



NEWLY POSITIVE

EXPERIENCES OF HIV ACQUISITION AND DIAGNOSIS IN AUSTRALIA TODAY

FINDINGS FROM THE NEWLY POSITIVE STUDY (2023–2026)

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ACKNOWLEDGEMENT OF COUNTRY



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FOREWORD

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It is not uncommon to consider HIV infection one of the worst things that could happen to a person. Since the outset of the epidemic, HIV infection has been socially and culturally constructed as a *stigmata* – a sign – of something else: sexual immorality; deviance; irresponsibility; lack of self-control; drug use; foolishness; doing something unnatural or wrong. In short, a moral verdict on a person.

The historical associations of HIV with immoral or unnatural sex – which are socially constructed but nonetheless widespread – tend to engender phobic responses: avoidance, denial, disavowal, dissociation, projection, displacement, ritualisation and so on.

These are defences: ways of dealing with unbearable prospects; of excluding certain aspects of the world from conscious integration; of taking distance. Habits and arrangements are put in place, often quite deliberately, to avoid having to encounter or confront an unbearable fate. Sometimes they work; other times these structures promote ignorance of a possibility that is more likely to happen than a person arranged in this way is capable of appreciating.

It doesn't have to be this way. HIV is no longer a death sentence. People who have some practical experience socialising, befriending, loving, or living alongside people living with HIV come to understand that it is manageable – certainly not the end of the world – and that with treatment, people living with HIV may live as long and well as anyone else.

Those familiar with such experiences may thus be more capable of thinking pragmatically about the possibility of infection and how to prevent it, and therefore more receptive to HIV education. Science now accepts that people who use treatment effectively to maintain an undetectable viral load (UVL)

cannot pass on the virus. This solves a problem that people with HIV have historically worried about a lot: how to avoid passing on the virus. But it also means there is less and less impetus for people with HIV to share their experience of living with the condition with others. As a result, fewer people are exposed to the ordinariness of living with HIV today than was once the case.

The *Newly Positive* study provides nuanced, contextualised insights into these experiences, inviting reflection on the sociohistorical, cultural, and institutional conditions that give them the quality and shape they have today. As a research corpus it is incredibly valuable – not only for its practical policy relevance but for what it reveals about how experiences of HIV have changed over time in connection with particular historical developments and sociocultural circumstances, and what remains the same.

Our current HIV policy settings depend on people at risk testing regularly, knowing their status, and if found positive, accessing antiretroviral therapy and appropriate care. These principles have been broadcast widely and the HIV epidemic is under better control in Australia than in most other places. Yet almost 40% of HIV diagnoses in Australia are classified as late diagnoses. For treatment as prevention to work, it is crucial to understand and address the circumstances in which HIV testing and treatment is avoided.

The present report contextualises this figure in important ways, pointing to the circumstances and situations in which HIV diagnosis occurs and how it is anticipated and experienced by people in different social, cultural, economic, and biographical situations. It provides exactly the kind of information needed to tailor HIV programs and policies more effectively to the circumstances of the epidemic in this country, in their ever-changing form, expression, and reality.

EXECUTIVE SUMMARY

This report presents findings from the Newly Positive study (2023–2026), a qualitative investigation of contemporary experiences of HIV acquisition, diagnosis, treatment and care in Australia.

The study involved interviews with 51 people diagnosed with HIV in the previous 12 months and 15 physicians providing HIV care. Particular attention was given to the experiences of temporary residents and recently arrived migrants, who comprised a substantial proportion of participants.

The findings provide insights into perceptions of HIV risk, prevention practices, testing, diagnosis, treatment, peer support and clinical care, and identify opportunities to strengthen Australia's efforts to eliminate HIV transmission.

KEY FINDINGS

HIV acquisition reflects contemporary social and prevention contexts

Most participants were able to identify a likely exposure event associated with acquiring HIV. HIV acquisition was overwhelmingly attributed to sexual exposure – occurring within the context of context of relationships, travel, migration, changing sexual networks, or variations in HIV prevention practices. Participants' accounts highlight the importance of understanding HIV acquisition as relational, shaped by specific social contexts rather than individual behaviour alone. Newly arrived migrants often described challenges navigating Australia's sexual and prevention cultures, particularly when moving from contexts where condoms were the primary prevention strategy to one in which PrEP and U=U are central.

Gaps remain in prevention, testing and HIV literacy

While awareness of PrEP was common among gay, bisexual and queer men (GBQ men), newly arrived migrants often had limited knowledge about how to access PrEP and frequently assumed it would be unaffordable without Medicare. Most participants had previous experience of HIV testing, but testing histories

varied by sexuality and gender. Newly arrived migrants often reported uncertainty about where to access testing and some delayed testing because of concerns about visa implications. Women and heterosexual men had generally lower levels of HIV risk awareness and less experience with routine HIV testing.

Rapid treatment initiation and high levels of engagement in care are now the norm

Most participants were linked to HIV care quickly following diagnosis and commenced antiretroviral therapy (ART) within days or weeks. Almost all the participants were taking treatment and were retained in care at the time of interview. The recently introduced Commonwealth program providing treatment to people without Medicare was viewed positively by both participants and physicians and was seen as substantially reducing barriers to treatment access. Participants generally described contemporary HIV treatment as easy to take, associated with few side-effects, and highly effective.

U=U is transforming life after diagnosis

Most participants achieved an undetectable viral load within a few months of commencing treatment and understood that having an undetectable viral load meant they could not transmit HIV sexually. Achieving viral suppression was described as a significant milestone that improved mental wellbeing, reduced anxiety and enabled a return to sexual and social confidence. Many participants intended to rely on U=U as their primary strategy for preventing HIV transmission to sexual partners. At the same time, accounts from participants indicate that HIV-related sexual stigma persists despite widespread acceptance of U=U science. Prior to diagnosis, some participants actively avoided sex with HIV-positive partners even when they were taking PrEP themselves, suggesting that stigma cannot be addressed through education about U=U alone.



Peer support remains a critical component of the HIV response

Peer navigation and peer support services were highly valued, particularly by newly arrived migrants. Participants described peer workers as providing practical information, emotional support and connections to community. Physicians also regarded peer navigation as an important complement to clinical care. However, both participants and clinicians reported delays accessing peer navigators in some settings, suggesting a need for further investment in peer support services.

Migrants continue to face distinctive challenges

Although newly arrived migrants generally reported positive experiences accessing HIV treatment and care, concerns remained regarding HIV testing, prevention access, health-system navigation and the potential implications of HIV for visa status. While

the expansion of free HIV treatment has addressed a significant barrier to care, participants' accounts indicate a continuing need for targeted information and support for newly arrived migrants.

Overall, the findings demonstrate the effectiveness of Australia's contemporary HIV treatment and care systems while highlighting ongoing challenges in prevention, testing, HIV-related stigma and support for newly arrived migrants. The report identifies opportunities to strengthen health promotion, service delivery, policy and research to support progress towards the goal of eliminating HIV transmission in Australia.

NEWLY POSITIVE

RECOMMENDATIONS

Drawing on the findings presented in this report we offer a series of recommendations for policy, health promotion, service delivery and research. These recommendations are intended to enhance or refine – rather than replace – existing approaches.

1. Policy

- Ensure timely, affordable access to PEP for people not covered by Medicare, including by exploring subsidised or no-cost pathways within the 72-hour window.
- Incorporate HIV prevention information – including how to access free HIV testing, low-cost PrEP, and PEP – into arrival materials provided to migrants, with links to community-designed resources such as the *SafeDownUnder* website.

2. Health promotion

- Develop targeted education resources for newly arrived GBQ men from Asia, Oceania, and Latin America to help them navigate Australian sexual and prevention cultures, including how to access free or low-cost HIV testing, PrEP, and PEP.
- Develop messaging about the typical symptoms of HIV seroconversion illness to help GBQ men recognise symptoms and seek timely testing.
- Develop stigma-reduction messaging specifically addressing stigma toward potential HIV-positive sexual partners of GBQ men – distinct from broader U=U campaigns, and focused on the social and relational dimensions of exclusion.
- Develop messaging encouraging GBQ men to align HIV and STI testing frequency to their current risk practices, particularly when PrEP use changes or is discontinued.

3. Clinical care and services

- Integrate HIV testing whenever women present for STI screening, and create regular opportunities within routine clinical visits for GPs to discuss sexual health with patients.
- Develop clinical guidance and support pathways for GBQ men who are discontinuing PrEP or transitioning to on-demand dosing, to maintain appropriate testing frequency and access to prevention.
- Increase awareness of HIV seroconversion illness among clinicians in general practice and emergency settings, to reduce missed opportunities for earlier diagnosis.
- Expand peer navigation services nationally to support newly diagnosed people – particularly newly arrived migrants – in linking to care and understanding their treatment and visa-related entitlements.

4. Research

- Conduct social research investigating the factors shaping HIV-related sexual stigma and the exclusion of HIV-positive partners within contemporary GBQ communities.
- Include detailed questions about the sexual networks and practices of newly diagnosed participants in the 12-month period prior to HIV acquisition in future seroconversion studies.
- Conduct social research examining the role of GBQ sexual networks in the sexual learning – including sexual cultures and sexual health knowledge – of young GBQ men and newly arrived GBQ migrants from Asia and Latin America.

INTRODUCTION AND BACKGROUND

CHANGING HIV EPIDEMIOLOGY

HIV notifications in Australia declined by 27% between 2015 and 2024. This overall decline, however, masks significant variation by population. Among Australian-born gay and bisexual men – who comprise the majority of new HIV cases – notifications fell by 54% over the same period. Among men born outside Australia, the decline has been far more limited: 15% among men born in Asia, and 9% among men born in other regions (King et al., 2025). The slower progress among overseas-born men reflects differential access to testing, treatment, and PrEP even as overall coverage has improved (Holt et al., 2024; Yu et al., 2024), alongside sexual mixing patterns that contribute to higher transmission risk and delayed viral suppression among newly arrived men (Medland et al., 2019; Medland et al., 2018).

While the proportion of notifications among migrants attributed to male-to-male sex who likely acquired HIV after migration has declined – from 63% in 2016 to 35% in 2024 (King et al., 2025) – the risk of post-migration HIV acquisition remains significant, particularly among men from Asia and Latin America (Gunaratnam et al., 2019). This pattern is consistent with the international literature (Lewis & Wilson, 2017; Palich et al., 2024; Poglia Mileti et al., 2024; Santoso et al., 2022).

Of the estimated number of people living with HIV (PLHIV) in Australia at the end of 2024, 94% had been diagnosed. Of those diagnosed, 97% were retained in care and 95% were receiving ART; of those on treatment, 98% had a suppressed viral load (<50 copies/mL). Across the total estimated PLHIV population – diagnosed and undiagnosed combined – 88% had a suppressed viral load (King et al., 2025).

Undiagnosed infection and late diagnoses

The remaining 6% of PLHIV in Australia are undiagnosed, and this proportion is highly uneven across populations. Undiagnosed HIV is highest among people born in Southeast Asia, estimated at 23%. Considering region of birth alongside risk exposure, undiagnosed HIV is highest among people born overseas with heterosexual risk exposure (45%) and lowest among Australian-born men with male-to-male sex as their risk exposure (2%) (King et al., 2025).

A significant proportion of people who remain

undiagnosed will go on to be diagnosed late – with a CD4 count below 350 cells/ μ L – by which point they often have more advanced disease, poorer health outcomes, higher healthcare costs, and greater risk of onward transmission (McGregor, 2022). In 2024, 38.4% of HIV notifications in Australia were classified as late diagnoses (King et al., 2025). Late diagnosis was most common among people born in Southeast Asia (58%), Oceania excluding Australia (53%), and sub-Saharan Africa (47%); among people reporting heterosexual risk exposure (54% across 2020–2024); and among men reporting male-to-male sex, most commonly among men born in Southeast Asia (52%), men aged 50 and over (47%), men reporting sex with both men and women (39%), and men living in remote areas (38%) (King et al., 2025).

Biomedical prevention strategies

The overall decline in new HIV cases in Australia is attributed to two main biomedical prevention strategies operating in parallel: high rates of PrEP use among HIV-negative gay and bisexual men (Grulich et al., 2018; Ryan et al., 2020), and high levels of viral suppression among PLHIV, which prevents onward transmission – treatment as prevention, or TasP (Bavinton et al., 2018; Callander et al., 2023; Cohen et al., 2016; Ryan et al., 2020). Early initiation of ART is accordingly not only a clinical intervention but a core public health strategy.

This combination has not, however, closed every gap in the prevention and treatment cascade. In 2024, an estimated 13% of all PLHIV in Australia were not virally suppressed: 49% of this group were undiagnosed, 24% were diagnosed but not in care, 13% were in care but not on treatment, and 15% were on treatment but had not yet reached viral suppression (King et al., 2025).

A stalling decline

Despite these substantial gains, progress has recently stalled: more than 700 new HIV diagnoses have been reported in each of the past two years, and the decline in diagnoses among gay and bisexual men has slowed (King et al., 2025). Part of the explanation lies in PrEP itself. PrEP initiations have plateaued (Kirby Institute, 2026) and around 40% of users discontinue, often in ways that do not correspond to actual changes in HIV risk (Ellard et al., 2025; Medland et al., 2023; Murphy & Ellard, 2025; Philpot et al., 2023). As a result, PrEP coverage among those eligible under national

guidelines remains below the 95% targets set in national and state strategies. Since PrEP became widely accessible in 2018, prevention research has concentrated heavily on awareness and uptake; while this has clarified individual-level influences on biomedical prevention use, it offers limited insight into how different groups understand HIV risk or practise prevention day to day.

Access barriers for overseas-born men

The slower decline among overseas-born men, and their higher rates of undiagnosed and late-diagnosed HIV, are best understood alongside research on the specific barriers this group faces in accessing HIV prevention and testing services (Philpot, 2022). These include perceptions and attitudes shaped by social, cultural, and institutional practices in men's countries of origin, associated with lower HIV literacy and reticence to access HIV-related services. Additional barriers include apprehension about a positive result, fear of visa cancellation, concerns about confidentiality, and lack of confidence navigating the Australian healthcare system, including access to PrEP (Cornelisse, 2022; Philpot, 2022).

Current policy settings

These shifting demographics sit within a policy environment explicitly committed to eliminating HIV transmission by 2030 and to meeting the UNAIDS 95-95-95 targets (Australian Centre for Disease Control, 2024). The *Ninth National HIV Strategy 2024-2030* sets new goals across prevention, treatment, quality of life for PLHIV, and stigma reduction.

Recent policy developments provide important context for the Newly Positive study. During the study period, the Australian Government introduced and subsequently extended a program providing HIV treatment to people ineligible for Medicare. These reforms form part of a broader investment in HIV elimination, including an additional \$68.5 million over three years from 2026-27 to expand access to HIV treatment and pre-exposure prophylaxis (PrEP) for people without Medicare coverage (Commonwealth of Australia, 2026). Together these measures address longstanding equity gaps in prevention and treatment access for overseas-born PLHIV and those at risk.

