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# RISE

RECENT DIAGNOSIS & THE IMPACT OF  
SUPPORT ON THE EXPERIENCES OF HIV

Experiences after HIV  
diagnosis



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Report on findings from a qualitative cohort study of people recently diagnosed with HIV

Dean Murphy  
Steven Philpot  
Brent Clifton  
Graham Brown  
Jeanne Ellard  
John Rule  
Chris Howard  
Garrett Prestage  
on behalf of the RISE study team.

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## **Chief Investigators**

Garrett Prestage<sup>1</sup>, Graham Brown<sup>2</sup>, Jeff Jin<sup>1</sup>, John Kaldor<sup>1</sup>, Rebecca Guy<sup>1</sup>, Andrew Grulich<sup>1</sup>, Limin Mao<sup>3</sup>, Basil Donovan<sup>1</sup>, Christopher Fairley<sup>4</sup>

## **Project Staff**

Brent Clifton<sup>1</sup>, Dean Murphy<sup>1</sup>, Steve Philpot<sup>1</sup>, Petrina Hilton<sup>2</sup>, Mohamed Hammoud<sup>1</sup>

## **Project Advisory Committee**

Garrett Prestage<sup>1</sup>, Graham Brown<sup>2</sup>, Dean Murphy<sup>1</sup>, Jeanne Ellard<sup>5</sup>, John Rule<sup>6</sup>, Suzy Malhotra<sup>7</sup>, Chris Howard<sup>8</sup>, Lisa Bastian<sup>9</sup>, Steve Philpot<sup>1</sup>, Brent Clifton<sup>1</sup>

<sup>1</sup>The Kirby Institute, University of NSW, Sydney, Australia, <sup>2</sup>Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia, <sup>3</sup>Centre for Social Research in Health, <sup>4</sup>Melbourne Sexual Health Centre, <sup>5</sup>Australian Federation of AIDS Organisations, <sup>6</sup>National Association of People Living with HIV Australia, <sup>7</sup>Living Positive Victoria, <sup>8</sup>Queensland Positive People, <sup>9</sup>Department of Health, Western Australia.

## **Further information**

For more information, please contact Associate Professor Garrett Prestage, The Kirby Institute, Wallace Wurth Building, UNSW Australia, Sydney, NSW 2052, AUSTRALIA Email: [gprestage@kirby.unsw.edu.au](mailto:gprestage@kirby.unsw.edu.au) | Telephone: 02 9385 0900

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## Executive Summary

This is a report on the findings from the RISE Study from the first two rounds of qualitative data collection (to the period ending 30 May 2021). In total, 28 people have taken part in in-depth interviews, and over three quarters have already completed a follow-up interview. The report also includes findings from another component of the RISE study that comprises in-depth interviews with community-based HIV service providers.

Participants reported a range of different reactions to diagnosis. Many participants described their reaction in terms of shock and disbelief, indicating that diagnosis with HIV remains a significant event in individuals' lives.

Whereas participants had few concerns regarding the direct impact of HIV on their health, they reported a range of other concerns at the time of diagnosis, including worries about career-related restrictions, restrictions on living/working in other countries, and possibilities for becoming a parent.

Many participants did not know a great deal about HIV at the time they were diagnosed, however almost all knew that early or immediate treatment was generally the norm.

Overall rates of linkage to, and retention in HIV clinical care are high among study participants. Treatment coverage was also high with most people starting HIV treatment within the first few weeks or months of diagnosis.

Although achieving an undetectable viral load (UVL) was also an important component of participants' accounts of treatment (including ensuring that there was no risk of transmission to sexual partners, many participants – including gay men – had only limited knowledge about UVL prior to their diagnosis.

Participants' experiences of peer support were largely positive. Online peer support was valued by almost all the study participants because it offered information and support through a medium that could be consumed at a time of convenience and that allowed for multiple levels of participation (active participation, or a more passive form of generalised support and information).

Informants from community-based HIV organisations felt that online peer support done by groups like TIM complemented the more structured forms of peer support such as workshops and peer navigation that aim to enhance ongoing connection to the broader community of people living with HIV.

The COVID-19 pandemic has reshaped the way all services are offered across Australia. HIV, medical, and support services have had dramatic changes to the ways they work and the types of support they offer to their respective communities. In response to the pandemic, the RISE study was reoriented to capture the impact upon PLHIV and community organisations. Qualitative interviews describe these impacts.

Most participants stated that the pandemic had not had an impact on their HIV care, except some reported having telehealth appointments, with mixed beliefs about their benefits. Isolation and mental health concerns were often cited as negative impacts of social distancing and lock-down restrictions, but this was not necessarily related to living with HIV.

Within the community sector, the pandemic necessitated a move to online and phone-based peer support as little face-to-face work could occur. This change has had both positive and negative impacts. Online peer support offered access for a greater number of people. However, traditional modes of support, such as workshops, did not easily translate to an online space. Evaluation of types of online peer supports will help community organisations offer the most useful content and delivery for their communities.

Impacts have also been felt throughout the community workforce, although this impact varied across jurisdictions. Lockdown restrictions and social distancing was felt more deeply and for a longer period in Victoria and New South Wales, whereas Queensland and Western Australia experienced fewer workforce impacts.

## Study description

The RISE study (which refers to ‘Recent Diagnosis and the Impact of Support on Experiences of HIV’) explores people’s experiences of being diagnosed with HIV and the changes in their lives following diagnosis. Specifically, it investigates: experiences of receiving a clinical diagnosis; access to – and use of – HIV clinical and peer-support services; and overall well being. In addition, the study examines risk factors associated with HIV infection in the contemporary era.

RISE is a national project funded through a NHMRC Partnership grant.

The RISE study has ethics approval from the Human Research Ethics Committee of UNSW Sydney and commenced recruitment in December 2018.

## Eligibility

Eligibility criteria for the study include: being over 16 years of age; having been diagnosed as HIV positive since 2016; and living in Australia.

## Recruitment

Enrolments occur through three main sources:

- referrals from HIV community organisations and partners
- referrals from clinics (sexual health clinics and general practice)
- online enrolment, including paid promotion and shared or curated content

## In-depth interviews

### Methods

The qualitative arm of the RISE Study is comprised of semi-structured in-depth interviews. Interviews explore participants' experiences of diagnosis, HIV treatment and monitoring, HIV infection, previous HIV testing, sex, relationships, disclosure, and peer support. Follow-up interviews explored the impacts of COVID-19 on participants' lives and any changes (including access to HIV clinical care and support) since their last interview. Interviews have generally been between 90 to 120 minutes in length. They have been audio-recorded and then transcribed verbatim and de-identified, with each participant selecting a study pseudonym. First-round interviews were conducted with 28 participants, and 17 of these participants have now also completed follow-up interviews. The demographics of the interview participants are described in the table below, and these demographics are based on the first interview with participants.

### Participants

Demographic	Number ( <i>n</i> =28)
<i>State/territory</i>	
VIC	9
NSW	8
QLD	7
ACT	1
TAS	2
WA	1
<i>Age</i>	
18–25 years	1
26–30 years	12
31–35 years	5
36–40 years	2
41–45 years	3
46–50 years	3
51–55 years	1
56+ years	1
Mean	35.25 years
Median	32 years
<i>Diagnosis Year</i>	
2016	7
2017	8
2018	5
2019	6
2020	2
<i>Place of Birth</i>	
Australia	18
NZ	1
UK	2
W. Europe	1
E. Asia	2
S.E. Asia	1
Southern Africa	1
South America	2

## Experiences prior to HIV diagnosis

### Mobility

The issue of mobility within Australia prior to HIV diagnosis was identified in the accounts of several gay men in the study. For these men, relocating between jurisdictions was associated with discontinuity in their sexual-health care in the period prior to acquiring HIV. For several men, this disconnection from sexual-health care also meant losing access to PrEP. For example, Hamish (male, gay, 35 years) provided the following account of stopping PrEP after moving cities:

*I had been on PrEP previously, and that was quite effective, which is why I sort of kick myself.*

Why did you stop? Had you run out?

*I'd run out and I'd moved to [current city] and so I sort of hadn't established ... I was in a really odd sort of space in my own head, in life, and it was just like I couldn't be bothered with a lot of things. And unfortunately, that was one of them.*

Reflecting their lack of connection to services, these men also had specific reasons for seeking the HIV test that was associated with their diagnosis – for example a suspected seroconversion illness or treatment for a symptomatic sexually transmissible infection – rather than it being part of routine testing. The fact that men who had previously been well connected to HIV prevention and sexual-health services became disconnected from these services after moving to a new jurisdiction suggests a need for both a more formalised process for interstate referral of patients and provision of information about local sexual-health services by community organisations for new arrivals.

