging earlier treatment.

Aside from the uncertainty about whether or not to start treatment, most were enthusiastic about the prospects for effective treatment once they did start (Figure 3). The vast majority said that treatments would extend their lives and improve their health, while putting them in control of their HIV infection. Side effects were the major concern for most men.

Many of the newly-diagnosed men in this study started with considerable trepidation and not too much knowledge about HIV treatments. After they have had the chance to talk it through with their doctors and with peers, they seem to relax and become more enthusiastic about treatment, although some of that trepidation remains, especially around side effects, at least among men who have not yet started treatment.

Concern about side effects is almost universal among people contemplating antiretroviral treatment, and in some ways is an unfortunate by-product of years of treatments education focused heavily (but necessarily) on dealing with toxicities like lipoatrophy, metabolic syndrome, pancreatitis, and bone disorders. The early drugs that caused those debilitating toxicities are no longer in use, but the idea that HIV drugs are hard to tolerate remains. The same issues are now arising in discussions about Truvada as PrEP – online forums are littered with concerns about Truvada side effects, despite that drug being generally very easy to take. Community organisations and medical practitioners should be acutely aware of the need not to overstate the impact of side effects, and to emphasise the positive benefits of these medications.

The impact of antiretrovirals on infectiousness was an important factor for some men in the decision to initiate treatment. This was seen both as an expression of a personal commitment not to pass HIV on and, to a lesser extent, an altruistic desire to be part of the end of HIV (Down et al., 2014). The desire to avoid anxiety over the possibility of transmitting HIV, to protect the health of their partners, and to feel unburdened of the social stigma of HIV were all aspects of this.

‘I’m ashamed’

The impact of HIV stigma on people with HIV can be profound and debilitating. For newly-diagnosed men, coming to terms with the stigma of HIV can be especially difficult. For some of these men, they are on a journey from the stigmatiser to the stigmatised.

While the study does not address stigma per se, the impacts of stigma can be detected in many of the findings.

Participants tended to place high expectations of disclosure on their positive partners pre-infection, but struggled themselves with disclosure after their own diagnosis. While almost all men had had casual sex with at least one partner since their diagnosis, often with a partner of unknown serostatus, only a quarter had disclosed their HIV status (Tables 56, 57, 60). This is not to suggest any participants had placed their casual partners at risk, and indeed, it appears that they mostly have instituted changes in their behaviours that would mitigate against that possibility, but it does expose the different views about the utility and ease of disclosure among HIV-negative and HIV-positive gay men.

When asked why they had not tested sooner, many men said they feared the result or simply ‘did not want to know’. HIV in the twenty-first century is a treatable, manageable condition. So, for many of these men, the fear of a positive result can be seen as a manifestation of stigma. While participants in the early years of the Seroconversion Study were justifiably concerned about their survival, for today’s seroconverters it is stigma, not ill-health, that presents the biggest challenge. Having to tell friends and family, having to disclose to sexual partners, and fear of sexual rejection are all major challenges for people with HIV, due to the stigma around the disease.

Many men in this study had incorrect ideas about legal requirements for disclosure, or were unsure whether they were required to disclose (Table 97). The legal requirements for people with HIV vary by state, and many people rely on doctors or peers to advise them about these requirements. Better education around legal issues, as well as nationally-consistent laws, are needed to reduce this uncertainty.

Disturbingly, some of these men have not spoken to anyone close, or only to one or two other people, about their diagnosis, even after many months of living with HIV. This is an all too common scenario – some newly-diagnosed people feel a powerful sense of shame and may consider themselves as having failed their community or themselves by contracting HIV. It is saddening to think of people dealing with HIV without the support of close friends or family – this emphasises the ongoing need for support services for newly-diagnosed PLHIV. Indeed, the men in this study who had access to peer support were more likely to have disclosed their HIV status than were those who had less peer support (Prestage et al., 2016).

‘Where can I get support?’

The newly-diagnosed men in this study sought out support from a variety of sources depending on their needs. This includes HIV-sector-run services and programs, as well as informal sources such as online forums and friendship networks. For some, participation in the Seroconversion Study itself was an opportunity to speak candidly and confidentially about their experience, perhaps for the first time.

Many participants said they had taken part in programs for newly-diagnosed people, such as the Genesis/Phoenix workshops (Table 103). Those who had done so rated the experience extremely highly. Read in conjunction with the apparently lonely experience some men have post-diagnosis, with few or no positive friends who can provide support, these peer support programs have considerable utility and should be supported. AWARE, a new workshop for newly diagnosed people has recently started in Queensland. Phoenix is now also offered in South Australia as well as Victoria.

As the HIV landscape continues to change, those who find themselves part of a shrinking population of newly-diagnosed people, and PLHIV who do not have an undetectable viral load, are likely to feel like they are missing out on the benefits of PrEP and TasP. The demand for support services could fall due to declining infections, but the importance of peer support for these men will likely grow.

Peer support programs and community-based PLHIV organisations are a critical mechanism for addressing the knowledge gap many newly-diagnosed men have, for quieting the fears resulting from information overload about treatments, prevention, legal requirements, etc., and for building the resilience positive people need to overcome HIV stigma. These programs also have the potential to increase antiretroviral treatment uptake, support adherence, reduce community viral load, and lead to better long-term health outcomes across the community. Research into their impact is being developed in Australia.

Conclusion

Seven hundred and seven very human stories lie behind all the figures and tables in this report. For each of those 707 gay and bisexual men, receiving their HIV diagnosis will undoubtedly have been a life-changing experience; for many, a moment of profound crisis. Yet the picture that emerges is an encouraging one: the majority seem have come to terms with their diagnosis and are moving on with their lives. They continue to seek a balance between risk and pleasure as they did before, albeit now as a person living with, rather than at risk of, HIV.

The major themes that emerge are not new. Most accept the need for treatment, but worry about side effects and toxicities, at least until they start taking antiretrovirals. They seem highly engaged with the need to prevent transmission, yet struggle to meet the same standards of disclosure they expected of others before their diagnosis. They are coming to terms with HIV stigma, yet many of them remain disconnected from community-led peer support services.

These 707 men have not been able to take advantage of the new paradigm of combination HIV prevention – employing biomedical advances like PEP, PrEP, and TasP in combination with condom-based safe sex and risk reduction strategies. Those advances have either come too late or not been adequately promoted to this group. Disturbingly, many of these men misapprehended the level of risk their sexual activities entailed, thinking they were at low risk of HIV. Would these men have accessed PrEP if it was available?

Support services for newly-diagnosed PLHIV remain critically important. Many of the men in this study live lives increasingly peripheral to the homogenous ‘gay community’ of the past. HIV prevention agencies and those supporting PLHIV face considerable challenges reaching those in need of their services.

HIV stigma remains an almost intractable, insidious and destructive force in our community. Its impact can be seen on practically every page of this report. Stigma reduces testing, decreases treatment uptake, makes disclosure more difficult, and creates a harmful divide between HIV-negative and HIV-positive gay men.

The 707 men who participated in this iteration of the Seroconversion Study, and the many hundreds in the previous iterations, represent the failings of HIV prevention. These are the men who fell through the gaps, even as we narrowed those gaps with improvements in prevention technology and a more nuanced understanding of risk. There are still gaps, and unfortunately some people will continue to fall through them. Our challenge as a community is to continue to narrow them, to build bridges across them, and to support and care for those who fall through.

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