These policy commitments and the changing demographic profile of new diagnoses point to the need to attend closely to the contemporary contexts of HIV seroconversion and diagnosis, and to referral pathways into HIV clinical care and ART initiation – particularly for the overseas-born populations now driving a growing share of new diagnoses. The *Newly Positive* study has provided an opportunity to examine these issues from the perspectives of both people newly diagnosed with HIV and the physicians prescribing their ART.

A note on terminology

Migrant/migration

In this report, 'migrant' and 'migration' refer to people newly arrived in Australia and temporary residents, including international students. We use these terms in line with the United Nations definition of a migrant as any person who changes their country of usual residence – a broad categorisation that encompasses movement across international borders regardless of legal status, reason for moving, or length of stay.

Gay, bisexual and queer-identifying (GBQ) men

All study participants were asked about their sexual and gender identities at the time of interview. The term GBQ men refers collectively to all men who used one of these descriptors. Identity does not always correspond to sexual practice, and the study also includes men who engaged in male-to-male sex but did not identify as gay, bisexual, or queer.

DESIGN AND METHODS

The *Newly Positive* study uses qualitative methods and is guided by four research aims:

- Identify risk factors associated with HIV seroconversion.
- Understand current experiences of HIV diagnosis.
- Describe pathways of linkage to, and retention in, HIV clinical care, including treatment initiation.
- Better understand the specific experiences and needs of people diagnosed with HIV who are temporary residents and/or recently arrived in Australia.

Recruitment for the study was national, and all people aged over 18 who were newly diagnosed (within the previous 12 months), were eligible to participate. A range of recruitment strategies were used including, promotion by peer navigators in PLHIV organisations, social media posts/advertisements, and postcards and posters displayed in high-caseload general practice clinics, public sexual health clinics, and in the infectious diseases departments of two hospitals. The study was also promoted through advertisements and articles in HIV community newsletters.

The physicians were recruited through existing HIV sector networks, and through publicly available lists of s100 prescribers in Australia. Invitations were only sent to physicians who were currently providing HIV care and were eligible to prescribe ART.

Data for the study were collected via semi-structured in-depth interviews. Interviews with newly positive people typically took between 60–90 minutes to complete, and were conducted face-to-face, or via videoconference or phone, with the majority conducted via videoconference. Interviews with physicians were all conducted via videoconference and took between 30–45 minutes. Interviews were audio-recorded and transcribed. All transcripts were anonymised with PLHIV participants given a pseudonym and physicians given a numerical identifier.

The interview data were analysed for recurrent themes and patterns using an inductive constant comparison method (Goetz & LeCompte, 1981). Data were thematically coded/sorted using the qualitative data software program, NVivo 15. This enabled cross-referencing and an analysis of themes and modes of expression, including the contexts and practices associated with managing HIV risk, seeking HIV testing, and receiving an HIV diagnosis.

The *Newly Positive* study received ethics approval from the La Trobe University Human Research Ethics Committee, Monash Health Human Research Ethics Committee, and Alfred Health Human Research Ethics Committee.

The *Newly Positive* study was also endorsed by the ACON Research Ethics Review Committee and the Thorne Harbour Research Endorsement Panel, both of which are state-based LGBTQ community organisations.



PARTICIPANTS

Fifty-one people newly diagnosed with HIV were recruited and interviewed between December 2023 and February 2026. Fifteen physicians working in the field of HIV were recruited and interviewed between March 2025 and June 2025. The socio-demographic details of the participants are described in the following tables.

PEOPLE RECENTLY DIAGNOSED

TOTAL	51
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Gender & sexual identity

Heterosexual female	6
Heterosexual male	4
Bisexual male	6
Gay male	35

Age

Median = 39 years

20–29 years	10
30–39 years	17
40–49 years	12
50–59 years	7
60–69 years	5

State/territory

NSW	14
QLD	4
Tasmania	1
Victoria	29
WA	1
SA	2

Region of birth

Australia/NZ	21
East/SE/South Asia	13
Latin America	6
Sub-Saharan Africa	3
United Kingdom	4
Caribbean	1
Middle East	1
Oceania	2

Year of diagnosis

2022	2
2023	15
2024	22
2025	12

PHYSICIANS

The 15 physicians interviewed were all involved in the treatment and care of people newly diagnosed with HIV including prescribing ART. These interviews allowed the research team to better understand and contextualise the health care experiences and needs of people newly diagnosed with HIV. The tables below provide an overview of the different professional roles and the state/territories represented in the sample.

TOTAL	15
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Disciplinary background

Sexual health	9
Infectious diseases	3
General practice (s100 prescribers)	2
Immunology	1

State/territory

NSW	5
Queensland	2
South Australia	3
Tasmania	1
Victoria	4

HIV TESTING AND SEXUAL HEALTH CARE PRIOR TO DIAGNOSIS

Participants' accounts of HIV testing and sexual health care before diagnosis provide insights into patterns of service use, missed opportunities for testing, and engagement with HIV prevention.

HIV testing is a critical first step in the care cascade: it enables people to know their status and, if positive, to be linked to treatment, which improves health outcomes and prevents onward transmission (Cohen et al., 2016). This chapter outlines participants' histories and experiences of HIV and STI testing prior to their diagnosis, the settings in which they tested, and the barriers, enablers, and missed opportunities that shaped whether and when testing occurred.

HISTORIES AND PATTERNS OF HIV TESTING

Gay, bisexual and queer men

The majority of GBQ men had a history of HIV and STI screening prior to diagnosis, with most reporting testing at least yearly. Testing frequency was not fixed, however, and many described adjusting it in response to changes in their sexual activity, entering a relationship, or changing their PrEP regimen. Men who shifted from daily to on-demand PrEP, or who discontinued PrEP altogether, often stopped testing at the same frequency because the three-monthly prescription cycle – which includes an HIV test – no longer applied. For some, testing frequency also dropped during the COVID-19 pandemic, both because they were having less sex during lockdowns and because attending health services was discouraged.

A small number of men had longer gaps between tests. One participant, a migrant from Papua New Guinea, had a seven-year interval between his last HIV-negative test and the test at which he was diagnosed. Only two men in the study had no prior HIV testing history at all; both were bisexual, lived within predominantly heterosexual social milieus, and had no connection to gay community.

Women and heterosexual men

Of the four heterosexual men in the study, only one had ever had an HIV test, which had been in the 1990s as part of occupational health screening for an overseas position. Heterosexual men generally

associated HIV testing with gay men, a framing illustrated by Ned's response when asked about previous testing:

Never. I've had very little sexual activity in my life [...] I didn't have that much sex in my life, and not gay [sex]. (Ned, heterosexual man, 34, Ireland)

Five of the six women in the study had had at least one HIV test prior to their diagnosis, typically in the context of pregnancy care. Outside pregnancy, however, HIV testing was largely absent from their sexual health histories, even for women who were undertaking regular STI screening. Helena, for example, had been having annual STI checks but discovered after her diagnosis that these had never included an HIV test:

Well, only when I was pregnant. [...] Do that when you're pregnant because [...] I went to my doctors, I was getting blood tests done every year for sexual diseases and that. I had asked her, I said, 'In any of the tests is there anything about HIV?' And she goes, 'No, we would've never tested you for HIV'. (Helena, heterosexual woman, 49, Australia)

Rhonda had been having regular STI screening following the start of a casual sexual relationship with a partner who regularly travelled to high-prevalence countries for work. When asked whether HIV had crossed her mind in this context:

And you mentioned that you sort of knew he did that – he went to Thailand. And given that you're only perhaps having sex with him a few times a year, did you ever think about HIV?

Never crossed my mind. Other diseases, yes. But I was quite good with my doctor. I was very open with him saying, look, because I'm not dating anybody either. I have sex with him. Occasionally we go away on little holidays because were both single and some companionship. And so, he would test me, but the last time he tested me for HIV was two years ago, and now he's angry that he hasn't tested further. (Rhonda, heterosexual woman, 61, Australia)

Rhonda later revealed that her doctor had been periodically including an HIV test in her screening without telling her:

[He was] testing me without me knowing. I trust him. I've been going to him for a long, long time. He's given me my annual bloods [...] And he was just sliding them in there just to make sure. (Rhonda, heterosexual woman, 61, Australia)

Taken together, Helena and Rhonda's accounts point to a consistent pattern: discussions about HIV risk and prevention are largely absent from clinical encounters with women, even when those women are engaging with sexual health services. In Rhonda's case, her doctor appears to have made a private judgement that some HIV testing was warranted, without inviting her into a conversation about why – a practice that bypassed informed consent and foreclosed any opportunity to discuss her risk or consider prevention options such as PrEP. Women are not defined as a priority population in the Australian epidemic (Australian Government, 2024), reflecting the low overall prevalence. Nevertheless, offering an HIV test whenever women present for STI screening would be a low-burden way to improve timeliness of diagnosis and create space for meaningful conversations about sexual health and risk.

LOCATIONS, CONTEXTS, AND TESTING TECHNOLOGIES

GBQ men accessed HIV testing across a range of settings, including HIV-specialist and general-practice GPs, community-based testing services, and public sexual health clinics. A small number also used HIV self-tests. Branko valued the flexibility of being able to combine settings depending on his level of concern, using community-based home tests routinely and attending a public sexual health clinic when more worried. He also used mail-order self-tests for chlamydia and gonorrhoea through a Queensland government scheme:

So, I went into the [public sexual health clinic]. I went into there and got that done. So, if there's anything that I'm worried about, I'd go to [public sexual health clinic]. Other than that, I just go to [HIV testing service run by community

organisation]. I have a home test, it's super easy. I usually do home tests and then obviously with syphilis, once you've had it, it shows up as positive all the time anyway, so there wasn't really much I could do about that. So, all the others, I've usually just got home tests unless I was really worried and then I went into the sexual health clinic. (Branko, gay man, 30, United Kingdom)

Branko was the only participant who mentioned using self-tests for STIs other than HIV.

Newly arrived GBQ men

Newly arrived GBQ men typically accessed STI and HIV testing at public sexual health clinics or community-based testing services. They generally learnt about these services through online searches or through friends from their home country who were already living in Australia, rather than through connections to local gay community:

But then here, I have to do that. And in most places, and I had a sex with[out] condom, and I was like, I'm so scared and all [those] things. I have to surf the web out to see where can I get tests and all the things. (Jett, gay man, 29, Indonesia)

Although most newly arrived GBQ men had access to free STI and HIV testing in their countries of origin, some had avoided public services there because of discriminatory attitudes toward gay and queer men, and because of concerns about their sexuality or results being recorded in government systems:

I always went to this private sexual clinic in Jakarta because I don't want to be exposed in [a] regular hospital because even in regular hospital they need to see the doctor. And the doctor is not LGBT friendly. They're so judging, they are asking a lot of questions and I'm afraid [of] the bureaucracy. So, I went to the very popular private sexual clinic in Jakarta, which is already known by people that it's very discreet. (Torin, gay man, 37, Indonesia)

The availability of accessible and non-discriminatory sexual health care varied considerably across countries of origin and sometimes within countries depending on location. Three GBQ men from Indonesia described avoiding public sexual health services for the reasons Torin outlined; a fourth, Rakeem, described living in a part of Indonesia with a visible LGBTQ community, where public clinics were non-discriminatory and he had felt comfortable accessing HIV testing, PrEP, and eventually HIV treatment. GBQ men from Latin America generally did not raise discrimination as a concern in relation to HIV testing in their countries of origin.

BARRIERS, ENABLERS, AND MISSED OPPORTUNITIES FOR TESTING

Cost and access

A key enabler of HIV testing for GBQ men was access to free or low-cost services. This was particularly important for newly arrived migrants without Medicare coverage. Quinn, a migrant from China who was studying in Australia, knew he could ask his family for money to cover a test but was reluctant to add to their financial burden. He had felt persistently tired and unwell from 2019 onwards but did not seek medical attention:

*But sometime when from 2019 on that year my whole body feeling very tired, always want to sleeping and sometime fever but I just maybe on that time it's winter, winter season I didn't thinking on that way I have HIV still just maybe a simple health problem.
(Quinn, bisexual man, 30, China)*

Quinn was eventually diagnosed in hospital in 2023 with conditions associated with advanced HIV disease, including Kaposi Sarcoma. His last HIV-negative test had been a self-test accessed from a vending machine in China in 2015. Although all international students in Australia are required to hold Overseas Student Health Cover (OSHC), very few participants mentioned using private insurance to cover sexual health screening – whether because of uncertainty about coverage, gap fees, or privacy concerns. Cost was also raised as a barrier by a small number of Australian-born GBQ men who did not live near a public sexual health clinic or community-based testing service and had difficulty finding a GP who bulk-billed the full consultation fee.

Visa concerns

Some newly arrived GBQ men avoided HIV testing because they were uncertain what a positive result would mean for their visa status, and specifically which government agencies would receive information about their results. Nicky, who had arrived on a holiday visa from Fiji and later applied for a protection visa, described his avoidance in terms of fear:

*I just had this big stigma towards it. I fear having to, fear having to have it. It's very scary for me.
(Nicky, gay man, 25, Fiji)*

Nicky was ultimately diagnosed through the medical examination required as part of his protection visa application – a process he came to view as having saved his life:

I feel like before that I would've died if they had refused my applications. Cause if they had refused my application earlier, I wouldn't even have gotten the chance to do the medical examination. So that needed to happen to me to find out about my diagnosis. If they had refused it earlier, if my grounds were not as, if they didn't find my grounds as genuine, they would've refused it. And I wouldn't even gotten the chance to go and get my health examination done. And I would've never known. I would've never known. And then I could eventually die. (Nicky, gay man, 25, Fiji)

Missed opportunities: seroconversion illness

Two Australian-born participants described experiencing flu-like symptoms some months before their HIV diagnosis – symptoms that, in retrospect, were likely seroconversion illness. In both cases, they had presented to a hospital emergency department during this period, and in neither case was an HIV test performed. Elijah described what happened:

I think it was around probably February from what I can remember, because I ended up getting very sick about three weeks later. And so, through my appointments at the Alfred, the first appointment, the doctor or the registered nurse said that most likely I had acute HIV sickness because I ended up having to go to the emergency being so sick. But they didn't do HIV tests. (Elijah, bisexual man, 40, Australia)

Jaco also presented to emergency with symptoms that initially suggested a cardiac event, given a pre-existing mitral valve stenosis diagnosis. Once a heart attack was ruled out, he raised the possibility of seroconversion himself:

“

SHE GOES, POTENTIALLY IT COULD BE. AND I WAS ACTUALLY GOBSMACKED BECAUSE THE DOCTOR AT THE HOSPITAL BASICALLY TURNED AROUND AND SAID, YOU SHOULD GO TAKE THAT TO YOUR LOCAL GP INSTEAD OF JUST TESTING ME THEN AND THERE.