In addition, other mobility-related issues are also still relevant (1-6). For example, several of the gay and bisexual men interviewed believed that they acquired HIV while travelling, or living temporarily, in other countries.

## Experiences of Pre-Exposure Prophylaxis (PrEP)

A significant proportion of gay male participants had some experience of either taking, or seeking out, PrEP, prior to their HIV diagnosis. Only one participant in the interview arm of the study was still taking PrEP (following an on-demand strategy) at the time he was diagnosed with HIV; however, several other gay men had discontinued PrEP prior to acquiring HIV. Only one had stopped taking PrEP in consultation with his doctor:

*I was on PrEP for a little bit, but it wasn't really agreeing with my kidneys, so I had to stop it. [...] I was getting really bad pain and urinating was really starting to hurt. So, they just assumed ... There wasn't really any test done though, which is kind of, looking back on it, a bit weird. I just described how I was feeling, and they just suggested for me to come off. (Falco, male, gay, 28 years)*

However, despite having clinical support, there were no tests performed to investigate the symptoms Falco described. Another participant also stopped because he experienced side effects (*I felt there was some side effect making me uncomfortable* [Bernard, male, gay, 28 years]). Another had run out of PrEP while travelling overseas. Although this situation occurred only shortly before he returned to Australia, he did not actually renew his supply of the drug upon his return (and in fact did not ever resume PrEP). A small number of other participants had also been on PrEP implementation studies but stopped PrEP after moving interstate because they believed they could no longer participate in these studies and did not seek out other ways of accessing PrEP.

Two men were actively seeking PrEP at the time they were diagnosed, and the test associated with their diagnosis was part of the screening process for PrEP. Another had discussed PrEP with his GP (in a regional city), but the GP had been unwilling to prescribe it because it was not 'evidence-based', so he did not pursue it further and was not provided with information about how to access it elsewhere. Several other participants

had either considered PrEP, or discussed it with their health-care provider, but it had not been actively followed-up beyond this point. One participant reported that his GP (at a suburban practice) was 'dismissive', so the issue was not pursued.

*He was actually quite dismissive about it [so] I just kind of walked away and went, 'Okay, it's too much hassle.' And probably at that point I should have asked for an HIV test at the same time but didn't. (Dexter, male, gay, 50 years)*

Another participant was living in SE Asia and did not believe he could access PrEP there. And another had considered PrEP but did not believe he was at high risk to warrant it. (However, given that his sexual practices tended to vary when he and his partner were travelling, he would have been a potential candidate for intermittent or seasonal PrEP).

### Previous experiences of HIV testing

Some participants described negative experiences in their interactions with clinical services prior to the HIV test associated with their HIV diagnosis. In some cases, the negative attitudes and/or assumptions they experienced had a direct impact on either their HIV testing practices or their efforts to access PrEP. One gay male participant described how his regular GP had lectured him about his sexual behaviours when he tested in the past.

*She would give me a bit of a lecture every time I went there about, you know, 'I know what you gay men are like,' and all this sort of stuff. And I thought ... it was a bit uncomfortable... I just got jack of the lectures that I would get every time I went in there. (Tobias, 47 years)*

As a result, Tobias felt disinclined to be tested until he ultimately discovered a community-based sexual health service that had gay-male clinicians.

Dexter, another gay-male participant – whose experience discussing PrEP with his GP we have just described – reported that he had fallen out of a testing routine after he had moved interstate. While he was previously being tested biannually, his move coincided with a dramatic change to that pattern i.e. to

not testing *at all* for more than a decade. He attributed this change to his new GP's limited sexual literacy in relation to gay men's health, which as a result made him feel uncomfortable talking about his sexual practices:

*So, it was actually far longer than five years. [...] With moving into the suburbs, not having the cute gay doctor, I just got out of the habit of actually having that conversation. You're dealing with suburban GPs, and you'd have to go through the whole conversation of disclosure and all the rest of it. And it was so much easier in [other capital city] where everyone understood why you were asking to have this done, and you didn't have to get that lecture every time. So, I was just falling out of the habit of actually requesting it to the point where I just didn't get it done anymore.*

Both female participants explained that when they had sought sexual health tests in the past, their clinicians had never included an HIV test. One described how her doctor admitted having never tested her for HIV because she was a 'white woman' and therefore perceived her as not being at risk.

*So why do you think she was only testing you for STIs and not HIV?*

*Because I'm a white woman. She outright admitted that to me. That was why she stopped, why she never tested me for it: because I'm a white woman, I'm not at risk. (Jasmin, 26 years)*

These accounts indicate that the attitudes and assumptions that clinicians express in their interactions with patients can have a significant impact on experiences and patterns of testing. Consequently, many opportunities to explore sexual histories are missed – and therefore also to test for, and diagnose, STIs and HIV, or to discuss prevention options such as PrEP.

Reasons for testing at diagnosis were quite varied. They included: a high-risk event for HIV transmission; a suspected seroconversion illness; screening for PrEP; a regular sexual-health check; investigation of other health issues; sperm donation; and to fulfil a visa requirement.

## Experiences of HIV diagnosis

Diagnoses took place in a diverse range of settings, often outside sexual health and s100-prescriber networks, including: suburban and regional GP practices, walk-in bulk-billing practices, hospital emergency departments, other health services, HIV specialists, and in visa or insurance contexts. The ways in which participants were informed about their positive test result varied considerably. In one case – of an Australian citizen living overseas – the result was revealed to employers first. There were also examples of information about the diagnosis being revealed in unusual ways, often making the experience more traumatic. For example, the participant seeing information about HIV written on documents prior to being informed of the diagnosis or interpreting it from a print-out of pathology results. Among gay men, diagnosis was often in the context of diagnosis with another STI.

Diagnoses were often spread across time and space – reflecting changes in technologies and testing patterns, so it was not always possible for participants to describe their diagnosis as a single event. For those who received a reactive result on a point-of-care test or an indeterminate result (and were told it was ‘likely’ to be positive), the period before having the diagnosis confirmed was experienced as a liminal zone (‘a brief “in-between” time’).

Variations from normal or expected clinical processes were important ‘clues’ or ‘cues’ that led to some people anticipating their diagnosis. Some of the changes to the technologies and protocols related to HIV testing – such as new clinical procedures that obviate the need for clients to return to clinics for negative HIV antibody test results – have had quite a noticeable effect on this pre-emption. Being contacted by a clinic and asked to return for test results forces patients to consider the possibility of a positive diagnosis of HIV. Some study participants therefore recollected how they expected their diagnosis. Rufus (male, gay, 28 years) described his experience in the following way:

*On the Thursday morning I got a call from the GP just to come in to discuss the test results, which, as soon as she said that, I just knew*

*straight away. And then, so, when I went in there, she was like, ‘Did anybody drive you here?’ And I was like, ‘Oh well, now I definitely know.’*

Even in those instances when gay male participants had not anticipated a positive result, they sometimes indicated that they thought their doctor may have expected them to consider it as a possibility. As Tobias (male, gay, 47 years) noted, *I guess she just thought I had an expectation that I might have it. And maybe that’s why she thought I’d asked to go on PrEP [pre-exposure prophylaxis]*.

For women in the study, and for heterosexual men, a diagnosis of HIV was suspected only after ruling out other possibilities, or more commonly, was a complete surprise. As Jasmin (female, heterosexual, 26 years) recounted:

*They had already called me, going, ‘Look, these two, two people are going to come and meet you there and they just want to talk to you.’ They didn’t tell me why. They didn’t tell me what was going on. They just told me that they wanted to talk to me, that it was important that I come in as soon as possible. And I had no idea what was going on. I didn’t even click that there could be a problem.*

As this excerpt indicates, Jasmin had no expectations at all in relation to possibility of a HIV diagnosis, and this surprise may have been exacerbated by the fact that the diagnosis was given in the context of a different service [a blood donation service].

Participants reported a range of different reactions to diagnosis. One of the most common ways participants described their reaction was in terms of shock and disbelief (‘shocked and confused’, ‘odd sensation’, ‘out-of-body experience’, ‘numb’). Other emotions reported by participants were related to their beliefs about how they acquired HIV (for example anger in the case of some participants – notably female participants – who believed their partners were denying their HIV-positive status). However, these emotions were generally more associated with the period following diagnosis, rather than at the time of being diagnosed.

Some gay/bisexual men's accounts nonetheless drew on narratives of inevitability.

*I had been getting ready for that moment for my entire adult life. [...] One of my thoughts was like, 'Oh, it actually happened.' Like, you know, I think as gay men we all, in some respect, expect to become HIV positive or at least we mentally prepare ourselves to become HIV positive. You know, that's definitely a legacy of the epidemic. So, in that way I was like, 'Oh wow, okay, so this thing since I've been expecting since I was 16 has happened'.*  
(Flynn, male, gay/bisexual, 27 years)

Accounts of inevitability could be thought about to some extent as an insight into the historical association of HIV and gay/queer sexuality, and not specifically related to the individuals themselves. However, the accounts of some of the gay male participants in the study indicated that diagnosis was sometimes associated with feelings of shame, and a belief they 'should have known better'.

Participants with up-to-date knowledge about antiretroviral therapy and treatment-as-prevention, etc. drew on this knowledge in responding to news of their diagnosis, both at the time of diagnosis and in the immediate post-diagnosis period. Starting therapy was important in establishing a sense of 'control'. However, while this sense of control was important, it was primarily related to the health implications of an HIV diagnosis. The social (and other) implications were generally considered to be both negative and outside the control of people diagnosed with HIV, and were not fully realised at the time of diagnosis.

## HIV clinical care

### Linkage to, and retention in, HIV care

Referrals to specialist HIV physicians usually occurred in a very timely manner, even when participants were being referred from a non-s100 GP, a regional centre, or across jurisdictions. Referrals often occurred on the same day as the HIV diagnosis, or the following day, and were facilitated by public health units or support programs. (Only a minority of participants were diagnosed in high-caseload practices.) A small number of participants were actively involved in their own referrals – in cases where the participant (in these cases, a gay man) knew of a specific high-caseload practice or HIV clinic. However, even when referrals were undertaken very efficiently, participants' experiences varied significantly. As Jasmin (female, bisexual, 26 years) noted: *'After being told and having bloods done, I was then driven directly to [hospital-based HIV clinic]. It made me feel dirty and disgusting the way they did that to me.'*

The period before receiving specialist HIV care was often described by participants as a period of uncertainty and was also often characterised by a lack of information. However, even before the COVID-19 pandemic, video-conferencing support was sometimes offered for regional participants. (It would seem that these participants could also benefit from immediate referrals to peer-based support services, and specifically to peer navigation services.) Most participants reported that after having multiple HIV clinical care appointments in the first weeks and months after diagnosis, their HIV clinical visits now occurred approximately every six months. Some also added that they would actually prefer more frequent appointments.

### Antiretroviral therapy

Only one participant had not yet started treatment at the time of being interviewed for the study. Most had started treatment within a few weeks of diagnosis. However, participants were not always offered immediate treatment when seroconverting.

All participants also had very strong beliefs in effectiveness of treatment. Most participants, however, did not know a great deal about HIV at the time they were diagnosed, which suggests that more needs to be done to improve HIV literacy (7). However, almost all participants knew that early or immediate treatment was generally the norm.

Achieving an undetectable viral load (UVL) was also an important component of participants' accounts of treatment. UVL provided evidence of treatment effectiveness, as well as ensuring that there was no risk of transmission to partners (e.g. U=U). However, many participants – including gay men – had only a very limited knowledge about UVL prior to their diagnosis, which suggests that more attention needs to be given to promoting – and building confidence in – UVL as a prevention strategy among HIV-negative men (8). As Rufus (male, gay, 29 years) described:

*The only undetectable person I'd ever known, it was a guy that lived near to where I was living when I was in [city where diagnosed]. And like I met up with him a couple of times and he told me about undetectable but didn't really go into a lot of detail, but just said that it was not infectious. And that was the only thing that I'd ever really heard about it from that perspective.*

Related to the focus on achieving UVL as being the primary or 'ideal' goal, participants had concerns about HIV transmission when they had detectable virus (for some this concern was still present if their sex partners were on PrEP). UVL was often described in opposition to feelings of infectiousness experienced by participants when they were still detectable. Some described the attainment of UVL status as either a moment of liberation, and/or a time at which they could acknowledge and pursue sexual interests, and in particular, condomless sex. In the following excerpt (Flynn, male, gay/bisexual, 27 years) draws an analogy between UVL and being on PrEP in this regard, and in fact suggests that UVL is superior to PrEP.

*But, as soon as I was told I was undetectable, I knew that that was the new... the cage has opened and now I feel a lot... it's almost like*

*I'm back on PrEP. Like it's far more reassuring, far better... And, before, where it [the medication] was a choice, it's now not a choice. But, you know, taking my HIV meds is also liberating, you know. Reaching an undetectable viral load is liberating just the same way as, like that's why I sort of say, it feels like I'm back on PrEP now.*

Flynn's account also draws attention to the symbolic importance of UVL. Attaining UVL was associated with reclaiming a responsabilised identity (as a person living with HIV), and in some cases was compared with feelings of shame they had experienced in relation to their diagnosis. UVL also created a symbolic connection to an imagined global community of other PLHIV, which was quite meaningful for many participants.

## Experiences of peer-based HIV support

The most commonly used HIV peer-support service among participants was the private Facebook group of the The Institute of Many (TIM). In terms of official peer-support services, around one third of participants had some experience with peer navigation services after their diagnosis with HIV. A slightly higher number had taken part in workshop-based peer-support programs. In addition, a number of participants had participated in social support groups that were organised by PLHIV organisations.

Referrals from clinical services to peer-based HIV support occurred in both direct and indirect ways. In making direct referrals, health-care providers facilitated direct contact with services (at the diagnosis visit, or at sometime soon after) or obtained permission from the participant to provide their contact details to the organisation that delivers these services. Indirect referrals mostly comprised health-care providers giving participants information about support services with the understanding that they could initiate contact with these services if and when they needed them.

A recent study of GPs in Queensland found that the absence of direct communication pathways with peer navigation was a key challenge (9). However, peer navigation was highly valued by these service providers as a bridge to health and social care systems, and as part of patients' support networks. In addition, peer navigators played an important role in assisting with the interpretation of clinical information, as well as normalising HIV, and reducing fear and stigma (9).

For those who accessed peer support (workshops, one-on-one support, social support groups, and peer navigation), the experience was positive, often affording an opportunity to find others with similar experiences, as well as creating a sense of belonging. As Amber (female, heterosexual, 29 years) noted, it was particularly valuable to have peer support for specific groups such as women, because of the ways in which gender frames experiences of living with HIV.

Why do you think having that support from other women is important?

*Because they understand. They have similar struggles to what I would in aspects of my life because of my HIV status. And it's nice to get their perspective on how everybody deals with something differently, and to be able to pick which way is going to work best for you.*

Others also noted the specific topic areas covered in peer support – such as disclosure and negotiating sex – as important features, in addition to the emphasis on a peer-based – or horizontal – transfer of information and experience.

*[The peer-support workshop] spoke directly to disclosure. It spoke directly to getting back into the dating scene. It spoke directly to health. It spoke directly to all of those types of things. And to understand that there were others in the community who were in this scenario but much farther down the track timewise, it gave me confidence that this was going to be okay. (Ronny, male, gay 42 years)*

Participants also commented on the social and cultural aspects of peer-support activities:

*The majority of the people that go are gay men but even us heterosexual women are very openly accepted and, you know, they like getting our opinion on things as well. (Amber, female, heterosexual, 29 years)*

A few participants who had accessed peer navigation services believed that they were not well matched with 'peers', in terms of other criteria apart from HIV status, such as age, gender, or length of diagnosis. Among participants who had accessed workshops, there were comments on their scheduling, timing, and composition. Also, some had avoided peer-support workshops because they disliked group-based activities, or had concerns about confidentiality or privacy.

Online peer support through the private Facebook group, TIM, was highly valued. As Rhys (male, gay, 35 years) noted:

*It's generally pretty good. Sometimes there's a lot of debates on there and people get really angry. It's a complex thing to manage I'm sure*

*but it's been a great thing to be a part of.  
They've answered a lot of my questions about  
health providers, relationships, navigating  
disclosing to people.*

This type of support could be participated in – or consumed – in a number of ways (i.e. active participation, or more passively as a source of generalised support and information). Most participants reported that they engaged in this more passive way, usually by receiving push notifications from the Facebook group. Barriers to more effective participation included: processes for joining (approval; link to social media account); and the risks associated with engaging in online discussion (i.e. tone of responses).