(Jaco, gay man, 44 man, Australia)

”

In both cases, an HIV test at the point of emergency presentation would likely have led to an earlier diagnosis. Other participants recalled experiencing rashes or flu-like symptoms around the time of likely infection that they did not connect to HIV at the time. Gene, for example, had sought treatment from his GP for an itchy rash on one leg without either himself or his doctor suspecting HIV. These accounts point to two parallel gaps: clinician recognition of seroconversion illness as a prompt for HIV testing, and community awareness of the symptoms associated with seroconversion.

Across the range of participants and settings represented in this study, a consistent picture emerges of missed opportunities for earlier HIV diagnosis – through absent or incomplete STI screening, cost and access barriers, visa-related fears, and failure to recognise or act on seroconversion symptoms. Participants’ accounts also show that newly arrived migrants face particular concerns about the confidentiality of HIV test results and the implications of a positive result for their immigration status, concerns that can delay testing for years.



HIV PREVENTION AND RISK REDUCTION PRIOR TO DIAGNOSIS

Participants described a range of strategies for managing HIV risk. Their accounts provide insights into contemporary prevention practices and the logics that shape decisions about sex and risk.

Women and heterosexual men had little or no recent engagement with HIV prevention. For most, this reflected being in a monogamous relationship, having little sexual activity, or not perceiving HIV as personally relevant – including, in some cases, when they did have casual partners. Among GBQ men, condoms and PrEP were the most commonly used prevention strategies. Very few described behavioural strategies such as serosorting, limiting sex to oral sex, or strategic positioning as risk reduction approaches. Most Australian-born men were familiar with U=U, though few had relied on a partner's undetectable viral load (UVL) as a prevention strategy prior to their own diagnosis.

CONDOMS

Among GBQ men who were not using PrEP, most did not use condoms consistently, or deferred to their partners' preferences. Laszlo described his approach as roughly split:

So, you do use condoms?

I don't always practice unsafe sex. In fact, a lot of my partners are condoms only. So, it was a 50-50 [thing]. (Laszlo, bisexual man, 58, Australia)

Nicky, who had very few sexual partners prior to moving from Fiji to Australia, left the decision to whoever he was with:

Would you use condoms with people?

Well, it [they] prefers it. What's the word? Some people do and some people don't.

And so, for you, would you sort of be guided by what the other person wanted?

Yeah, I just sort of go with the flow. (Nicky, gay man, 25, Fiji)

Most newly arrived GBQ migrants had routinely used condoms in their countries of origin, where condoms were often the culturally preferred – and sometimes the only – available HIV prevention strategy. A notable exception was Dirk, from Papua New Guinea, where both cost and social stigma limited access:

When you were having sex back in PNG, did you use any form of, risk reduction, whether that's condoms or asking [about status]?

Sometimes [...], But most times I don't.

And can I ask, is that because it's not the culture?

Number one is they are expensive. They're expensive in PNG. [...] And, if you put them in readily available places, people are ashamed to go to these readily available places to pick them up. They would rather go discretely to pharmacists to buy them. But they're expensive in pharmacies. (Dirk, gay man, 42, Papua New Guinea)

Consistent condom use among GBQ men in Australia had declined to 13% by 2023 (Broady, 2025), reflecting the widespread uptake of biomedical prevention. Condoms remain part of the prevention landscape for many, but – as some newly arrived participants' accounts suggest – in a context of high PrEP and TasP use, they are not always the accepted norm.

UNDETECTABLE VIRAL LOAD

Knowledge of UVL prior to diagnosis was largely limited to GBQ men, and even among this group very few described relying on a partner's UVL as a prevention strategy. Branko was one of the exceptions – not using PrEP himself, he had made a practice of asking partners about both their PrEP use and viral load status:

So yeah, there's a lot of unprotected sex. I would generally, I thought I was being relatively clever about it. Obviously, I was massively incorrect, but I would generally ask them if they were on PrEP because I figured that if they're on PrEP then it's probably fine. Or if they were undetectable, then if they're undetectable, that's generally also fine. So usually, I would ask those questions. (Branko, gay man, 30, United Kingdom)

Wilden was similarly confident in the science of UVL:

So sometimes on Grindr people indicate their status and once or twice a guy would say, "Oh, I'm undetectable. I'm on treatment." Which to me was usually a sign that they're much more likely to not transmit anything than less. So that was always a green flag in a way, if someone said that. (Wilden, gay man, 47, Australia)

Callan was in a long-term open relationship with an HIV-positive man and relied on his partner's UVL within that relationship, while using on-demand PrEP with casual partners.

Others had heard of U=U but did not fully understand it, or retained doubts about the reliability of viral load suppression. Kieran's account shows how awareness of U=U did not necessarily translate into willingness to act on it:

I was going to ask you about that, what you knew about HIV.

Enough to be ignorant about it, enough to be just as much involved in the stigma as the next person.

And by that, do you mean you would avoid people with HIV sexually?

Absolutely. Absolutely. Even undetectable. I was ignorant in the sense that I did not know that they couldn't pass it on.

Had you heard of it before, like undetectable, 'U=U' and all those things?

Yeah, I'd heard it. Couldn't comprehend what it actually meant. (Kieran, gay man, 36, Australia)

BEHAVIOURAL RISK REDUCTION

Explicit behavioural risk reduction strategies were largely absent from participants' prevention accounts. Although it was common for GBQ men to assume their partners were HIV-negative or on PrEP, this was rarely articulated as deliberate serosorting. Kieran did sometimes check hookup profiles for PrEP use, but this was not a routine practice. Jett, a newly arrived GBQ migrant unable to access PrEP, was unusual in actively trying to negotiate prevention with partners:

I ask the people. I ask the people and sometimes to avoid them to feel offended. Sometimes I've explained why I asked that. It was because I'm a student and I can't access prep, but I always do tests routinely. I was too polite. (Jett, gay man, 29, Indonesia)

Jett is a rare example of a GBQ man seeking to explicitly negotiate a partner's PrEP use to manage his own risk. More often, reliance on partners' PrEP use was assumed rather than discussed. Only one man described strategic positioning as a prevention rationale, noting that one reason he had not filled his PrEP script was 'because I don't get fucked' (Barrett, gay man, 58, Australia). The dominance of biomedical prevention in Australian gay sexual culture is the most likely reason behavioural strategies had receded from participants' prevention repertoires, even when they were not themselves using PrEP or condoms.

PEP

A small number of GBQ men had accessed post-exposure prophylaxis (PEP) following a perceived risk exposure. Gustavo had used PEP in Argentina after a sexual encounter where he was uncertain whether a condom had been used:

I remember a case during that period that I was with a guy and I couldn't see where he, I mean, he threw the condom away and I couldn't just actually see it, so I went for PEP the day after. Okay. Even though I knew that we had had safe sex, and I never felt the condom breaking, but that was my fear. (Gustavo, gay man, 34, Argentina)

Gustavo recognised in retrospect that his decision had been overly cautious, but described PEP as having managed his HIV anxiety at the time. Other newly arrived GBQ men, including Santosh, only learned about PEP after their own diagnosis through online searching, and felt it was information that should be actively provided to newly arrived migrants.

Several men tried to access PEP after a risk exposure but could not do so within the 72-hour window. Julio, newly arrived from Peru, contacted a hospital immediately after a condom broke during sex, only to be told he would need to pay upfront:

When that happened, I got really scared. I tried to find support to access, which is post [...] post exposure prophylaxis. [...] I went to it, a hospital, which I can't remember which one was it. I went to a hospital, they told me I had to go to emergency, but I had to pay for it, and I didn't have the money, so I decided to wait for taking it. I think that's how I got it [HIV]. [...] they told me I had to pay upfront, and then later on my insurance was give back the money I spent. But at the moment [...] I didn't have the money. (Julio, gay man, 33, Peru)

Julio's account points to a concrete gap: where upfront costs prevent timely PEP access, financial barriers may directly translate into HIV transmission. Promoting PEP among newly arrived GBQ migrants and removing upfront payment requirements are achievable steps that could reduce preventable infections.

PREP

Awareness of PrEP was high among Australian-born GBQ men: 17 had past or current experience of using it and a few were in the process of accessing PrEP at the time of diagnosis. Several had discontinued PrEP or were not actively taking it at the time of acquisition, and described relying on the assumption that partners were on PrEP. Elijah had wanted to start PrEP but encountered a GP who questioned his need for it and made him feel uncomfortable about his sexuality; by the time he sought a prescription through a different doctor, he had acquired HIV.

A broader pattern of assumed protection emerged across the data. Kieran's account captures it directly:

Would you talk much about PrEP or prevention? Did it come up much prior to meeting?

It might come up. More often than not, though, it's a case of read their profile online and if it says it then it must be true. And so more times than not, no, it would not be spoken about.

And is that partially because you presume most people are on PrEP, or if you aren't, then he would be?

Yeah, I think there's this delusion that just because you're not taking it, they probably are. (Kieran, gay man, 36, Australia)

After diagnosis, many of these men were critical of having relied on others' PrEP use as their own risk reduction strategy.

Newly arrived GBQ men

Newly arrived GBQ men typically had no experience of PrEP before arriving in Australia, though it was more common among those from Latin America. Rakeem, from Indonesia, was unusual in having accessed PrEP in his country of origin through a connection to a visible LGBTIQ community there; he had discontinued during a period of depression and reduced sexual activity, also experiencing gastrointestinal side effects he attributed to taking PrEP and antidepressants concurrently.

GBQ men from Asia generally knew that PrEP was the predominant prevention strategy in Australia but were uncertain how to access it and assumed it would be expensive. Some had tried to navigate this by seeking partners who were using PrEP; others arrived with a perception of Australia as a low-risk environment that reduced their sense of personal risk.

PREVENTION LOGIC

While the preceding sections have described the prevention practices of GBQ men prior to their HIV diagnosis, we draw attention now to the meanings and rationales that shape those practices – what we call prevention logics. While biomedical prevention is central to contemporary HIV prevention policy, and our data confirm its centrality, our data also reveal other logics, ones that make sense within particular situations, even as they carry risk.

Prevention logic one: assumed protection

Some GBQ men who were not themselves using PrEP or TasP nonetheless understood their HIV risk as managed – or at least reduced – because they assumed or believed their partners were using biomedical prevention. For Jett, this logic emerged from a specific set of circumstances – financial precarity, relationship instability, and the disruption of COVID-19 – that made accessing PrEP of his own genuinely difficult:

Did you ever manage to access PrEP while you were here?

I was very poor. So, I never tried to buy one [PrEP] because my partner at that time, because we live, it was a hard situation between uncertainty of our continuity and also his situation financially because of the covid. He got dismissed by the company and he ended up being jobless and also supporting his family and I supporting him at that

time. And I also navigating this thing and I was probably just too naive then I'm just trusting that it's a PrEP culture in Australia (Jett, gay man, 29, Indonesia)

For Jett and others in similar situations, trusting in a broader culture of PrEP use was not naive – it was a reasonable adaptation to circumstances in which accessing individual protection was not straightforward.

Understandings of HIV in Australia were sometimes informed by media reports about elimination of HIV transmission, which contributed to perceptions of risk.

Out of all the countries I picked, I wanted Australia because I always thought, obviously this was one of my primary concerns from the start, I always had this thought if I go to the US I could get HIV. I don't know. It was always there in my mind. [...]. Because I did check that out and they said at that time they had said it's close to elimination in [inner] Sydney or something. And I was like, "What the hell?" So that means it probably does not exist there. (Santosh, gay man, 24, India)

Santosh's perception of Australian's access to HIV treatment also influenced his practices. As his account notes:

And that was the reason why I also let my guard down so many times because I always thought people here have access to Medicare, so even if you had it, you'd be on treatment for it, and you wouldn't be transmittable.

Prevention logic two: historical identity contrasting with contemporary practice

The second logic was most visible among Australian-born gay men, typically in their mid-to-late fifties at the time of diagnosis, who had lived in or around gay communities for much of their adult lives. These men had histories of active engagement with HIV prevention – as advocates of safe sex, as participants in community responses to the epidemic, and as witnesses to the losses of the pre-ART era. Yet in the period prior to diagnosis, their accounts suggest little engagement with contemporary prevention strategies. They were no longer using condoms, were generally not using PrEP, and did not describe their partners' HIV treatment or PrEP use as a form of protection.

Some had been involved in chemsex; others had drifted into social worlds that were predominantly heterosexual. One participant, for example, described how his social life had gradually reoriented around his workplace, moving him away from gay community and, with it, from the prevention conversations and norms circulating within it.

For several of these men, HIV belonged to a chapter of their lives they had lived through and survived. As Pierce (gay man, 57, Australia) reflected:

I knew about it [PrEP] through other people, but I guess I think it was because I'm a 50 something or 57-year-old gay male who hit the gay scene in the eighties who never..., I think just about every gay friend or gay male friend that I've got is HIV. And I've been through the journey with them and I know a lot about it through them, but I know only from their perspective basically it was that I didn't understand that they couldn't transmit it at all. (Pierce, gay man, 57, Australia)

Another similarly aged participant, Barrett (gay man, 58, United Kingdom), viewed HIV largely through the lens of the past, and primarily in relation to his ex-partner who was HIV positive. He recalled:

Back then, I used to watch him take 13 pills three times a day, stay alive. Some of them were the size of horse pills. And I remember nearly wanting to cry because he was literally, nearly choking to try and get them down. Diarrhoea all the time. Everything.

[...] you probably knew treatment was quite different now. Did you know that?

I had no idea because that relationship ended and along with that ended my HIV association. (Barrett, gay man, 58, United Kingdom)

Their disconnection from current prevention practices does not indicate ignorance of HIV, but instead a kind of temporal distance from it.

CONTEXTS OF RISK AND HIV ACQUISITION

Drawing on participants' accounts of how they acquired HIV, this chapter examines the social, cultural and relational contexts that shape HIV risk and acquisition.

Participants were usually able to identify a type of risk exposure – sexual, injecting, or other – even when they could not identify a specific event. Only a few participants, mostly women and heterosexual men, could not identify any partner, event, or exposure that might explain their infection. The majority attributed their acquisition to sexual exposure; a small number attributed it to medical procedures; and one attributed it to injecting.

RELATIONSHIPS

Current and past relationships featured in many participants' accounts of HIV risk, even when infection did not occur within a relationship, illuminating the social meanings of coupledness and the ways in which these can shape – and sometimes obscure – perceptions of HIV risk.