## Living with HIV

Participants frequently described a discrepancy between what they considered the medical and social experiences of living with HIV in the contemporary era. Participants knew that, medically, HIV was highly manageable, a message that was emphasised through their clinical encounters. However, they were also aware of the persistence of social stigma (including sexual exclusion), which was sometimes informed by their own previous attitudes to HIV and PLHIV prior to their diagnosis (10-12). These pre-existing attitudes therefore form an important part of the formulation or embodiment of internalised stigma. It was difficult for some participants to reconcile these different aspects (*'It was frustrating me that they felt out of 'sync', the medical reality and the emotional response to it'* [Jasper, male, gay, 32 years]), sometimes causing contradictions between their different experiences of, and responses to, living with HIV.

Whereas participants were generally confident that HIV was manageable through antiretroviral therapy, they sometimes reflected on the reasons for their emotional response to the diagnosis. The following excerpt from Cameron's (male, gay, 30 years) interview – in which he both emphasises and deemphasises the impact of HIV on his life – provides an example of this interplay.

*It's more just the like, 'Fuck. Fuck. I've got it.' It's just so annoying. I have to take a pill for the rest of my life. And that will weigh on me, like in a big way, and then, all of a sudden, I'm like, 'It's one pill.' Like, 'what's the big deal?'*

Whereas participants had very few concerns regarding HIV-related health issues directly, they had some other specific concerns related to HIV. These included: career-related restrictions (both actual and perceived); restrictions on living/working in other countries; questions about the possibility of becoming a parent; and access to, and control of, their health-related data – specifically HIV status.

Some participants referred to their diagnosis as a positive catalyst for change, mostly in relation to being more health conscious or

reassessing life goals. As Cameron (male, gay, 30 years) described: 'I feel improved. Like everything about me I feel is improved by it. And I don't think, so I don't regret that I'm HIV positive in that respect.'

*And then there was one guy who was a friend of a friend. And we were at a festival when I was living in [other city], and he was like, 'Oh yeah, I was quite relieved when I got it because now I don't have to be paranoid about getting it anymore.' And I was like, 'Well, I definitely was not relieved and I'm definitely not ecstatic that I have it. Okay.'* (Rufus, male, gay, 29 years)

Similarly, many participants, particularly those who had been diagnosed for a longer period, believed that over time, life 'normalised' in the sense that living with HIV had become more integrated into daily life, whether they publicly disclosed their HIV status or not. However, at specific moments, such as when disclosing to sexual partners, friends, family, and work colleagues, and when considering dating prospects, HIV came to the fore for some.

## Societal attitudes to HIV

Participants were asked about the attitudes of other people towards HIV in general, and PLHIV in particular. Many felt that HIV continued to be framed as representing the fault of the individual and that it was equated with promiscuity and irresponsible behaviour, as well as unhealthy and/or diseased bodies. Many also noted the persistence of HIV stigma, and in particular sexual exclusion. In the below excerpt, Oskar (male, bisexual, 24 years) describes how he believes that people who acquired HIV are generally positioned as reckless:

*I feel very vain talking about this but there is a strong sense of being erotically disqualified if you're diagnosed with HIV. And also, the perception that you fucked up, that you were reckless or whatever isn't fantastic.*

Oskar's description of feeling 'erotically disqualified' as a person living with HIV, invokes the idea of losing one's rights as a sexual citizen. Others expressed similar

sentiments in terms of having to seek validation from people who were not living with HIV:

*You feel like you need permission, and this 'Is that okay?' Or, 'I hope you don't mind' thing. You feel there's another level of validation that you need to go through. (Angus, male, gay, 28 years)*

Oskar and Angus' accounts both reveal how people living with HIV can be positioned as marginalised people who need to seek permission to gain space as legitimate citizens, thereby indicating internalisation of HIV-related stigma. However, there was nonetheless a sense that HIV treatment and subsequent UVL held the potential to contribute to a new narrative and identity about living with HIV. This new narrative is associated with a more antiretroviral-informed sociality (or biosociality), including the understanding of HIV as non-transmissible in the context of UVL, and therefore PLHIV as legitimate and equal partners in sexual contexts.

*We collectively can see the messaging that's coming out of the U=U campaign. And the other day Facebook shared an article on TIM [the Institute of Many] and the LGBT Facebook page shared it. Like there were 21 million followers. So, there's all these global things that are happening that are all positive. Yes, I think it's the start of a big swing, and the medications are enabling that. (Angus, male, gay 28 years)*

Here, Angus identified that the messaging about U=U being disseminated to communities was changing societal understandings of what it meant to live with HIV. However, there were specific limits to this 'new biomedical narrative' of living with HIV, which a few participants implied pertained mostly to circles within 'queer' communities or within other networks in which better than average HIV knowledge circulated.

## Disclosure to sexual partners

Most participants had been sexually active since diagnosis, and several participants have met a romantic partner in that period. Concerns about rejection by potential sexual and/or relationship partners (i.e. sexual exclusion) were experienced by many participants. Experiences of disclosing to casual sexual partners were diverse. The women in the study had rarely had sex since their diagnosis and when they had, it had been with people they already knew. Among the gay men, some said it was easier to disclose due to HIV biomedical prevention strategies, particularly to men on PrEP, but others said they still experienced rejection, even from men on PrEP.

The use of apps such as Grindr provided an opportunity for some to reveal their status online as opposed to in person, 'filtering out' those that would be unwilling to have sex with a person living with HIV. However, this concomitantly opened these men up to discrimination.

Some participants were unsure about whether they had a responsibility (or legal obligation) to disclose their HIV status to sexual partners, especially in the context of having an undetectable viral load. This uncertainty created considerable confusion or distress. However, participants' accounts often also revealed a sense of obligation regarding disclosure, and also pondered the appropriate time to tell a partner. The timing of disclosure depended on the connection they felt with this partner and the potential for an ongoing romantic relationship.

## Disclosure within social networks

Most participants had positive experiences with regard to disclosure to family and friends, but many nonetheless described the difficulties associated with disclosure. Apart from sexual exclusion (discussed below), there were very few examples of other forms of stigma (e.g. social exclusion, negative emotional responses, attributions of responsibility.) Attitudes to disclosure were mixed among participants – some were very discreet about living with HIV, some had told some close networks,

some were more open about their diagnosis and would share their status if asked, and some openly taken on activist roles or engaged in educational programs as a public figure living with HIV. Most were strategic with who they told, with some describing the tension between wanting to tell only those they trusted but finding it harder to tell these trusted people because of the shame they experienced in relation to their HIV-positive status.

Five participants had used social media as a platform to share their status with broad and public, but nonetheless controlled, networks. All participants who publicly disclosed on social media did so to take control of their own narratives. Publicly disclosing also symbolised a desire for one's voice to be heard, which one man described as releasing him from the 'sero-closet'.

*I'm told that I'm positive and all the advice that I'm being given is basically build yourself in your closet. And that just did not gel with me. And so, I started writing this blog. I publish my blog on Facebook so when I publish a new page, I actually put a link on my Facebook page, so people quite often go and see it. And a lot of the people that I work with are also friends on Facebook. And I don't hold back. So, I am quite open about being positive. I need to clarify that. (Dexter, male, gay, 50 years)*

However, several participants also discussed other issues associated with disclosure, including uncertainty about how others might respond – knowing it could never be untold – and also concerns about unduly burdening others with this information.

## Follow-up Interviews

Follow-up interviews (scheduled for approximately one year after the first interview) have occurred with the majority of participants. (All participants who have been contacted for a follow-up interview have consented and been interviewed.) As these follow-up interviews were all conducted after the start of the COVID-19 pandemic, additional questions were added to the interview schedule to explore participants' experiences. In particular, the interviews investigated the impact of the pandemic (and related restrictions) on participants' work and home life, finances, mental and emotional health, relationships and sex lives, and experiences of accessing HIV clinical care. From February 2021 follow-up interviews have also explored participants' attitudes and intentions related to COVID-19 vaccines. (Follow-up interviews have been conducted with 22 participants to date.)

Several participants had relocated since their previous interview. Three participants had moved to different Australian state; and two participants had returned to Australia from living in different countries in SE Asia. For one of these participants, this move was directly related to the COVID-19 pandemic, whereas the other had returned to Australia for other reasons in late 2019.