Amara moved to Australia from the Caribbean in 2014 and married an Australian man she had met in her home country. Prior to the relationship, she had practised systematic HIV and STI testing with new partners:

I was the type of girl who said that before I have a new sexual partner, were going to do a full panel test. [...] ended up chasing a lot of people [away]. But I think that was a good thing. Have a new sexual partner. You're going to do HPV, you're going to do HIV, you're going to do [...] gonorrhoea, chlamydia, and I need to see the results (Amara, heterosexual woman, 35, Jamaica)

In 2022, Amara discovered her husband had been having sex with other women and ended the marriage. In 2023, her ex-husband contacted her to say he had tested HIV positive. On receiving her own diagnosis, she reflected: "I did all the safe sex things, and the one place I was supposed to be safe is where I got it from" (Amara, heterosexual woman, 35, Jamaica). Her account illustrates how the emotional and

social safety of a committed relationship can make other risks – including infidelity and HIV exposure – effectively invisible, and underlines the difficulty of articulating how women and heterosexual men might foresee and act on HIV risk.

Miles met his current partner while on holiday overseas, at a time when he was taking PrEP. When they decided to pursue the relationship, he took considerable care to protect his partner:

So, I had been on PrEP for quite some time because when he arrived from overseas, I wanted this relationship – I wanted to give it a fair go. So, I had then stopped casual sex. I had gone through and had all of my tests a month or two before he came – abstained from anything, was tested again just before he arrived so that I was sure that there was no incubation period or any possibility that I was going to be responsible. (Miles, gay man, 63, Australia)

After three months they married, allowing his husband to apply for a partner visa. The visa process required an HIV test, which came back positive. Miles had focused on protecting his partner from HIV but had not continued PrEP himself; it was only after the diagnosis that it occurred to him that he should have done so until both could confirm their negative status. These accounts suggest that for GBQ men, the emergence of biomedical prevention may have changed how relationship agreements are negotiated – or whether they are considered necessary at all.

MOBILITY

Migration and mobility were factors in HIV risk and acquisition for both newly arrived migrants and Australian citizens and residents travelling abroad.

Newly arrived migrants

Of the 17 newly arrived migrants diagnosed after arriving in Australia, six likely acquired HIV prior to arrival and 11 likely acquired it after. Two were diagnosed while living in Australia but acquired HIV while travelling overseas. Dirk, for example, was living in Australia at diagnosis but acquired HIV on a visit to his home country of Papua New Guinea. Among those

who acquired HIV in Australia, acquisition typically occurred within two years of arrival.

Transition to an unfamiliar sexual culture, alongside limited knowledge of how to access PrEP or HIV testing, were recurrent factors. As Jett recalled:

When I first came to Sydney and they always negotiate on doing condomless sex, it was daunting because from what I know, it's like, damn, I was exposing myself to the risk and all that things, [...]. And it was another thing about the different system of healthcare in Australia and Indonesia is that a lot of medical services works by appointment [...] But in Indonesia, you can just come and get a test. (Jett, gay man, 29, Indonesia)

Some participants could not identify a specific event or partner to explain their infection. Aluna had travelled to Kenya for two months, intending to try for a pregnancy with her partner. She returned and took a pregnancy test, which was how she learnt she had HIV. She was still trying to make sense of how it had happened:

I just want to start by asking you what you think happened or how you think you got HIV

[...] I'm still thinking about it, how I get it. So, I haven't found out yet how I get it.

Any thoughts or any possibilities?

No. (Aluna, heterosexual woman, 24, Kenya)

Residents and citizens travelling abroad

Several Australian citizens and permanent residents believed they had acquired HIV while travelling for work or leisure. Declan went on holiday to Bali with friends, intending to have sex; he was in a new relationship at home and had been open with his partner about this. He attributes his acquisition to sex with a trans woman he met while out with a friend:

And then three days later I made contact with her again because [I am] really sort of into that sort of stuff. And then we went back out and we went to this place, and this place was absolutely amazing. There were people dancing around and things like that. And I met her friends and I got

treated like the royalty service. And then we went back to her house, and I went up the bum with no condom. And then I got, so yeah, that's sort of where I got it. (Declan, bisexual man, 25, Australia)

Gene attributed his infection to sex during an interstate holiday in Australia, though he could not identify a specific event and suspected he had forgotten to take on-demand PrEP with some partners.

ASSUMPTIONS AND TRUST

Participants reflected on the assumptions they had made about partners' HIV status and testing histories. Rhonda, for example, knew that the friend she occasionally had sex with also had sex with other women on work trips to Thailand. She assumed he had regular sexual health checks and would therefore not pass on any infection – but it turned out he did not test regularly.

Some participants used the concept of trust to explain their prevention decisions. Leo acquired HIV while living and working in Africa:

You talked about trusting the person, I guess. What led you to trust him?

I thought he was mature and I [found] in him maybe this kind of emotional support that I really lacked during my time, my life and something, I don't know, maybe he wanted to try, he said, and yeah, maybe it's kind of time of weakness, I would say. Yeah, I don't know, I wouldn't, yeah, I know trust is a big word because you might trust him in your maybe bank account. You might trust him in doing some good things to you. I know that during intimacy or something, it was really a mistake. (Leo, gay man, 49, Lebanon)

Reflecting after his diagnosis, Leo recast his trust as misplaced. In participants' accounts more broadly, trust operates less as a deliberate risk assessment than as an expectation embedded in sexual intimacy itself.

DRUGS AND CHEMSEX

Drug use featured in the accounts of HIV risk and acquisition of 12 men in the study – one heterosexual man and 11 GBQ men. Chemsex – the combining of sex and illicit drugs (Bourne, 2014) – was a recurrent theme. The majority of GBQ men who referred to chemsex were aged 50 or older and lived in inner-city neighbourhoods, a group that has otherwise seen dramatic declines in new HIV diagnoses in recent years.

Only two participants attributed their HIV acquisition directly to injecting. Lawson, who had a long history of injecting drug use and had never had an HIV test prior to diagnosis, believed exposure through shared equipment was the only plausible explanation for his infection:

I was a relatively heavy meth [user]. I didn't actually share syringes as such. I used to reuse my syringes and I'm presuming that I had somebody that I was having a shot with and they must have actually put theirs [...] with mine, [and] I've accidentally used [their] syringe. [...] I'm presuming that's the only way that I could have possibly gotten [HIV]. (Lawson, heterosexual man, 53, Australia)

One GBQ man had shared syringes with a sexual partner who was HIV positive and not on treatment. For most of the other GBQ men, drugs and chemsex provided a context for sexual risk-taking rather than a direct route of exposure. Gabriel made sense of his diagnosis through a broader pattern of risk-taking across his adult life:

How I think I got it? Okay. So [...], I've gambled with my sexual health for most of my adult life. [...] I feel in some ways I did everything I could to be in this situation that I'm in today. But just a lot of, if you want specifics, I guess a lot of unprotected random encounters. [...] So [...]. there's been a significant amount of drug use for most of my adult life and that sort of ties into the whole thing because poor decisions, blah, blah, blah, blah. Not worried about risk taking, behaviour, risky behaviour. So that all feeds into it. So that's how it happened. (Gabriel, bisexual man, 51, Australia)

Hudson regularly participated in chemsex, where crystal methamphetamine enabled extended, highly focused periods of sex:

Yeah, I mean, it's hard to explain. Once you are in that environment and you're high and you just want to basically get your dick out and you

want to have sex, you're not thinking about stuff. I'll walk the dog [...] but I'll forget to drink water; I won't eat. All that sort of stuff. So, it's pretty single-minded, pretty single-minded. (Hudson, gay man, 58, New Zealand)

Included in what chemsex prevented thinking about were HIV and PrEP. Hudson had initially used daily PrEP, which allowed him to engage in chemsex. When he shifted to on-demand PrEP, the environment of chemsex made managing the timing of doses difficult and he was often not covered. Wilden could not identify a specific acquisition event but believed it had occurred during chemsex:

Genuinely, [I have] no idea. And I don't really rack my brains to find out either. I probably went through for a few years for a long time, but certainly for a lot of the last three years, not the last year or so. I had quite deep depression and occasional binges on ice and occasional kind of sexy party maniac times. And in one of those times, I speculate with how frequently I've gotten tested. I would have had it for less than 12 months by the time I tested positive. So, no idea, chemsex, something happened, don't care who, don't care how. (Wilden, gay man, 47, Australia)

One newly arrived migrant described consuming drugs with a sexual partner without knowing what he was taking:

He introduced me to this substance that I didn't know what that was and claimed that [it was] amyl. While in Indonesian gay scene, I think people already know what amyl is. So, I think, well, okay, it's just amyl, I can have that. But it was different because it used pipes and it needs to be burned. But he said it was amyl? in a different form, so I'm just taking it. But then after the next day after that, I felt so horrible about my body and all that things and I start to look up on the internet and I found out that that [it] was meth and it was quite shocking. (Jett, gay man, 29, Indonesia)

Jett's experience illustrates how newly arrived GBQ men can encounter unfamiliar substances alongside unfamiliar sexual cultures. These accounts do not suggest a simple causal relationship between chemsex and HIV acquisition, but they do show that chemsex environments make adherence to on-demand PrEP – which requires anticipatory planning – particularly difficult, and raise questions about whether assumed collective protection through TasP and PrEP use in these settings may reduce individual vigilance.

CURRENT OR PREVIOUS PREP USE

Of the 41 gay, BGQ men in the study, 17 (41%) reported current or previous PrEP use. Most were Australian-born or long-term residents. Newly arrived migrants were substantially less likely to have used PrEP, although prior use was more common among participants from Latin America than from other regions – reflecting both greater PrEP availability in parts of Latin America and stronger connections to gay community there. Among newly arrived men from Asia, prior PrEP use was rare.

Five participants were taking PrEP at the time of HIV diagnosis – one daily user and four using on-demand dosing. **The daily PrEP user reported excellent adherence; this may therefore represent a pharmacological breakthrough infection, although definitive conclusions are beyond the scope of this study.** All four on-demand users reported inconsistent use. Gene recalled:

I was actually on PrEP, but it's on demand, so I believe that I forgot to take the medication when I was on holiday. That's just my explanations. I could be wrong. You're on demand, so you have to take two tablets just before sex and then one tablet the day after and another one in two days' time. So, I believe that I didn't take the medication correctly, so that could be it. Why I got [HIV]. (Gene, gay man, 40, China)

Two of these men explicitly linked their inconsistent on-demand dosing to chemsex. Hudson described multi-day periods of crystal methamphetamine use during which PrEP was not part of his thinking. Wilden, who had tablets available but rarely used them, described a period in which celibacy, depression, and occasional chemsex coexisted:

So, some of that 12 months you might have had been using PrEP on those occasions, other times kind of not [...]

Definitely. Mostly I wasn't.

But you knew about PrEP, you had...

Oh, I had tablets in my drawer. (Wilden, gay man, 47, Australia)

Twelve men had discontinued PrEP prior to seroconversion. Discontinuation was rarely a deliberate, risk-based decision: only four participants stopped PrEP intentionally – two because they perceived their HIV risk had reduced, one due to a belief it would interact with other medications, and one because he was entering a new relationship. For most, stopping PrEP happened gradually alongside broader disengagement from sexual health care – triggered by circumstances such as changing general practitioners, moving house, travelling for work,

running out of medication, or simply losing contact with prescribing services. Several intended to restart PrEP and were in the process of doing so around the time of diagnosis. Kieran's account was typical:

I stopped, I'd run out and then I'd stopped and life got in the way. Didn't go to a GP. (Kieran, gay man, 36, Australia)

These accounts point to discontinuation as a breakdown in continuity of care rather than a considered exit from prevention, and suggest there is a window of vulnerability between stopping PrEP and the intention to restart it that is not well addressed by current service models.

Several men who wanted to use PrEP encountered barriers to accessing it. Four participants – three newly arrived migrants (two from Latin America, one from India) and one Australian-born bisexual man – were unable to access PrEP before diagnosis. Their experiences included discouragement or perceived judgement from healthcare providers, uncertainty about eligibility, and difficulty navigating services. Elijah, an Australian-born bisexual man, had one unsuccessful attempt at accessing PrEP through a GP who questioned his need for it and made him feel uncomfortable about his sexuality; by the time he sought a prescription through a different doctor, he had acquired HIV. Two Latin American participants commenced PrEP around the time of their diagnosis and were likely already infected or seroconverting when it was initiated – cases better understood as HIV diagnosis occurring on entry into prevention services than as PrEP failure. One participant had been prescribed PrEP but never filled the prescription.

A further 11 GBQ men reported no knowledge of PrEP or only limited awareness. Many assumed it would be unaffordable or inaccessible because of visa or insurance status, or had come from settings where PrEP was uncommon or absent from prevention messaging. Several had heard of PrEP but misunderstood who could access it or how it worked. These gaps were most pronounced among migrants, bisexual men, and men outside established gay community networks – a reminder that PrEP literacy cannot be assumed, even among men engaging in behaviours associated with HIV risk.

Taken together, these accounts show that HIV acquisition among GBQ men in this study is best understood not as failure of PrEP itself, but as breakdown in PrEP as a broader programme of prevention and care – occurring across the full spectrum of awareness, access, initiation, adherence, discontinuation, and re-engagement. Structural inequalities in prevention access, particularly for newly arrived migrants, were a consistent underlying factor.

DIAGNOSIS

Participants were asked about their experiences of HIV diagnosis. Their accounts provide insights into the clinical, social and emotional contexts in which diagnoses occur.

For most of the 51 participants in this study, diagnosis occurred in Australia; six, however, were diagnosed outside the country – one an Australian citizen working in Africa, and five newly arrived GBQ men diagnosed in the countries in which they were living prior to arriving in Australia, with one further participant acquiring HIV in Australia but diagnosed on a return visit to his home country. Among those diagnosed in Australia, settings included specialist sexual health clinics, general practice, immigration testing services, hospital emergency departments, blood donation sites, and prison. Technological developments and modifications in testing protocols have changed the ways in which people first learn about their HIV infection (Grace et al., 2015). It is now common for GBQ men to receive a reactive result on a point-of-care test, which while not a formal diagnosis strongly suggests they have HIV. Similarly, because negative STI and HIV results are routinely delivered by text message, an unexpected request to attend in person may itself alert someone to the possibility of a positive result before they have been formally told.

REASON FOR HIV TEST

The reason participants came to have the HIV test that led to their diagnosis varied considerably: from routine sexual health checks to notification by a previous sexual partner, to testing as part of an immigration application.