It is likely that there would have been more mobility among participants if it had not been for the COVID-19 pandemic. At least one participant for example reported he was intending to move from Melbourne to Sydney as soon as that was possible.

Regarding changes in relationship, four male participants had ended relationships (with male partners) since their previous interview (although none attributed the ending of their relationship specifically to HIV). Another four male participants had started new relationships (three with a male partner and one with a partner of non-binary gender).

## Changes to HIV treatment regimens

Somewhat surprisingly, more than half the participants had changed their HIV treatment

regimens. The most common new regimen was Biktarvy, although some had also started Triumeq, and one, Dovato. (A couple of participants had switched between these Biktarvy and Triumeq due to adverse effects.) A few participants highlighted in their interviews that Biktarvy had emerged as a popular regimen among prescribers (*'...it was all the rage last year...'* [Flynn, male, gay/bisexual, 28 years]), and that they believed this fact had been influential in their doctor's recommendation to change to that particular combination. While most participants were content with their new regimen, the change to Biktarvy was associated with weight gain for one participant at the time of his follow-up interview (although he noted he was also less physically active because of COVID-19 restrictions).

For most participants who switched regimens, the reason for this change was the adverse effects they had experienced while on their previous regimens. These effects included: vertigo/dizziness (Genvoya and Eviplera); tinnitus (Genvoya), nausea/vomiting (Eviplera); fatigue (Genvoya and Triumeq), anxiety/depression (Biktarvy and Descovy/Tivicay) and weight gain (Biktarvy). There was also a desire to switch away from Genvoya because of the fact that it contains cobicistat (a pharmacokinetic enhancer of elvitegravir), which also interacts with other drugs. One female participant also switched to a regimen that was recommended for women seeking to become pregnant. Other reasons for switching regimens included a preference for regimens that were one-pill formulations and/or that did not need to be taken with food.

## Retention in HIV care

The accounts of the men who had moved interstate provided insights into experiences of establishing contact with HIV clinical services in their new state of residence. One participant described asking if his current clinical service provider (a sexual health centre) could liaise directly with his previous provider (also a sexual health centre). (However, while he had a counsellor in his previous home state, he had

not linked himself to a new one because he felt he had been too busy to do so.)

Upon his return to Australia from SE Asia, one study participant moved to a different state from the one in which he had lived previously. At the time of interview, however, his care was still being provided out of his previous home state. The reason he gave for not yet accessing care locally was because he was provided with six months of medication at his last visit and had therefore not needed to return to the clinic since that time. (He also said he was taking the time to investigate the different options that were available in his new city.) Receiving care via telehealth also enabled him to defer finding a new clinical care provider. (Therefore, the greater use of telehealth might also help overcome some of the issues raised earlier related to mobility, especially the delay in seeking out sexual-health and HIV-prevention care after relocating.)

## Experiences of the COVID-19 pandemic

COVID-19 has had diverse effects on participants. Although all participants noted significant changes, the impact varied greatly. The jurisdiction in which participants lived also had an impact on the degree to which they were affected. Many focused on the reduction or loss of social interactions, which only to some extent replaced by other – usually digital – means of interacting. Many also noted changes to work and employment (including loss of employment, precarity, changes to work roles, new employment opportunities, support via JobKeeper or JobSeeker, loss of business income, and inability to operate businesses as a result of restrictions). Regarding health, many noted decreases in physical health and also mental health (and wellbeing), including exacerbation of existing mental health conditions.

*Since things have started going back, I'm finding that the old social battery is not as good as it was and I get fed up very quickly with people when you go to the shops, and everyone's argy-bargy-ing to get everywhere, and not social distancing, and you just kind of just get ... it's overwhelming. (Angus, male, gay, 29 years)*

Participants also reported reducing sexual contacts (encounters and partners), and most avoided casual sex in the first months of the pandemic. This avoidance was also influenced by factors such as their work role e.g. in health care. However, some participants actually started new relationships during COVID-19 pandemic.

### Restrictions and physical distancing

Regarding COVID-19-related restrictions and physical distancing measures, participants generally reported being supportive of such measures and believing in their necessity. However, some also wondered about the longer-term effects of these pandemic measures, especially in relation to social cohesion between members of the community. For example, having to avoid coming into close contact with other people

was thought to perhaps undermine trust.

### COVID-19 – parallels with HIV

Because participants' experiences of HIV diagnosis were relatively recent, these memories provided an emotional template for reflecting on social responses to the current pandemic. As Angus (male, gay, 29 years) described:

*It just kind of was a bit of a flashback to those first few months after infection, which was only, what three years ago or something, whatever it was. So, it wasn't a super-distant, faded memory; it was still quite present. And then, yeah, people just being distrustful, especially on dating apps and stuff like that. (Angus, male, gay, 29 years)*

Some participants specifically reported that COVID-19 had incited memories of negative experiences of living with HIV, including shaming on dating apps. A participant who works at a hospital reported experiencing high levels of anxiety and stress (and had taken leave) as a result of COVID-19 which reminded him of the early period of HIV/AIDS (during which he was a support volunteer for a community organisation). He also changed treatment as he believed his depression/anxiety was exacerbated by the regimen he was previously on. Another participant who also works at a major hospital similarly reported an increase in pre-existing anxiety in the early months of the COVID-19 pandemic.

Participants sometimes also noted connections between HIV and COVID-19 in the language of experts and the media – including terms like ground/patient 'zero', blame, responsibility, 'positive', contact tracing. However, in terms of the social dimensions, some participants resisted the parallels between the two pandemics:

*I feel a little put off by people saying that they're similar because, no, we were, you know, especially in the early days, we still are, you know, a highly stigmatised group. Men that have sex with men and people using drugs, it's very different to the high-risk categories of, you know, nan and pop or your mum and dad. Yeah, I feel a little offended when, when people try and compare COVID-19 to HIV in a similar fashion.*

As this account from Flynn (male, gay/bisexual, 28 years) describes, this resistance was related to the way in which HIV disproportionately affected groups who were stigmatised as a result of their non-normative sex and drug use practices.

### Perceptions of COVID-19 risk

Many participants wondered – especially in the early months of the pandemic – whether they would be at increased risk of acquiring COVID-19 due to HIV status and/or whether they would experience poorer health outcomes if infected.

*I can't speak for every [PLHIV], but I mean, whenever something like this pops up, I guess you'd be stupid not to think about it in that way. (Falco, male, gay, 29 years)*

Over time, these concerns decreased, due to information accessed from different sources: doctors, media (incl. social media), community organisations, and online PLHIV peer groups, such as TIM. However, concerns decreased mostly in relation to risk of *infection* with SARS-CoV-2 (i.e. COVID-19), rather than about the likelihood of poorer health outcomes if diagnosed with COVID-19.

*I haven't really been concerned about it purely because I got onto medication really quickly and my CD4 is perfectly fine, and I'm not any more susceptible to anything than anybody else, normally. (Amber, female, heterosexual, 30 years)*

*There was a lot of misinformation to begin with that I thought was a bit scary. People were like, "Oh, I'm going to get it because I'm already immune-compromised," and that wasn't actually the case. (Percy, male, gay, 27 years)*

Concerns also decreased over time, in general, due to decreases in COVID-19 cases in Australia (although trends varied across jurisdictions).

Note: Most participants quoted above were interviewed prior to recent information e.g. [Statement from the ASHM COVID-19 Taskforce regarding the prioritisation of](#)

[COVID-19 vaccines for People Living with HIV](#) and the statement from NIH.

### HIV clinical care during the pandemic

While for some participants, HIV clinical care remained largely unaffected (or suffered only a temporary disruption), for other the changes were more significant and/or long lasting.

Several described how their HIV consultations had moved to telehealth appointments (with most preferring them in terms of convenience, although also desiring in-person contact). As Tobias (male, gay, 48 years) also noted, telehealth consultations conducted felt particularly odd because one's body was not physically present, and this strangeness was exacerbated when the consultation was by telephone only rather than by videoconference:

*I don't know what it is but it's kind of, yeah, I just sort of, I think it's just that physical kind of presence maybe. I don't know what it is but with my psychologist I'm happy to talk to him on the phone and via Zoom but, yeah, there's something about a GP that I don't know, I find unusual I suppose about doing it over the phone, that maybe ... not that he'll miss something but, yeah, I don't know.*

However, Tobias also reflected on the fact that, in his experience, consultations over the telephone could also to a different kind of attentiveness – one which enabled an exploration of different issues:

*And, to be honest, I think, you know, in some ways, the telehealth, it's probably the first time he's ever asked me, actually, whether I'd experienced any side effects from the medication and how that was going. I wonder whether he would have asked that if we had been face-to-face because he hasn't asked that before.*

The changes brought about by COVID-19 sometimes included experiences of HIV clinical care that did not involve any direct contact with a doctor at all. As Rhys (male, gay, 36 years) described:

*I didn't see the doctor at all. I just had the pathology done and the drugs given.*

So, did you have contact with the doctor?

*I was just told, if anything is strange in my results, he will contact me but, no, I didn't have [anything].*

One participant who received her care at a hospital was turned away when she tried to attend the hospital pharmacy to collect her medications on a day, she didn't have a clinic appointment. (She later managed to attend the pharmacy but only after she was given an opportunity to explain her circumstance to the hospital.)

Encouragingly, the one participant in the study who had received his HIV diagnosis during the pandemic, reported a very streamlined experience in terms of HIV clinical care. This participant, who is an overseas student was diagnosed in March 2020 in general practice after having sought care for an unrelated issue (at a clinic that offers flat-rate consultations to obviate the need for students to use their insurance). Upon receiving the diagnosis, he was referred immediately to HIV specialist care, which he accessed the following day (and also commenced antiretroviral therapy on that same day).

Regarding pharmacy issues, several participants reported being provided with prescriptions that included a greater number of repeats. Several also reported receiving a larger supply of their medications when filling prescriptions than they would have received normally (up to nine months' supply for one participant), however, others reported being limited to only two-months' supply (due to concerns at the pharmacy about stock-outs and/or shipping delays). And some participants recounted how they had been concerned at certain points early in the pandemic that their medication supply might be affected when they heard that HIV antiretrovirals were being used to treat COVID-19.

The form in which prescriptions were provided to participants also changed significantly, with many receiving e-scripts digitally on their devices or having these scripts sent directly to their preferred

pharmacy. Ronny (male, gay, 43 years) described this process:

*I get a prescription at the moment just for two months I think it is and, when I'm ready, they will send me the next prescription, or they will send my pharmacy the prescription directly. [...] They just email me, or I can, you know, I have the pharmacy app on my phone, and I can message them online, and they can just order it. They message me back and tell me when it's ready, yep.*

Participants also took advantage of postal options provided by some pharmacies. As Cameron (male, gay, 32 years) explained:

*Then I found out that I could also get my meds delivered from [sexual health centre], which was also great, because I think I was panicked a little bit by having to explain to police why I was so far out of my radius.*

There was a couple of notable changes to experiences of testing for HIV clinical markers. Overall, there was a trend towards less frequent monitoring of HIV clinical markers. Also, given that these tests needed to be conducted in person (either at a medical clinic or a pathology centre), some participants who were having telehealth consultation were sometimes asked to attend pathology centres rather than their regular clinic. This change meant that pathology testing sometimes fell out of sync with consultations. Hamish (male, gay, 36 years), for example, described how he was at least four months late in presenting for pathology:

*I have had a referral there for the last 4 months and I haven't bothered with it because I keep forgetting about it during the day [...] The doctor mentioned how long it's been since I last had test results when I spoke to him [about another issue] and I went, 'Yeah, yeah, I've got to do that, I've been meaning to do that, I've got to do it'. So, I've got a referral and I am waiting to do it.*

Therefore, there has been a delinking of the relationship between HIV clinical care consultations (and ARV prescribing) on the one hand, and CD4 and viral-load testing on the other.

## Peer support during the pandemic

As will be described in more detail in the later section of this report about service provision by community-based organisations during the COVID-19 pandemic, many HIV peer-support activities were conducted via video-conferencing platforms (notably Zoom) during this period. This transition received mixed reactions from participants (and potential participants) in these activities. Several people valued the way in which the video-conferencing format made participation less confronting (they were able to *'hide behind a wall'*) and/or more convenient. For example, Hamish (male, gay, 36 years), reported in his follow-up interview that he had attended a peer-support activity during COVID-19.

*[My doctor] signed me up for [workshop for newly-diagnosed men] and I went to one session of that and then missed the next two and I actually finally did a [workshop] session about 3 months ago on Zoom and it was really good. I think it would have been better in person, if I had done it before COVID.*

As Hamish describes in this excerpt, he had registered for an in-person peer-support workshop soon after his HIV diagnosis, but only attended the first session before dropping out.

However, some people found that the video-conferencing format made participating in these activities either less satisfactory or in some cases even less secure. Even Hamish (from above) discussed these limitations.

*There wasn't much scope for personal experience, and I don't think it was the sort of forum for it, because it's not really a personal space. You don't know the other members. You haven't met them. A lot of them have their cameras off and things like that, so it's a bit anonymous and I don't feel that comfortable discussing it with faceless [people] on Zoom, yeah and also the sessions are recorded, which they stipulate.*

Confidentiality was also an explicit concern for others such as Zaid (male, gay, 41 years).

*I would have a real problem with doing it on the Internet or, you know, on-line groups or,*

*COVID-safe situations where it's able to take screenshots of whatever I say.*

Other comments about the video-conferencing format related to the fact that it was more difficult to converse online, that participant numbers were unpredictable, and that the intimacy created through sharing experiences with others in the same physical space was unable to be replicated in an online environment. However, conversely, some participants also reported that they found it easier to ask questions without fear of judgement when they were taking part in peer-based activities via videoconference.

## COVID-19 vaccines – attitudes and intentions

Since February 2021 additional interview questions were added to explore participants' attitudes and intentions regarding COVID-19 vaccines. Vaccine intentions likely to be influenced by range of factors. These include: personal factors (e.g. beliefs/concerns about safety and efficacy, perception of risk); social processes/norms (e.g. beliefs about what others will do, media, policies); and practical issues (e.g. availability, ease of access, information).

Overall, participants reported positive attitudes towards vaccines. Most indicated that they were likely or highly likely to get vaccinated, although there was variation in the degree to which they considered it an urgent issue. One participant in particular, however, was much less enthusiastic about vaccines, although he also indicated that he would get vaccinated for a specific purpose (esp. overseas travel)

As discussed earlier, perceptions of COVID-19 risk for people living with HIV have fluctuated over the period of the pandemic. However, by the time the vaccine rollout commenced in Australia, most studies investigating the issue had reported that PLHIV were at both increased risk of acquisition of COVID-19, and of poorer outcomes if infected, so had been included in phase 1b of the rollout. Inclusion in this category was therefore a factor in determining participants' overall willingness to get

vaccinated, although this motivation was tempered somewhat among participants in states where the risk of COVID-19 was considered low.

However, some concerns were raised about the safety and efficacy of vaccines. For example, Bunji (male, gay, 43 years) revealed concerns about the interaction between vaccines and the immune system, specifically CD4 cells.

*I received the flu vax two years ago and my CD4 was eaten away [...] The ingredients that are in the COVID vaccine, are they going to do the same thing like the flu vaccine?*

Another participant wondered whether there was a possibility that vaccines could affect current or future treatments for HIV, and this concern was increased by the sense that he was in a priority category (with all other PLHIV) so would be ‘one of the first to get a vaccine’.

*I wonder if the new vaccines coming up would actually have any impact with the medication that I am on. I know according to news I am considered immunocompromised, so I would be one of the first to get a vaccine. (Cooper, male, bisexual, 33 years)*

Another issue of some concern was related to the specific vaccine product that people would be getting. In general, the fact that most people would be receiving the AstraZeneca vaccine was accepted, although there was clearly a preference for the Pfizer vaccine. However, as Zaid (male, gay, 41 years) said, ‘as long as elderly people get the good stuff’ it was acceptable that others, such as PLHIV, received the AstraZeneca vaccine.

Getting vaccinated during phase 1b also raised issues about privacy and confidentiality for younger participants. As Cooper (male, bisexual, 33 years) noted:

*I imagine myself in a queue and it's just all these old people and then there is me and it's sort of like “what are you doing here?” [Also], do I also have to let my employer know that I have been vaccinated?*

Making an appointment to be vaccinated at clinics/centres also raised questions about the need for proof of eligibility (at the time of booking and/or vaccination), what documentation would be required, and the extent to which that information would be kept confidential.