Routine sexual health check

For many GBQ men, the HIV test associated with their diagnosis was part of a regular sexual health check – in some cases, as part of returning to, or starting, PrEP. Huck, for example, attended a convenient GP in Melbourne's CBD to discuss going on PrEP:

I think I had gone there it a few times for other things in the past and just, I don't know, it was just a convenient location and a good doctor, a nice doctor. So yeah, when I discussed going on PrEP, it was very easy and no drama really. (Huck, gay man, 39, New Zealand)

Because Huck was already on daily PrEP, the clinic's request to return for further blood tests did not initially concern him:

I had heard if I had picked up any other lesser STI, which had happened. Yeah, this was a bit of a funny one. I think I remember I was called to say that a test had been missed and that I needed to come in again, I think this was about a week later, and do some more blood tests. And in hindsight, I guess it was them being tactful or trying to get, do some more confirmation tests, [...] which I didn't really pay much mind to. (Huck, gay man, 39, New Zealand)

Symptoms and partner notification

A number of participants were tested for HIV as part of broader STI screening, either because they had symptoms or because a partner had informed them of a positive result. Several were diagnosed with HIV alongside another STI. Gustavo, for example, sought testing after recognising symptoms he associated with a previous syphilis infection:

Yes, looking back in time on that, during that period, there was one or two days that I felt a bit temperature, and I was working out and I didn't have the same energy as I used to have. [...] I thought, oh my god, syphilis again. I went to the doctor, I just asked for the exams. And that was December when I got diagnosed. (Gustavo, gay man, 34, Argentina)

Some participants were notified by a partner before having their own test. Amara was contacted by her ex-husband who told her he had tested positive; the marriage had ended because of his infidelity and, initially, she went to be tested out of anger rather than genuine concern:

So, I actually went out of spite immediately [to get tested] that to be able to tell him you didn't give me HIV [...] then with me going, I realized that there's a possibility that I may actually have [it], and all that zest and all that fervour just dissipates and overwhelming sense of fear just settles it. (Amara, heterosexual woman, 35, Jamaica)

As Amara's account shows, the test itself can shift a person's emotional register entirely, from defiance to fear, before a result has even been given.

Health complications

Three participants who were migrants and one Australian-born man were diagnosed in hospital settings; all were late diagnoses, with HIV testing prompted by investigation of complex or unexplained health issues. Quinn, for example, was experiencing cardiac and ophthalmic symptoms; after tuberculosis had been ruled out, he was tested for HIV and STIs and was subsequently diagnosed with both syphilis and HIV. Two further participants were diagnosed at immigration testing sites as part of visa applications.

Self-tests

Only three participants initiated the diagnosis process after a reactive HIV self-test result, all of them migrants. Two sought confirmatory testing at a sexual health service within days. The third, Omar, delayed going for follow-up testing out of fear about what a formal diagnosis might mean for his employment and visa status:

The website said I should go and do the test to [be] certified, but I can't go. [...] I got scared. [...] I said, I'm working here and if the government found out that I had this and they will tell to my work and then tell my boss and I lose my Job. So, I got scared. I didn't go or I said, these people will judge me. (Omar, gay man, 43, Philippines)

Several months after his reactive result, Omar found a local PLHIV organisation through an internet search; they supported him to attend a public sexual health clinic for confirmatory testing. One of the physicians interviewed offered a broader explanation for why migrants might favour self-testing, and for the barriers that follow even a reactive result:

And when I see people where they're saying, I don't want HIV testing, I'm like, you're going to need it because when you apply for permanent residency, the first thing that happens is they require you to have a HIV test. And the best thing is to have it diagnosed and have you on treatment at a good CD4 count. But they don't know that. And so, they've often avoided formal STI testing. I think those individuals would be much more likely to self test, but then even after the self test, the next step of actually seeing a clinician and that fear that it's going to prevent them from getting a visa. And unfortunately the reality is it will probably be a barrier in getting a visa. It's an automatic refusal they've got to put in for a waiver. It is a complicated process supported patients through that process in the

past. And that does contribute to the reason why people don't test because they haven't got a visa yet. (14-GP-HP SA)

Self-tests can be an important first step in linking people to diagnosis, care, and treatment, but only where users see a clear and confidential pathway to confirmatory testing.

DELIVERY OF DIAGNOSIS

Although participants often could not recall much detail about the diagnostic encounter itself, most felt it was handled well. A key detail that was remembered was being told early that effective treatment was available and that they could expect a healthy life. Participants were diagnosed in a wide range of settings – general practice, sexual health clinics, blood donation sites, immigration health services, prison, and hospital – yet even in non-specialist settings most felt the diagnosing clinician was sensitive and sufficiently informed to offer some reassurance. Gabriel, diagnosed in prison, captured this mix of care and isolation:

But anyway, yeah, they were wonderful. I want to say right now that the staff in the prison were wonderful to me. Really, really, really helpful, really nice. But still, it was very, very shocking. And it felt more alone, felt more isolated. (Gabriel, bisexual man, 51, Australia)

A small number of participants expressed dissatisfaction with aspects of their diagnosis. Dirk felt the doctor communicated the diagnosis well but was let down when the pharmacy the doctor referred him to for his ART prescription did not exist. Huck's main concern was with how a preliminary phone call – before his results were confirmed – had been handled:

And it was probably, well maybe that was quite soon after that initial test, but I do remember getting a phone call from just the medical centre receptionist and just, it did sound, it was a strange phone call, that's for sure. Saying [...] that some tests, some more results were delayed or something like that. And to avoid all sexual contact basically. [...] I do remember at the time thinking it wasn't handled very well or professionally, but I think I kind of framed it in my mind that it was a bit of an exception for them to deal with [...] I wasn't really angry about the way it was handled, but it did feel a little clumsy. (Huck, gay man, 39, New Zealand)

Physicians

We asked the physicians how they approached delivering a new HIV diagnosis. Most described conveying the result early in the clinical encounter and in a direct, clear manner:

Generally if it's in the clinic and I'm going to give someone their results, I'll call them in, obviously introduce myself, check I've got the right person, and then try and get to the point [...] and just say your results are back and just tell them that their HIV test is positive and then try and determine if they are surprised, shocked were they expecting this. (O2-SH-SA)

Physicians also emphasised the importance of quickly reassuring patients that HIV was no longer a death sentence, while being careful not to overwhelm them with information:

I think I have an approach which is I to of course be very gentle and sort of very still to allow them to just feel it. But above all to emphasise that, immediately emphasise that how incredibly treatable it is. And the phrase I always say to them is that when you look ahead, no door, every door will be open to you and there'll be light coming through every single door, meaning they can have children, they can do a whole lot of things in their work. They can very likely to live, have a life expectancy of a similarly aged person who's not HIV positive and try and explain the positives. (12-ID-Vic)

So, in terms of practical steps, sort of making introductions, then sort of explaining that this test has been done and a bit of a background of what it's been done. And then I try not to be too indirect or beat around the bush. I try to be quite direct and say that the test has shown that you have HIV and then let that breathe for a moment. (O3-ID-Vic)

For some physicians, giving a new diagnosis had become a relatively rare part of their clinical practice, as most of their patients arrived having already been diagnosed elsewhere and referred for ongoing care. Referrals came from community-based testing services, general practice, immigration testing sites, hospitals, and prisons. Physicians in public sexual health settings were the most likely to be still delivering diagnoses directly, and were also more likely to be seeing newly arrived migrants. One physician described the pattern he observed among overseas-born GBQ men:

And so, people especially who've come to Australia to study, we have a pretty significant cohort of clients who come to Australia, typically men who have sex with men and that they struggle a little bit to adjust to the culture of really infrequent condom use. And so they come to Australia and get to an environment where there's efficient partner change, minimal condom use and it takes them a while to get onto the prep bandwagon. And so we've had a pretty solid number of clients who would've been great for PrEP and they'd avoided getting HIV in their home countries and come here and the cultures a bit different. (O1-ID-HP Qld)

Physicians also noted that visa-related concerns were among the most pressing anxieties for newly diagnosed migrants, and that these were concerns they did not always feel equipped to address.

REACTIONS TO DIAGNOSIS

Regardless of whether a positive result had been anticipated, participants were typically shocked by their diagnosis, often feeling overwhelmed, struggling to take in information, and fearing the worst. Although most could not recall much of what was said during the initial consultation, most remembered being reassured that HIV was treatable and no longer a death sentence – an assurance that, in the immediacy of shock, did not always register:

I felt like it was a death sentence in my mind. I'm like, I think I was thinking in my head, Skyfall by Adele, this is the end. I could have sworn a montage of my life played in five seconds. And I was told, and they were quite lovely telling me that, oh, it is not a death sentence. You can still have a long, happy, fulfilling life. I swear to God, it went over my head. I heard what they were saying. It wasn't registering in my head. (Amara, heterosexual woman, 35, Jamaica)

Reactions were, unsurprisingly, shaped by participants' prior knowledge of HIV. For those with more experience or understanding of contemporary treatment, the diagnosis, while still unwelcome, was less catastrophic:

The education basically helped. It didn't shock me because I wasn't overly distraught about it. I mean it's obviously never nice to find out, but even the nurse said, she goes, you're very cool, calm and collected about it. I said, I've been around it long enough to know how it works that you can live with it and definitely the education helped. (Jaco, gay man, 40, Australia)

A small number of older GBQ men experienced their diagnosis through the lens of an earlier era of the epidemic, when HIV routinely meant death:

I grew up in the eighties where everyone was, all of my friends were dropping off around me. It wasn't the day that went by that we didn't go up to St. Vincent's. And I think we're seeing them for the last time. And so in my head, not being a part of the gay scene or anything like that, not keeping up on the news or anything, being quite ignorant, I think with regard to the situation, I didn't realise how advanced medicine had become. I have three very close friends who have been positive since the eighties. They're very healthy, always have been. And I don't think I've ever considered them as being positive. So, when it hit me, I just thought, oh, I'm next. That's it. My last hour. (Grayson, gay man, 56, Australia)

For participants who were migrants, the diagnosis brought immediate uncertainty about visa status. Tariro, a heterosexual woman from Zimbabwe, was with her husband and two children in the final stages of applying for permanent residency at the time of her diagnosis, placing not only her own future in Australia in doubt but that of her entire family. Physicians were generally able to reassure patients that test results would not be shared with immigration authorities, but could not offer certainty about the longer-term consequences for residency applications. Some migrants went to considerable lengths to avoid a formal diagnosis in Australia for this reason. Santosh, from India, suspected he had HIV but chose to access antiretrovirals from India rather than test in Australia:

I'm still really scared of accessing it in Australia just because of my visa and I am on a visa, and if they find out I have a health condition that's going to cost the government over \$51,000 or something, they will not issue me a visa. So that's one of the reasons why I haven't got into the system yet for accessing ART. I just get it from India. (Santosh, gay man, 24, India)

Many newly arrived migrants were also initially concerned about how they would afford treatment, though in most cases the person delivering the diagnosis was able to explain that treatment would be provided free of charge.

LATE DIAGNOSES

Nine participants would likely be classified as late diagnoses, based on their CD4 count at diagnosis and/or the presence of other health conditions associated with advanced HIV disease. Of these,

four were women, two were heterosexual men, two were overseas-born GBQ men, and one was an older Australian-born GBQ man – a pattern consistent with current national epidemiological data.

Late diagnosis made the experience of receiving an HIV diagnosis considerably more complex, as participants were simultaneously managing other serious health conditions. Two migrants had been hospitalised before diagnosis and both received substantial bills for their hospital stays. While most had responded well to ART, some continued to experience health problems arising from the delayed diagnosis.

The data provide insight into both individual and systemic factors contributing to late diagnosis. Among the four women, one could likely have been diagnosed earlier had HIV testing been included in her routine annual STI screening. Two of the women were from high-prevalence countries, and encouraging HIV testing among migrants from such countries is particularly challenging when a positive result may jeopardise plans to remain in Australia permanently – unless the person holds a protection visa. Among the overseas-born GBQ men diagnosed late, the common factors were limited or no connection to gay community (either in their country of origin or in Australia), not knowing how or where to test, concerns about the cost of healthcare, and uncertainty about visa implications.

Many of these participants could not recall experiencing symptoms. Some had felt intermittent fatigue in the year or two before diagnosis; others had been investigated for unrelated conditions before HIV was identified. Cliff, an Australian-born heterosexual man in his sixties, had experienced several years of deteriorating health before HIV was detected:

And it was only detected because I was having some memory issues and my doctor decided to test me for early onset dementia, and that's when it showed up. Now I've had some pretty poor health over the last three or four years, so I was kind of surprised that it only really came up now after having almost been on a deathbed with kidney failure a couple of years ago and stuff like that. (Cliff, heterosexual man, 68, Australia)

Quinn, a migrant from China, had felt tired in the year before his diagnosis but had avoided seeking medical attention because, without Medicare coverage, he was worried about the cost to his family. Nicky had similarly experienced fatigue and suspected he might have acquired HIV, but feared what a positive result would mean for his visa.

HIV CLINICAL CARE AND TREATMENT

This chapter examines participants' experiences of treatment and care following diagnosis, including linkage to services, treatment initiation, retention in care and viral suppression.

LINKAGE TO CARE

Most participants were linked to HIV care rapidly after diagnosis, regardless of where they received their diagnosis. In some cases, referral pathways were established before participants were informed of their result. For example, Helena was diagnosed through a blood donation service, which had arranged an appointment at a hospital HIV clinic before she received her diagnosis from them.

One participant was diagnosed while in prison. Managing the emotional impact of the diagnosis while ensuring other prisoners remained unaware of his HIV status was challenging. However, he described receiving excellent support from the prison health service. Within days of receiving his result, he spoke by phone with a doctor from a public sexual health clinic and attended a face-to-face appointment several weeks later, where he commenced ART.

Newly Arrived Migrants

Two participants were diagnosed during immigration health screening. In both cases, appointments with public sexual health services were arranged immediately and attended within a few days of diagnosis.

Several participants who had been diagnosed before arriving in Australia were taking antiretroviral treatment prescribed in their country of origin. Rakeem, for example, had commenced treatment in Indonesia and was in the process of linking to HIV care in Australia. Although an LGBTIQ health service was unable to facilitate access to the Australian Government treatment access scheme for people without Medicare, it connected him with a public hospital that could.

Santosh had not established HIV care in Australia but continued to access treatment and clinical monitoring during visits to his home country.

TREATMENT

Initiation of Treatment

For most participants, linkage to care and treatment initiation were rapid and uncomplicated. The majority commenced ART within weeks of diagnosis and often much sooner.

So reactive [point-of-care-test] and she asked me if I want the medication yet and I wasn't sure, [...] if it's correct. So, she told me you can wait until we confirm the confirmatory test. It was a couple of days afterwards and I rushed back in after the call again to get the medication. (Lôc, gay man, 32, Vietnam)

Delays in treatment initiation were uncommon. Jett, who was diagnosed before the introduction of the Commonwealth-funded treatment access scheme, waited three months while compassionate access to medication was arranged.

Physicians

Most people who received a reactive point-of-care test at a community-based service were rapidly linked to a sexual health clinic. One infectious diseases physician described the process:

If they don't have an STI that needs management, then [...] they'll have a peer stay in contact with them while that process is underway. [...] There are a handful of false positives along the way, but [...] once the Western Blot is positive, they'll have a same day referral to the sexual health service [...] and get seen by a nurse for a standard initial review. We'll have a set of bloods done with confirmatory testing and all the baseline bloods and then we'll get an appointment with a prescriber ideally within three working days and hopefully then start it. (O1-ID-Qld)

Some physicians commenced treatment at the first appointment, even before all baseline test results were available, because contemporary regimens such as Biktarvy carry a low risk of resistance-related complications.

While physicians supported early treatment initiation, they also emphasised the importance of ensuring patients were ready to begin treatment:

Often younger people I find just let's start: 'I want to treat it and get on with it.' They're already moving on to the next step of being treated. Others, they're too fragile in the moment and you don't really know enough about them. And they might be on other medications and you may not have enough blood tests to be sure their kidneys are good, all that stuff. So, it's just case by case is the principle, and they might just be reeling and they may not want to start treatment [or be] fearful of medications you pick that up a bit as you're with them. (12-ID-Vic)

Generally, physicians' accounts closely mirrored participants' experiences of rapid referral and treatment initiation.

As noted elsewhere in this report, newly diagnosed participants were often concerned about treatment costs, particularly temporary residents and other migrants who did not have Medicare access. Physicians were overwhelmingly positive about the Australian Government scheme providing free ART for people without Medicare:

For us it was a seamless transition. It actually didn't change a lot of what we did [...], it didn't change how we explain things to patients or how we actually started people on treatment. In the past we did, as you alluded to with the compassionate programme, we have to fill out forms and then wait for an approval from the drug company, which they tend to do fairly quickly. So, there might be a potential wait of one or two weeks, but now it's immediate so we can just start someone straight from our pharmacy stocks. (07-SH-Vic)

Some physicians, however, reported uncertainty about aspects of the scheme, particularly access to injectable treatment. One infectious diseases physician commented:

So, I think at least with oral therapies, I haven't had any issues. And then the only thing that I haven't really tried is injectable therapies with people who don't have Medicare. I think potentially that argument of, because obviously the injectables cost more, that argument that you should put someone on injectables instead of oral therapy. (03-ID-Vic)

Importantly, the current scheme provides access to all HIV treatments listed on the Pharmaceutical Benefits Scheme (PBS).

One sexual health physician also raised concerns that government-funded treatment may, in future, have unintended implications for visa applications:

I wonder whether in the long term whether it is going to impact visa applications and things like that because previously the medications were provided on compassionate access by the drug company, so there actually was no cost [...] to the government, whereas obviously they're absorbing that cost now. And so, I do probably have concerns from that perspective that that may be a factor, whereas previously it was reasonably easy to get around it, it really wasn't a cost, whereas now they're the full cost, which is significant for HIV medications. (08-SH-QLD)

This observation points to a potential contradiction between public health policy and immigration policy.

Regimens and Side Effects

Thirty-three of the 51 newly diagnosed participants were taking Biktarvy, a three-drug regimen comprising bicitgravir, emtricitabine and tenofovir alafenamide.

Regardless of regimen, participants generally described HIV treatment as easy to take, with side-effects typically reported as mild and resolving within the first few weeks.

Some participants taking Biktarvy reported weight gain, although few were aware that this has been associated with Biktarvy and other INSTI-based regimens. Tariro had gained weight after commencing treatment but had decided, in consultation with her physician, to remain on Biktarvy:

So, for now, my doctor, my GP had said we try diet and stuff and then if it doesn't help then we can look at changing the medication. (Tariro, heterosexual woman, 43, Zimbabwe)

Branko also experienced weight gain after starting Biktarvy but managed it through increased exercise:

I remember them [doctor] saying that I gained a lot of weight, so then I just did so much cardio. (Branko, gay man, 30, United Kingdom)

Adherence

All participants reported taking ART daily. For some, adherence was straightforward because they were already taking other daily medications. Others developed routines that helped them remember their treatment.

I've got a pill box and I've put that right next to the sink and it's a brightly coloured one and it hits me in the face every time I go because I do my hair, I get ready for work, whatever it might be. I'm always, I'm using the bathroom in the morning. So that's the reminder[...]. Whereas if it wasn't there, if it was sitting next to the coffee machine, I would still forget it. (Elijah, bisexual man, 40, Australia)

Apart from a participant who had discontinued treatment, Jameson was the only participant in the study who reported ongoing difficulties with adherence. His situation was unusual because he concealed his ART from his partner. Although she knew of his diagnosis, she did not support the use of Western medicine, requiring him to hide his medication in his work vehicle.

Like I said to [name of HIV doctor] I do forget them occasionally. The hardest one was we went away in [...]. We were camping and trying to sneak them in was the hard part. And as soon as you hear a pill bottle rustle, it's like, oh, what's he doing? [...] So, I managed to do that. But I generally, because I don't work every weekend, so some days if I'm not working, I don't work on a Sunday or a Saturday, I generally forget. (Jameson, bisexual man, 37, Australia)

Despite generally high levels of adherence, some participants felt injectable treatment would suit them because remembering daily medication remained burdensome.

It takes away that fear of missing out on daily. There's a few times that I've gone, oh shit, I haven't taken my drug. I haven't taken for one or two days. And you take it every day and you miss one or two days. Every blue moon is [not] a problem, right? [Yeah.] So, there's no panic there, but I just like that idea of that. (Hudson, gay man, 57, New Zealand)

Injectable treatment

We asked all participants if they were aware of injectable treatment and whether it was an option they would be interested in. Of the 49 participants on treatment at the time of interview only two were

already taking injectable treatment, both reported positive experiences of using it:

The injections to me have given me a freedom of a lifestyle, which means that I can sort of not dismiss my responsibilities. But as I said, it's not something that's tattooed on my forehead. (Miles, gay man, 63, Australia)

Injections are a lot less work. So, I choose that one. (Lôc, gay man, 32, Vietnam)

Most participants had a broad interest in accessing injectable treatment, but when they were made aware that it involved a two monthly injection, administered by a doctor or nurse they, were often less interested as they did not want to have more frequent medical appointments. As noted above, a few participants thought it would work well for them as they found daily adherence difficult and one or two were interested because they found swallowing medication difficult. Others thought having the option of injectable treatment would make it easier to travel. For a small number of participants it was appealing because, it would free them from the daily reminder of their HIV:

. But I do ask my doctor about Cabenuva [...] Because even though now [...] I can accept the condition, I still feel like taking that pill every day: it just reminds me. I don't want to be reminded every day like, oh, you're having this [HIV]. (Torin, gay man, 37, Indonesia)

Overseas-born participants

Some temporary residents and other migrants thought injectable treatment might not be available to them because they did not have access to Medicare, and one participant had been told he could not have it:

Has your doctor ever talked to you about injectable treatment, or have you ever asked them about it? Have they mentioned it?

Well, that was really interesting in the way that when I asked, they told me that it was just for people with Medicare and just with pretty much citizens or something. And as I'm not like from here, it was like, and I'm getting the treatment for free. I am not going to say anything. I just said, 'Oh, yeah, that's fine'. (Agustin, gay man, 28, Chile)

Agustin knew the information was untrue because he knew other people without Medicare who were accessing it. However, his migrant status made him feel that he could not challenge what he was being told by the doctor.

RETENTION IN CARE

Retention in care, that is health care services, being able to keep patients, engaged in treatment, monitoring and care, is an essential part of achieving individual and population level viral suppression, and ensuring HIV-positive people have good health over their lifetime (ASHM, 2024). Most participants in the study were retained in care, including engaging with treatment and having ongoing monitoring of their viral load and CD4. While a small number of temporary migrants who were diagnosed prior to arrival were not currently receiving HIV clinical care in Australia, all were on ART at the time of interview. Only one participant, an Australian born gay man, was not retained in care at the time of interview. He had been diagnosed by an s100 prescriber in a high caseload clinic, but had soon after stopped treatment and had not returned to see his doctor. (He was subsequently linked to HIV care.)

Overseas-born participants

Of the overseas born migrants who were diagnosed in Australia, all were retained in care at the time of interview, and all were accessing care in public sexual health clinics, which meant that they not only had access to ART but also to care related to their HIV. A few of the GBQ men who were diagnosed prior to arrival were taking treatment that had been prescribed in the country where they'd been living previously, but all of these men were in the process of or planning to connect to care in Australia before their medication ran out. One participant who was diagnosed on a visit to his home country of India was continuing to access both his treatment and care in that country. At the time of interview, he had not yet had any contact with the health system in Australia, primarily because he was concerned about what it might mean for his visa status if his diagnosis was known.

Our data show data show high rates of retention in care, mirroring the picture reported in the cascade of care, but our data, also show that some of potential gaps in retention, including, people who are diagnosed outside of Australia and who are not accessing ART or monitoring and care in Australia.

VIRAL SUPPRESSION AND U=U

Most participants achieved an undetectable viral load within approximately three months of commencing treatment. Achieving viral suppression was both a clinical and emotional milestone. Knowledge of viral load among participants was very limited prior to their own HIV diagnosis. Achieving viral suppression carried multiple meanings: it provided concrete evidence that treatment was working, it marked a temporal before-and-after in participants' accounts of living with HIV, and it reconnected many people to a sense of physical and psychological normality that had been disrupted by diagnosis. Undetectability was generally understood as an ongoing state – one that required continued engagement with treatment. Even occasional viral 'blips', where a single result briefly exceeded the limit of detection, tended to reinforce rather than undermine this sense of stability, serving as confirmation that the viral load remained under control.

Participants frequently described embodied effects associated with reaching an undetectable viral load: feeling better, increased energy, improved confidence, and a lift in mental health. These were often articulated in contrast to the period between diagnosis and suppression, which several described in visceral terms – feeling 'sick', 'anxious', or 'contagious'. Santosh's account captures this vividly:

During the entire time from my diagnosis until the point I tested and [was] undetectable, I always felt like, 'Oh, I'm sick. Something's there inside me.' It was affecting my mental health. (Santosh, gay man, 24, India)

Reaching undetectability, then, was not only a *clinical* milestone but an *affective* one – a shift in how participants inhabited their bodies and understood themselves in relation to HIV. Several described the moment of receiving an undetectable result in terms that evoked a kind of release. The connection between viral load and sexuality was particularly significant, and was felt as well as understood intellectually:

So, when I tested undetectable, I felt so good because I'm like, okay, I had it in me, but it's not there anymore, and I cannot – there's no way – I can transmit this to anyone else, too. (Santosh, gay man, 24, India)

DURING THE ENTIRE TIME FROM MY DIAGNOSIS UNTIL THE POINT I TESTED AND [WAS] UNDETECTABLE, I ALWAYS FELT LIKE, 'OH, I'M SICK. SOMETHING'S THERE INSIDE ME.' IT WAS AFFECTING MY MENTAL HEALTH.

(Santosh, gay man, 24, India)



*[It] means that I'm back to normal and I don't put in risk other people. My partner is – we are – serodiscordant. So, he's negative and I am positive. So, in that sense, it's just like I feel more like, yeah, back to normal or something.
(Augustin, gay man, 28, Chile)*

These accounts illustrate how U=U – undetectable equals untransmittable – operates not only as a public health message but as something participants felt in and through their bodies, and specifically in relation to sex. Non-transmissibility is, in practice, contingent on the embodied routine of taking medication, and participants generally understood this: undetectability was experienced as something maintained through ongoing adherence, not simply conferred by a test result.

For participants who were late diagnoses, reaching viral suppression often took on additional weight, given the severity of illness that had preceded treatment. Most achieved suppression soon after commencing treatment, though there were exceptions. Amara, who had been diagnosed late and was still working toward an undetectable result at the time of her interview, described what reaching that threshold would mean to her:

How do you think you'll feel when you reach that undetectable viral load?

I'm going to buy myself a cake, a really pretty cake, red velvet and chocolate. [...] And I'm going to be happy.

[...] And tell me a bit about what will make you happy about that? What does that sort of signify,

*Because that's the closest to being normal I'll ever have again, and undetectable viral load. That's literally the best I can get.
(Amara, heterosexual woman, 35, Jamaica)*

Amara's account – 'the closest to being normal I'll ever have again' – captures something that appeared across several participants' accounts: undetectability as a form of recovery, but also as a ceiling, a new kind of normal that was defined partly by the permanence of diagnosis.

At the time of interview, almost all participants were engaged in HIV care. One participant was not in care, and two were not taking treatment. One had previously started treatment but had been off therapy for six months after being referred to a hospital pathology service for blood tests he did not attend, having been unsure where to go; he had not returned to his doctor since and also described difficulty taking medication consistently. The other participant not on treatment was an elite controller – someone able to maintain a suppressed viral load without ART.

The near-universal engagement with care in this sample is encouraging, but it also points to a potential gap in the broader population: people who have been diagnosed in another country but are not accessing treatment either there or in Australia. Reassuring migrants that HIV care is available in Australian public health services at no cost is important; harder to address is the concern – warranted in some circumstances – that engaging with HIV care in Australia may have implications for visa status. Finding ways to communicate clearly and accurately about what linking to care in Australia does and does not mean for immigration matters remains an unresolved challenge.

SEX AFTER HIV DIAGNOSIS

HIV diagnosis can reshape how people think about sex, intimacy and relationships. This chapter examines the ways participants navigated these changes after diagnosis.

DISCLOSURE

Of the participants who were in relationships at the time of diagnosis, most had positive experiences when they told their partner they had HIV. For example, Declan, who identified as bisexual, had only recently started seeing his girlfriend before going on a previously planned trip to Asia. He had been open with her that he planned to have sex with other people while travelling, but had not anticipated having to tell her shortly afterwards that he had acquired HIV. Despite the relationship being new, they had stayed together and by the time of interview had also moved in together.

Telling a partner was nonetheless often fraught, particularly where there was concern that the diagnosed person might have already transmitted HIV to them. This was less of an issue for some participants because they had not been sexually active with their partner in the relevant period. Helena's partner was very supportive when she disclosed but then ended the relationship abruptly after testing HIV negative himself. Callan, who was in a relationship with an HIV-positive person, did not face concerns about onward transmission. He was fairly open with casual partners about his status and found that most were comfortable relying either on their own PrEP use or his undetectable viral load as prevention.

UNDETECTABLE VIRAL LOAD

Most GBQ men in the study believed UVL was an effective means of preventing onward transmission and planned to rely on it. Trusting the science of UVL did not, however, always mean being open about HIV status with sexual partners. Some participants were comfortable not discussing their status precisely because they trusted their UVL to prevent transmission; others had noted their undetectable status on hook-up app profiles rather than disclosing directly in conversation.