Regarding social norms, most participants believed that their peers would get vaccinated. The idea of ‘herd immunity’ was also invoked by some participants as well as a sense of obligation to get vaccinated in order to protect others in the community (as well as themselves). The idea of returning to ‘normal’ life was also a collective ideal that was referred to by study participants in relation to vaccine expectations and intentions. And even the participant who exhibited the most hesitancy indicated that he would get vaccinated in order to travel overseas to meet a potential sex partner he’s been chatting to online.

This same participant also noted that expressing cautious attitudes towards vaccines could evoke strong responses from others such as work colleagues.

*People do get quite aggressive when I say, “No, I don’t want a flu vax or no, I’m just going to wait about this COVID vaccine, and I tell them, ‘Mind your business’.*

Given that participants in this study are very well connected to clinical services as a result of their positive HIV status – and have very positive attitudes towards biomedicine in general – it is perhaps not surprising that they held mainly positive attitudes towards vaccination, and intended to get vaccinated. They also believed HIV to be an advanced field of medicine, and that they had benefited significantly from biomedical developments, so these positive attitudes to HIV care were extended to other areas of medicine.

A notable exception to this overall positive attitude towards the health system was noted in relation to Aboriginal Australians.

*That inter-generational fear that’s passed down. A lot of indigenous people won’t take medications. They don’t trust medications and that’s been passed on to me through my mother, my grandmother, and all that.*

In terms of practical issues related to getting vaccinated, participants often indicated a preference for receiving vaccines at pharmacies, mainly because they were perceived as more convenient. (Although, at the time of writing, only a small number of pharmacies have been approved for delivery of COVID-19 vaccines.) The following participant, who indicated a preference for vaccination at a pharmacy, believed that rollout through pharmacies would make vaccines more accessible, and also reduce the risk of coming into contact with other patients who may be 'sick'.

*Because doctors are fucking annoying and it's all sick people there. [...] You know, if you want to go to a good doctor, they're a fucking mile away and you can never get an appointment to a good one. (Zaid, male, gay, 41 years).*

Otherwise, there was a preference for receiving vaccines through their usual HIV clinical care provider, mostly for reasons of privacy and/or confidentiality.

*To be honest, I'd be getting it through my S100 prescriber only because I wouldn't want to deal with the normal medical community asking those types of questions. There definitely is a fear of being discriminated against in the normal, general medical community. [...] In my experience, when you meet people who aren't HIV-literate, you tend to get a bit of a standoffish vibe, or you even get that just feeling of judgement. You know, there's a form of discomfort there. And sometimes that does follow with inappropriate questions, which doesn't always happen but there's always those people who are like, "Oh, but how did you get it? Oh, are you infectious? Oh, can I catch it? Oh, do I need secondary precautions? Should I be wearing a gown?" That kind of vibe. (Percy, male, gay, 27 years)*

Not all participants were aware that they were part of the phase 1b group in the vaccine rollout and that they were therefore eligible to receive a vaccine, regardless of their age.

The processes involved in getting vaccinated were also not very clear for some participants. Communication with clinics and/or vaccination centres could be difficult and/or unclear. Also, participants did not necessarily

know if they would be contacted by their GP or whether they should make contact themselves. And some confusion existed in relation to the documentation required in order to get vaccinated i.e. referral letter(s) from GP.

## Community Service Providers – HIV and COVID-19

The COVID-19 pandemic had a major impact on how PLHIV organisations delivered services to their clients. In March 2020, Australian federal and state governments sought to contain the spread of COVID-19, banning foreign nationals' entry to the country and a 14-day hotel quarantine system was implemented by the state and territory governments. State governments began closing their borders to residents of other states, limiting the movement of people across the country. Mass gatherings were restricted, non-essential businesses and public venues were forced to close, impacting on people's employment circumstances. Governments also imposed restrictions upon leaving the house unless for essential purposes.

The work delivered by HIV community organisations was not deemed essential in all jurisdictions (however, in Queensland, for example, QPP services were defined by the department of health as 'essential' workforce). As a result, the offices of many organisations were vacated and new work from home arrangements were established. The impact upon communities of people living with HIV, particularly service users, and staff has not yet been documented. We aimed to understand the impact of COVID-19 on support services for PLHIV and the understand health and social issues faced by PLHIV through the pandemic to date.

### Methods

Two interview schedules were developed by the study team and reviewed by members of an advisory group who support the study. Changes were made by consensus of the group. Both interview schedules were developed for semi-structured interviewing (21) with one schedule for service providers who had been previously interviewed in 2019 and one for service providers who were being interviewed for the first time. Topics included referral pathways, experience of HIV diagnosis, peer support, relationships with other services, HIV treatment and COVID-19. Interviews were conducted via Zoom and the

recordings were captured via Zoom audio and REV. Recordings were transcribed verbatim, were de-identified and reviewed for accuracy. Pseudonyms are assigned to each of the interviewees. As data was collected transcripts were reviewed by the study team and results were discussed via Zoom. The interview schedules were updated after this meeting, placing more emphasis on peer support and COVID-19 and de-emphasising referral pathways and relationships with other services. These changes enabled more in-depth exploration of the concepts of peer and community, in line with the research question of the RISE study.

Transcripts were imported into NVivo and coded based on emerging themes and the research question and a preliminary analysis was conducted. The results of this analysis were discussed with the study lead investigator and feedback was provided – a process of rigour called triangulation. A second analysis was conducted by reorganising the codes in NVIVO and an inductive thematic analysis was conducted.

Twenty-one service providers were interviewed from across the country: Five; New South Wales, Four; Victoria, Two; Queensland, Two; Western Australia, Two; South Australia, one each from Tasmania, the Northern Territory and the Australian Capital Territory. The remaining three interviewees did not work or volunteer in specific jurisdiction rather offer peer-based support to PLHIV regardless of their residence. Seventeen are paid staff within HIV community organisations while four were not paid staff as they were attached to unfunded groups. All interviewees are residents of Australia. Three of the interviewees identified as female and eighteen as male. Most of the interviewees disclosed themselves to be living with HIV, though this was not a question which was asked as part of the demographic data.

### Findings

These results are understood through the experience of the support workers, not by the service users and should be understood in this context. The emerging themes discussed

below are: understanding community needs with a syndemic perspective; adapting peer support and the role of community groups in a 'COVID safe' world; and negotiating a digital divide and addressing issues of digital equity.

## Understanding the needs of communities

Interviewees described how COVID restrictions had both economic and social implications for communities. They explained how they had engaged in multiple processes of communicating with service users and other PLHIV in order to understand the needs of the communities with which they worked:

*Well essentially, we went through our database determined who had been part of our organisation over the last number of years and we cold-called everyone living with HIV in [state]. We asked all of them essentially the same questions, 'how are you and at the moment is there anything we can do for you?'* (Joseph)

This quote demonstrates how service providers worked to understand the issues facing members of the HIV positive community, and how they commenced needs assessments to understand the challenges emerging due to COVID-19. In addition to direct person-to-person contact by organisations, online forums like TIM provided workers with insight into some of the concerns playing out for members of the community.

Overwhelmingly, interviewees cited psychosocial concerns as the primary issue discussed with community members.

*I think being physically isolated is taking a big toll on people, even in some of the online spaces, social inclusion to events. The fear around COVID-19 is one thing that the conversations around loneliness and feeling alone are definitely coming through.* (Ben)

Anxiety, loneliness, and isolation were commonly described by the interviewees as impacts of restrictions aimed at reducing the spread of COVID-19. However, it was not just issues of isolation that workers were

discussing with clients. The economic effects of the lockdown were also discussed.

*Lost jobs or less income through Job Keeper and those types of things, so people might say \$1,500 bucks a fortnight is pretty good and I might say, 'it's pretty good unless you've got a \$1,500 a fortnight home loan' or something like that.* (Joseph)

This quote identifies the financial implications moving from employed work to Job Keeper or Jobseeker could have on a person's life. One interviewee described the intersection between financial insecurity and HIV treatments when recalling the situation in which one client found themselves.

*One guy was just trying to get his computer fixed and he's like, 'I don't have money for food or meds.' If I'm going to be isolated, I still want to have them. So, there's all these other issues going on at the same time and they were the main ones they were asking us, medication and food.* (Marcel)

This quote exemplifies how lost employment might result in reduced capacity to afford necessities like HIV treatments or food during periods of isolation, indicating how those on the economic fringes have been particularly impacted by COVID-19. Despite these issues, this was not the majority experience of PLHIV across the country, according to service providers. Most PLHIV required little extra support during the pandemic, and were happy with infrequent communication: *'for others, it was "yeah, listen once a month" or you know "just put me on your email list and send me your weekly emails, that's enough"'* (Joseph).