Reactions from sexual partners when HIV status was disclosed were mixed. Ravi had listed his undetectable

status on his profile but was subsequently challenged by a partner who had not read it:

When I came to know my viral load is undetectable and transmittable, I had my first intimate, it was just like a blowjob [...]. It was clearly mentioned in my profile saying that I'm undetectable and untransmittable [...] He didn't look into it. And then after everything is done, he started texting me, asking me, Hey, I didn't know about your status. Now I'm checking out your profile. I came to know about your status, so can you share me your reports and everything, et cetera and et cetera. Then I ended up calling Melbourne Sexual Health Centre. There was a whole drama, went along for three to four days and after that it was a bit traumatic incident for me. (Ravi, gay man, 26, India)

PREP USE BY PARTNERS

Because most participants were relying on – or planning to rely on – their own UVL to prevent onward transmission, the PrEP use of their sexual partners rarely featured in their reflections on post-diagnosis sex. Where it did arise, it was typically as a supplementary option rather than a primary strategy. Tariro and her husband were using condoms post-diagnosis. When asked in the interview whether PrEP might be an option for her husband in future, she said:

I was preferring condoms, [because] he doesn't have to take any medications necessarily, but if he decides he wants to go for PrEP, that would be fine for me. But it's something that he has to decide on. (Tariro, heterosexual woman, 43, Zimbabwe)

Tariro was not averse to her husband using PrEP, but saw it as a decision that was his to initiate rather than hers to propose.

Elijah and his female partner had used condoms in the early months after his diagnosis. By the time of interview, they were relying on his UVL within the relationship. His partner was also considering starting PrEP for her own protection with other partners:

I just wondered if your partner and you ever talk about her going on to PrEP?

She has thought about it, but it's more of that if somebody else has HIV that's undiagnosed. (Elijah, bisexual man, 40, Australia)

A few GBQ men were not prepared to rely on a partner's PrEP use in the period prior to them reaching UVL. This was not because they didn't believe PrEP was effective, but rather because it did not ameliorate their sense of themselves as infectious. As Jett said:

So, I am highly aware that I am risky and I don't want... It's something that is hard for someone to experience. It's not something that is just simple. So I don't want any other person to, even though that they're saying they have PrEP or whatever[...], because [...] the way I see myself change because of [HIV], I'm not really worthy of sex at that time because I'm still having HIV. That make sense? (Jett, gay man, 29, Indonesia)

Jett's account points to a dimension of post-diagnosis sexual life that goes beyond the science of transmission. An unwillingness to rely on a partner's PrEP use can be associated with complex feelings about infectiousness and, in Jett's case, self-worth. Part of this reasoning seems to be related to taking personal responsibility for prevention through one's own UVL, rather than depending on a partner's prevention. This is not about trusting the science of undetectable viral load and its impact on sexual transmission but rather its symbolic effects – about reclaiming a sense of oneself as a non-infectious person, and about the moral dimensions of that process that the PrEP use of a partner alone cannot restore.

CONDOMS

GBQ men

Among Australian-born GBQ men, and men who had migrated to Australia more than a decade before diagnosis, condoms were rarely described as a prevention strategy for onward transmission after diagnosis – even in the period before they had reached undetectability (noting that most participants reached undetectable within three months of diagnosis). Some chose to avoid sex or deliberately sought partners who were using PrEP during this window. A small number used condoms post-diagnosis, though typically to manage STI risk rather than HIV transmission concerns.

Of the six men who identified as bisexual, all accepted that being undetectable meant they could not transmit the virus to a partner. Declan and his girlfriend continued to use condoms after he became undetectable, but for contraceptive reasons rather than HIV-related concerns. A few gay men said they used condoms when a partner wanted to, though usually in situations where they had not disclosed their HIV status.

Newly arrived migrants

GBQ men from Asia and Latin America mostly used, or planned to use, UVL once they reached undetectable. Dirk, a gay man from Papua New Guinea, had a more complicated relationship with UVL. Post-diagnosis, his priority was avoiding other STIs, which meant he wanted to use condoms – a shift from his pre-diagnosis practice, when condom use had been inconsistent. At the time of interview, he was working out how to negotiate this with partners.



I STILL USE CONDOMS. BEFORE, I DON'T USE THE CONDOMS, OR BEFORE I DON'T THINK ABOUT IT.

(Dirk, gay man, 42, Papua New Guinea)



Dirk was concerned that his post-diagnosis shift to using condoms might raise questions from men in his sexual network:

Although these are not random people, but these casual sex partners, they were quite surprised. Like you've changed, you..., [I] just said this is a new year and I've decided to change my approaches. So, for me, it's not only protecting me; it's also protecting them. And I just thought I didn't want to...

Dirk, wanted to protect himself from STIs but he also worried about how partners might react if he discussed his HIV status with them or suggested they consider getting an HIV:

I am juggling between what to do and I don't think I am confident about myself and my own situation before I wanted to help them. I mean, [what if] I said to go and get a test, what if they are positive and then what they come back and attack me and what they can blame me. So, I'm just trying to work out and so I'm playing different scenarios. (Dirk, gay man, 42, Papua New Guinea)

There is an irony in Dirk's situation: his UVL protects his partners from HIV, but his decision to use condoms – motivated by a desire to protect himself from other STIs – risks revealing his HIV status in a context where he does not yet feel safe to do so.



Women

As discussed in the chapter on HIV testing and prevention, condom use had been uncommon for most women prior to diagnosis, typically because they had been in relationships they understood to be monogamous. At the time of interview, one woman reported using condoms with her husband as her preferred approach to prevention, and did not anticipate this changing unless he chose to start PrEP.

Rhonda was familiar with U=U and said it was something she would be willing to rely on in future, but only within a committed relationship. She had arrived at this position through discussion with her HIV doctor:

She's like a social worker and a doctor all in one and said, how do I navigate that[sex/relationships]? And she said, well, when you start off a relationship and then you get to the stage where you want to sleep with somebody, you use a condom. It's just as simple as that because you don't know if he's got anything. He doesn't know if you've got anything. Then when it progresses and if you're getting serious and you're going to walk down the aisle, she said, you need to have that conversation before you say your I dos. (Rhonda, heterosexual woman, 61, Australia)

For Rhonda, the science of UVL is not in question. Rather, its appropriate use is situated within the context of a committed relationship – a framework shaped as much by trust and relational progression as by the prevention evidence itself.

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IT'S JUST AS SIMPLE AS THAT BECAUSE YOU DON'T KNOW IF HE'S GOT ANYTHING. HE DOESN'T KNOW IF YOU'VE GOT ANYTHING.

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PEER SUPPORT

Participants and physicians reflected on the role of peer support following diagnosis. Their accounts highlight the practical, emotional and social contributions of peer-based services.

Peer support is accessible through PLHIV organisations and LGBTIQ community organisations, and includes peer navigators – trained individuals with lived experience of HIV who provide non-clinical support to people with HIV, including helping them navigate health and social service systems.

PEOPLE LIVING WITH HIV

Linkage to HIV clinical care typically also meant that participants, particularly newly arrived migrants, gained access to a broader range of support: peer navigators, PLHIV organisations, social workers, and psychologists. Most participants were aware of these services, but the level of engagement varied considerably.

Some Australian-born GBQ men did not engage with formal peer support, either because they felt their existing networks already provided sufficient support, or because they felt their needs in relation to HIV were adequately met through treatment and clinical care. Huck, for example, prioritised getting into a routine and getting on with life:

I was made aware of those kind of things. [...] I kind of took the approach of just not overthinking it too much and not stewing [...] and just a very kind of getting on with life kind of approach whether that's healthy or not, I don't know. [...] It seems to have worked for me so far. [...] I think the swiftness with just being referred to the right people and getting on treatment as quickly as possible and just getting into a routine for me was the best thing to do. (Huck, gay man, 39, New Zealand)

Others engaged with peer support for a specific purpose and for a limited time. Jaco's diagnosis coincided with a period of insecure housing and a large number of outstanding fines that he lacked the means to pay. He received practical assistance from a PLHIV organisation, which he greatly valued, but did not feel the need to continue engaging after those issues were resolved:

They helped me with being in a good position, obviously wellbeing in a good position in terms of feeling comfortable. If I need to have any issues with HIV, I can talk to anyone in there. They're all good. They were brilliant. (Jaco, gay man, 44, Australia)

Jaco had resolved his housing and other financial issues by the time of his interview but was considering donating to the organisation as a way of showing his appreciation.

Several participants described working with a peer navigator in the early months after diagnosis as being helpful. For Elijah, reaching out for peer support had required overcoming a habitual reluctance to ask for help:

[I] reached out to [name of PLHIV organisation] through the peer support. That was another avenue that I grasped onto as well, which I felt in previous times when I have looked for peer support, it's been difficult to feel like I deserve to have that peer support type of thing. I'm very much a people pleaser and don't like to be the person asking for help. [...] So that was part of that journey. And it was both the professional and both the peer support were avenues that were very, very good. Very good. (Elijah, bisexual man, 40, Australia)

Later in his interview, Elijah described the peer navigation relationship as drawing to a natural close:

Yeah, I've had a couple of conversations with [name of peer navigator] [...] but I think that's also coming towards that end of that journey as well.

Because?

Because it is more for people who are in crisis and I think I am very well adjusted to the life that I am going to live now. (Elijah, bisexual man, 40, Australia)

Peer support was often especially important for newly arrived migrants, particularly those whose HIV diagnosis was accompanied by a range of other health and social complexities. Ntando, a 39-year-old woman from Southern Africa, collapsed and was hospitalised only a few weeks after arriving in Australia. She was diagnosed with HIV in hospital; when the friends she had been staying with learned of her diagnosis, they asked her to leave. Through a social worker at the sexual health clinic managing her HIV care, Ntando was connected to several PLHIV organisations and a peer navigator, who collectively worked to support her – helping to find emergency accommodation and negotiating with the hospital to have her bill reduced or written off.

Peer navigators played an important role for newly arrived migrants in helping them understand and navigate Australia's health system, offering the perspective of someone with firsthand experience of living with HIV, and providing social connection

to other HIV-positive people. Dirk, a gay man from Papua New Guinea who had been living in Australia for several years, had not engaged with the local gay community during that time. His peer navigator became an important resource, helping him link to HIV care and offering ongoing social connection:

I had one-to-one engagement with one person, and we share a lot of personal stories around our sexualities and our challenges and the journey so far [...] Where resources are, I guess he seems to know more about this and I'm relying on him for providing me leads. And sometimes when I am occasionally just want to have a chat message and I talk about things and then we catch up for coffee. (Dirk, gay man, 42, Papua New Guinea)

Dirk valued the fact that his peer navigator was not only HIV positive but also gay and a migrant – making him a peer in multiple respects. This kind of matched experience was significant for a number of participants. Newly arrived GBQ men from Asian countries, in particular, described difficulty making social and sexual connections with Australian-born gay men and local gay scenes; peer navigators and PLHIV organisations helped some of these men build local connections and engage more fully in social life post-diagnosis.

PHYSICIANS

Physicians described routinely providing information about peer support – including peer navigators and newly diagnosed groups – to newly diagnosed patients. One physician working in a public sexual health service explained how closely peer navigators were integrated into their clinic:

I tell all my new diagnoses about it. I tell the ones that maybe I've never met before that I'm maybe seeing who may see another consultant and it's the first time I see them just to ensure that they know about it. They [peer navigators] are present in clinic every week, which is really helpful because I've already gotten a relationship with one of the peer navigators from another district with other patients. I found it incredibly helpful. Some of my patients are fairly marginalised and it's been really helpful to have the peer navigators even just to have that kind of conversation. [...] Go and sit and have a chat and catch up about patients and just to find out how they're doing and you get little snippets of information that may help. (13-SH-HP NSW)

A sexual health physician in South Australia gave a specific example of how a peer navigator had enabled better care for a patient in circumstances where clinical communication was constrained:

They come into clinic with patients and often provide information that we may not have got from the patient. There was one man who, it is really tricky [...] he doesn't speak any English. He was married then he separated from his wife. He's working as a fruit picker, but he would come in with an interpreter, and I was always really kind of so worried about asking about STIs [and] sexuality because I didn't want to embarrass him or cause him any compromise with the interpreter in the room. Anyway, the peer navigator, because he'd been using Google translate with him, determined he was sometimes having sex with men, which was brilliant because I hadn't been able to ask that. (O2-SH-HP SA)

A physician in a regional setting identified peer navigation as a significant gap in what they were able to offer locally:

We would love to have a peer navigator. We have patients that would really like to set up a peer navigation service. So, we have to refer, I mean we're only an hour and a bit from Sydney, but we have to refer people up to Sydney and we use ACON services. But it would be really great to have a peer navigator in the service. It would really be such a benefit for those patients that are newly diagnosed. We have a halftime social worker, so we do have a social worker [...]. (10-SH-NSW)

This physician noted that while a social worker provides important support, what is distinct about peer navigation is access to someone with firsthand experience of an HIV diagnosis. She felt there were patients in her practice who would make good peer navigators, but that without funding for such a position, this remained out of reach:

It would be really great to have a local peer navigator, and we just hook everyone up with a person that they can actually just talk to about what that experience is like. (10-SH-NSW)

These accounts point to peer support as a flexible but unevenly available resource following HIV diagnosis. Its value is not uniform: some people engage intensively in the early months and move on; others draw on it briefly for a specific purpose; and some do not engage at all. But for those who are more isolated – newly arrived migrants navigating an unfamiliar health system, or people facing complex social and material challenges alongside their diagnosis – peer support can be the difference between a managed transition into care and a more precarious one. Physicians' accounts reinforce this view: peer navigators contribute something that clinical care alone cannot provide, and the gap between services where peer navigation is embedded and those where it is not represents a genuine inequality in the care available to newly diagnosed people across Australia.

REASONS FOR PARTICIPATION

Participants' reflections on taking part in the study provide insights into how newly diagnosed people understand their contribution to research and helping others after diagnosis.

During the process of setting up recruitment and promotion of the Newly Positive study, community workers, peer navigators, and healthcare providers often asked whether newly diagnosed people might find it emotionally difficult to take part in a study focused on their experiences of HIV acquisition and diagnosis so soon after diagnosis – at a time when they might still be processing what had happened and adjusting to taking medication. We acknowledged that participation would not be right for everyone, but noted that earlier Australian seroconversion studies had successfully recruited newly diagnosed people willing to be interviewed shortly after diagnosis. Those participants had typically been motivated by a desire to reflect on their experiences in the confidential space of an interview.

In this study, we did not specifically ask participants why they had chosen to take part, but many offered their reasons unprompted during the interview. What is striking about these accounts, taken together, is how consistently they are oriented outward rather than inward. Almost without exception, participants framed their participation not as something they were doing for their own benefit – to process, to make sense of, to work through – but as something they were doing for someone or something else: another person, a service, a future. The most common reason given was a wish that their experience might, in some way, help somebody else:

For some newly arrived migrants, participation was explicitly framed as a form of reciprocity – a way of giving back to the services that had supported them, or to Australia more broadly for providing access to treatment. Rodrigo described his motivation in terms of gratitude toward the clinical staff who had cared for him:

Melbourne Sexual Health Centre nurses are there. They're amazing. It's like I can't thank them enough. That's why I wanted to do this, because I want to thank them and they need to educate all these people in the community on how to speak to patients, how to be nonjudgmental and how to be empathetic. They just make you feel comfortable. (Rodrigo, gay man, 41, Philippines)

For others, participation was about contributing to a collective account of HIV acquisition and diagnosis – adding their experience to a shared record rather than keeping it private:

I mean, from a personal point of view, I guess I feel like I can kind of contribute to, I don't know the broader story by participating in things like this. I'm actually pretty happy to, and I don't feel a responsibility to, but I think it's something that I can do. (Huck, gay man, 39, New Zealand)

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THE WHOLE OBJECTIVE OF ME GIVING YOU ANY INFORMATION IS HOPEFULLY TO HELP SOMEBODY ELSE.

(Lawson, heterosexual, 53, Australian)

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And for others again, participation was a way of connecting to research more broadly – specifically to future research that might advance treatment or contribute to a cure:

What I was waiting – or maybe aiming – to discuss was about the cure [...]. So, using this research for future researchers and availability for cure, I did tick in on the box that I would like really to receive some information and updates about what's going on and if there is any other maybe research project I can be able to help with. So, I put my hand up for it. (Leo, gay man, 49, Lebanon)

Helping somebody else, repaying a service, contributing to a collective story, linking into a future cure: these are all relational and future-oriented framings. None positions the interview as a space for the participant's own immediate processing of the diagnosis. This is not to say that participants experienced no benefit, or that reflecting on their experiences in a confidential setting cannot be valuable; several participants likely experienced both at once. It is to say that when participants accounted for their own participation in their own words, they did not reach first for a therapeutic frame. They reached for an ethical and/or collective one – organised around reciprocity, gratitude, and contribution to others, rather than around their own emotional needs in the aftermath of diagnosis.

This matters beyond the immediate question of recruitment ethics. The protective instinct that prompted community workers and clinicians to ask whether newly diagnosed people could safely be approached for research is not unfounded, and researchers working in this space have a genuine duty of care. But that instinct also risks installing a particular, and partial, idea of what a newly diagnosed person is – someone defined chiefly by vulnerability, whose relationship to disclosure must be managed and protected, rather than someone who might also be reaching, quite deliberately, for ways to be useful, to repay, or to make a difference for others in the wake of a significant life event.

Our participants' own accounts suggest that the figure of the newly diagnosed person as primarily fragile and in need of shielding sits uneasily alongside the figure who appears repeatedly in this data: someone already oriented outward, already thinking about who else their experience might serve. Taking the latter seriously means recognising that a desire to contribute, to reciprocate, or to be of use can itself be a legitimate and considered basis on which someone navigates a recent diagnosis – not evidence that the gatekeeping question was misguided, but evidence that it may have been asking only half of the right question.

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MELBOURNE SEXUAL HEALTH CENTRE NURSES ARE THERE. THEY'RE AMAZING. IT'S LIKE I CAN'T THANK THEM ENOUGH. THAT'S WHY I WANTED TO DO THIS, BECAUSE I WANT TO THANK THEM AND THEY NEED TO EDUCATE ALL THESE PEOPLE IN THE COMMUNITY ON HOW TO SPEAK TO PATIENTS, HOW TO BE NONJUDGMENTAL AND HOW TO BE EMPATHETIC. THEY JUST MAKE YOU FEEL COMFORTABLE.

(Rodrigo, gay man, 41, Philippines)

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DISCUSSION

This report presents findings from interviews with people newly diagnosed with HIV and the physicians providing their care, conducted as part of the *Newly Positive* study. The study sample reflects the current epidemiology of HIV in Australia: in terms of the proportions born outside Australia and the breakdown by gender and sexual identity, it tracks current HIV notification trends closely. One notable difference from surveillance data is the proportion of participants who acquired HIV after arriving in Australia, which is higher in this sample than in national figures. This distinction is notable: infections that occur after arrival are, in principle, preventable, and the accounts of newly arrived participants offer particular insight into the circumstances, knowledge gaps, and system failures that allowed those infections to occur.

Australia is one of only a few countries in the world to have used qualitative methods systematically to investigate the social dimensions of HIV seroconversion, and the only country to have done so continuously over more than three decades (Ellard, 2024; Murphy et al., 2023). The *Newly Positive* study continues that tradition, with participants' accounts illuminating both their pre-diagnosis lives and the pathways they navigated following diagnosis.

HIV ACQUISITION AND PREVENTION LOGICS

Participants were, in most cases, able to identify an event or events they believed had led to their HIV infection. What varied considerably, however, was the extent to which they had recognised themselves as potentially at risk beforehand. This variation was strongly shaped by gender, sexuality, and the social and cultural contexts in which sex occurred.

For women and heterosexual men, HIV was largely absent from their sense of personal risk – its possibility foreclosed by their sexuality, by monogamous partnerships, or by a general sense that HIV was something that happened to other kinds of people. Prevention strategies, including testing, were rarely part of their sexual lives, and diagnosis was more likely to arrive late and with less preparation.

Addressing HIV risk among women and heterosexual men in Australia remains a genuine challenge: the pathways through which risk might be recognised and acted on are much less developed for these groups than for GBQ men, and no clear model yet exists for how to reach them effectively.

For GBQ men, HIV was part of their imaginaries – something known to be possible and requiring management. But awareness did not straightforwardly translate into consistent prevention practice. PrEP shaped prevention thinking across this group, including for men who were not themselves taking it. Approximately 40% of the GBQ men had current or past PrEP experience, but for many others PrEP still shaped how they understood risk. Some operated with an implicit assumption that their partners were on PrEP, conceptualising Australian gay sexual culture as a 'PrEP culture' in which protection was distributed collectively across a network rather than individually ensured. This logic becomes a significant vulnerability when partners' PrEP use is assumed rather than negotiated. Among men who had discontinued PrEP, the dynamic was particularly pronounced: some appeared to retain an implicit sense of protection from PrEP even when they were no longer taking it.

PrEP discontinuation emerged as more prevalent and structurally complex than is often recognised. Our data suggest it is common across GBQ men broadly, not just among specific subgroups. Critically, most discontinuations were not deliberate, risk-based decisions: they tended to happen through disruptions to health routines – changing GPs, travelling for work, the Covid-19 pandemic, or drifting out of the testing and prescribing cycle PrEP requires. Because PrEP is embedded in a regular testing regimen, stopping PrEP tends to mean stopping routine HIV and STI testing as well, removing a key mechanism for early diagnosis.

A distinct group were older Australian-born GBQ men whose HIV-related worldview was shaped by the earlier decades of the epidemic – by loss, grief, fear, and activism – but who had become socially disconnected from contemporary gay community life and from current prevention strategies. Some were not using any form of prevention, or had drifted away from PrEP without a clear decision to stop. Reconnecting these men to HIV prevention requires approaches that acknowledge their histories.

Among overseas-born GBQ men, navigating an unfamiliar sexual culture was challenging, particularly for those from countries where condoms remained the dominant prevention norm. PrEP knowledge was variable and often low: among men from Southeast Asia, awareness was particularly limited, and even those who knew about PrEP frequently did not know how to access it or assumed it would be unaffordable. GBQ men from Latin America were generally better informed but often made similar cost assumptions. Critically, for those in this study who acquired HIV

after arriving in Australia, infection usually occurred within two years of arrival – before most had had time to build connections to the local gay community and the prevention knowledge that circulates within it.

The contexts of HIV acquisition also included specific social settings that shaped risk in ways not always consciously registered. Chemsex featured in some accounts, particularly in relation to PrEP inconsistency and on-demand dosing failures. Travel created contexts in which some men explored sexual practices outside their usual networks and without the prevention resources available to them at home. These contextual factors are part of how HIV acquisition happens in contemporary Australia, and responding to them requires more than individual-level education.

HIV TESTING AND DIAGNOSIS

All GBQ men in the study had some prior history of HIV testing, with most reporting testing at least annually, though frequency had been disrupted for some by the Covid-19 pandemic, PrEP discontinuation, loss of a regular GP, or changes in work patterns. Because PrEP prescribing requires regular testing, interruptions to PrEP access typically mean interruptions to testing as well.

There were meaningful differences in testing histories among bisexual men, which appeared to reflect the social and sexual milieus they inhabited. Those with some connection to gay and queer community had testing patterns broadly similar to gay men; those who had lived predominantly heterosexual social lives had no testing history prior to diagnosis, more closely resembling heterosexual men.

Heterosexual men in the study rarely had any prior HIV or STI testing history, and how routine HIV testing might be offered to this group in ways that improve timeliness of diagnosis remains an unresolved challenge. Most women had some testing experience, most commonly in the context of pregnancy care, but several reported STI tests that did not routinely include HIV. Integrating HIV testing into STI screening in general practice as a routine inclusion, rather than an optional add-on, could improve timeliness of diagnosis for both groups and create regular opportunities for GPs to discuss sexual risk and prevention options.

Around 17% of participants would be classified as late diagnoses – a smaller proportion than in current national surveillance data. This group included the majority of the women and approximately half of

the heterosexual men, as well as a smaller number of GBQ men, both Australian-born and overseas-born. Late diagnosis among GBQ men was associated with disconnection from gay community, from routine prevention practices, and from the testing patterns that community engagement tends to sustain.

Seroconversion illness was experienced by some participants before diagnosis, but rarely prompted HIV testing – either because symptoms were not connected to HIV or were attributed to something else. This is not only a community knowledge gap: the data include two cases in which men presented to emergency departments with seroconversion-consistent symptoms and were not tested for HIV, including one where HIV had been explicitly raised as a possibility by the patient. This points to missed diagnostic opportunities in clinical settings. The recent relaunch of the ASHM resource, *Could it be HIV?* (ASHM, 2026) is a positive step toward improved recognition of seroconversion symptoms among clinicians.

Newly arrived GBQ men faced specific difficulties accessing HIV testing – not always knowing which services to use and relying on internet searches and diaspora networks rather than connections to local gay community. This disconnection may itself be a risk factor: partners who are also marginal to the gay scene are less likely to be using PrEP or be embedded in the testing and prevention networks through which HIV knowledge circulates.

LINKAGE TO AND RETENTION IN HIV CARE

Following diagnosis, participants navigated a range of pathways into HIV clinical care. The type and location of the diagnosing clinician was one of the most consequential factors. Participants diagnosed through sexual health clinics or by GPs with HIV expertise were generally linked to specialist services quickly and with clear guidance. Those diagnosed in other settings – including emergency departments, general practice without HIV expertise, or overseas – sometimes experienced delays or gaps in the pathway to ongoing care.

Medicare coverage – or its absence – was a significant structural factor. Participants without Medicare faced uncertainty about costs, difficulty accessing subsidised medications, and in some cases reluctance to engage with services. The Commonwealth scheme to provide HIV treatment for people not covered by Medicare represents an important policy development, and this study

has provided an opportunity to evaluate its early implementation from the perspectives of both newly diagnosed people and their physicians.

Retention in care, once established, could also be fragile, vulnerable to disruption by changes in living situation, employment instability, interstate or international mobility, and uncertainty about visa status and healthcare entitlement. Patients who are geographically mobile – moving between cities or between Australia and other countries – present a particular continuity-of-care challenge that current clinical models are not always well designed to accommodate.

TREATMENT, VIRAL SUPPRESSION, AND LIFE AFTER DIAGNOSIS

Antiretroviral therapy and U=U were well understood by participants, and their significance for post-diagnosis life was substantial. Knowledge of U=U had greatly reduced anxieties around sex for many newly diagnosed people, reducing the felt imperative to always disclose their HIV status and opening up the possibility of sex without ongoing fear of transmission. This is consistent with the broader literature on the transformative impact of U=U on the lived experience of HIV.

An important finding, however, concerns participants' attitudes toward HIV-positive sexual partners prior to their own diagnosis. Avoidance of sex with HIV-positive partners was widespread among GBQ men in the study, even among those taking PrEP. Knowledge of U=U prior to diagnosis was often low, and only a small number said they had been willing to rely on a partner's viral suppression for prevention. This study's design – with interviews conducted close to the time of diagnosis, sometimes within weeks – provides a distinctive window onto these pre-diagnosis attitudes. The avoidance of HIV-positive sexual partners reflects more than a knowledge deficit: it is shaped by sexual stigma and by something closer to a moral framing of HIV-positive status in a potential partner. Addressing it will require engagement with the emotional and relational dimensions of stigma as it operates within gay sexual cultures, not only information about the science of viral suppression.

While social stigma was a significant concern for most participants, many also reported positive, affirming experiences of disclosing their diagnosis to friends, family, and sexual partners. Disclosure was generally selective, but where it occurred, it was

AVOIDANCE OF SEX WITH HIV-POSITIVE PARTNERS WAS WIDESPREAD AMONG GBQ MEN IN THE STUDY

often experienced as an occasion for connection and support rather than rejection. This more varied picture of the social experience of diagnosis is worth holding alongside the evidence on stigma.

For people without Medicare coverage, access to ART presented specific challenges during the study period. The Commonwealth scheme to fund treatment for Medicare-ineligible PLHIV is a significant equity measure; participants' and physicians' accounts suggest it supports timely treatment initiation and reduces patient anxiety about the cost of care.



CONCLUDING REMARKS

The *Newly Positive* study makes several contributions to the evidence base on HIV seroconversion and diagnosis in Australia. It extends a research tradition of more than thirty years, providing a contemporary reference point and tracking shifts in the epidemic's social dimensions over time. It offers detailed insights into groups – newly arrived GBQ men, women, heterosexual men, older Australian-born GBQ men – whose experiences are less visible in quantitative epidemiological and behavioural research. Its design, with interviews conducted close to the moment of diagnosis, provides a perspective on pre-diagnosis attitudes and prevention logics not accessible through research conducted at longer intervals.

Across all sections of the cascade, the study consistently finds that individual knowledge and motivation, while important, are insufficient as explanatory frameworks. The contexts in which people live, the social and sexual cultures they inhabit, the structural conditions they navigate, and the historical and cultural meanings they bring to HIV all shape what happens at each step.

Australia has achieved substantial reductions in HIV transmission and is committed to eliminating transmission by 2030. Sustaining and extending that progress – particularly in the populations where the epidemic is now most concentrated – will require a

differentiated, contextually responsive prevention and care system: one that reaches newly arrived GBQ men early, supports GPs in integrating HIV testing into routine sexual health care, engages with the complex prevention logics through which many GBQ men understand and manage risk, addresses stigma as a relational and moral phenomenon rather than only a knowledge deficit, and ensures that structural barriers – particularly around Medicare coverage and care continuity for mobile populations – do not determine who can access effective prevention, diagnosis, and treatment.

Australia is one of only a few countries to have used qualitative methods to understand HIV seroconversion across the entire history of the epidemic, and Australian seroconversion research has gained international recognition for its design and approach. The *Newly Positive* study team has collaborated with researchers in New Zealand on *Newly Positive Aotearoa New Zealand*, which commenced in 2026, and is working with researchers in Canada who are developing a seroconversion study there. The accounts of participants in this study – of how they understood risk, how they were diagnosed, how they found their way into care, and how they are living with HIV now – are the evidence base from which a response worthy of this moment can be built.



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