Most interviewees were likely to adopt a syndemic perspective to their approach to the community and service users. A syndemic is two or more epidemics interacting to produce an increased burden of disease in a population. When considering the psychosocial effects of COVID-19, interviewees described concern for people who were already socially isolated, who had comorbidities, or who were older: *'The epidemic reveals social problems and inequities, and if someone's already kind of experiencing those, they may be worsened'* (Stan). For some groups within the community, COVID-19 and the

impacts of lockdowns and social distancing caused isolation, whereas for others it only exacerbated pre-existing social isolation. Changes to government policies as they tried to cater for the needs of different peoples were also noted by interviewees as having greatest impact on those people who were socioeconomically disadvantaged or those who required more complex care.

*We've seen people being moved into hotels and things like that and have been very happy about all that, but we're also cognisant that these temporary accommodation arrangements for people who are in crisis accommodation are going to eventually come to an end, so we're concerned about what that might mean for long term future. (Ben)*

Another service provider highlighted the different experiences during COVID-19 between Indigenous and non-Indigenous PLHIV in regional settings.

*A lot of the reasons why we haven't heard from a lot of people is that they've been given extra payments and they haven't been reliant on us in the way of perhaps finance and transport and as that starts to decline, we will start to see more engagement with the service. (Farris)*

This interviewee was concerned that after the temporary accommodation arrangements and welfare payments were reduced or stopped, these clients would again face the same issues they had beforehand. Potentially, reconnecting these people with support workers as COVID-19 becomes better managed in Australia may prove difficult.

The practice of providing support through HIV community organisations is primarily done through a health promotion framework and the social determinants of health ethos is central to this practice. Socioeconomic factors and policy settings act as enablers or barriers to achieving health, and rarely exist in the context of a single issue. COVID-19 and its societal impacts do not just relate to COVID infection nor do they only compound social issues which are the primacy of PLHIV, rather they link to a range of other health issues such as mental health, comorbidities and alcohol and other drug use. The link between social

factors and health is clear and most interviewees believed a social determinants of health approach was appropriate.

### Effects on service delivery

HIV community organisations generally offer a range of peer-based support in the form of one-on-one peer support (peer navigation), workshops, education campaigns and social inclusion events, as well as psychosocial support work in the form of complex care case management, counselling, alcohol and other drug services, housing, financial support and food or larder services. Support for people newly diagnosed with HIV, ageing with HIV and PLHIV with comorbidities are the primary group of people who are regarded as service users, although not exclusively. Restrictions imposed to prevent the spread of COVID-19 across Australia saw most of the HIV community sector workforce move from the office to working from home, impacting on the delivery of face-to-face services.

Adapting these services were described in two ways by most of the interviewees. First, ongoing services moved online, primarily through video conferencing platforms such as Zoom. Second, the aim of the support provided and its value or perceived importance by the service providers themselves changed. Mass movement from the office to the home almost overnight saw a proliferation in the use of video conferencing platforms such as Zoom. Video conferencing platforms were described as presenting both opportunities as well as challenges for HIV community organisations.

*COVID-19 broke down a few barriers for us, it enabled us to reconnect with people, it broke down a barrier between some of this type of online interaction, it normalised it and so that was some of the bi-products that came out of COVID. (Joseph)*

According to this service provider, COVID-19 presented the opportunity to reconnect with community and to uptake new technologies to achieve this. There was also a sense that working online was something HIV community organisations should be doing regardless, and should continue to do in the

future: *'We certainly want to continue our online engagement, which is something we should always be doing anyway'* (Nate). Rather than presenting only challenges to engaging the community, COVID-19 provided opportunities to connect with people who may not have accessed services for multiple reasons prior to COVID-19 and connect different peer groups together in the process.

*We have had people who had never attended before, who are attending now, and that maybe because they were rural or they have a disability or they just have a busy life and they can't normally attend.* (Stevie)

*This for me was a really important shift for me in this space, is that it was an opportunity to remove gender and sexual attraction from the presentation of the group.* (Kyle)

These quotes articulate the opportunities afforded by the need to adapt to new ways of conducting support, breaking down existing barriers to engagement, such as geography. However, these new opportunities also themselves had challenges, which were mostly related to the changed nature of the dialogue when online, including non-verbal cues.

*There are some challenges with that, like picking up on the verbal cues, like you can only see people from this bit and so you know you can't see people, like I'm moving my hands around and fidgeting, so you can't see people's actual presentation and for me when I'm talking to somebody particularly who's recently diagnosed, I'm looking for a lot of non-verbal cues in terms of what's telling me what's going on for them, so that's not so bad one on one, but group work, oh man that's full on.* (Kyle)

This interviewee articulates the practical challenge of delivering group work online without the ability to look for visual cues that identify how a person might be feeling.

Confidentiality has long been the foundation of the services offered by HIV community organisations, which strive to create an environment where PLHIV can access services while maintaining a level of privacy and where the risk of disclosure is mitigated. Ensuring confidentiality is important in in-

person workshops or support groups because individuals will come into contact with other members of community. The below interviewee described the challenge for workers to maintain confidentiality in the online space.

*People are afraid their identity being disclosed online, because there's less control online, whereas physically you walk into a building and into a room, you have more control over that and you can see who's in the room, whereas online, some people think to themselves and I'm thinking from the perspective of a newly diagnosed person who's really cautious about their privacy, going online is, there's less control, you don't know who's watching, who's listening, it's just slightly different.* (Nate)

This participant believed people had more control in an in-person context, whereas they lacked the control to see who was participating in the online context, thus potentially threatening their confidentiality.

The type of services that are better suited to the online context and how best to deliver them has also been a consideration for service providers. One on one support has continued via video conferencing platforms. Peer navigation programs in some cases have adapted to meet the needs of community. Where a previous focus of these roles would be to provide support to navigate health systems, particularly soon after an HIV diagnosis, some of the focus has shifted towards providing connection for those experiencing isolation or at risk of poor mental health during COVID-19.

*We also let our referrers know that we were willing to take or we were actually anticipating this and encourage them to make referrals for people they were concerned about who are socially isolated or who are likely to be particularly vulnerable because of COVID-19 and the restrictions that are being placed on them.* (Stevie)

Offering support groups and workshops through the COVID period proved to be the largest adaptation challenge for service providers. Support that focussed on social isolation or was aimed at vulnerable sub-

populations of PLHIV such as long-term survivors increased during COVID-19 restrictions because they were easy to deliver and did not require engagement with structured content.

*I thought to myself, knowing how long it was going to be before we could be able to run an onsite program and not my [newly diagnosed] workshop, I thought to myself, 'what could we do in the meantime?' A medical session where it's basically all about HIV monitoring and treatments and it's a power point presentation delivered by [colleague] and it's not really about peer support, it's not really about sharing or anything like that, it's just basically information based and so I thought, 'that could easily be a webinar' and we did that, we did that last month. (Nate)*

However, this participant also acknowledged that not all modes of peer support could work online, believing that didactic approaches were more easily delivered than 'connection-based' peer-support, such as a workshop. There were perceived difficulties among service providers in adapting workshops to the online space and attracting people to them. Participants believed that generally the value of workshops for PLHIV was connection, belonging, and shared experience, and that this was difficult to recreate in an online space. As such, almost all workshops for PLHIV ceased running through the COVID period.

*So, at our retreat workshops for newly diagnosed people, social events, seminars, all of those things we've had to either move online which we have done some of that really successfully but there are certain things you just can't do in a webinar or in an online environment, so they just had to be put on hold. (Stevie)*

The ability to create a sense of connection was highly valued by service providers and seen as an important part of the kind of support people recently diagnosed with HIV should receive. Without it there was a sense that these people may be missing out: *'Someone newly diagnosed would usually have access to in-person support and seeing someone in person or attending a workshop and, I guess, right now, they're missing that' (Kenny).*

Service adaptation due to the COVID-19 pandemic needed to happen quickly and required major changes to the way that staff worked and offered services to PLHIV. This change allowed HIV community organisations the opportunity to offer programs online to a broad range of community members and allowed existing challenges such as geography to be overcome. However, this change presented challenges, both for service providers and community members. Moving forward, mixed models of service are likely to become the norm for HIV community organisations.

Evaluation of online modes of communication should be undertaken to understand if they best meet the needs of HIV community organisations and the communities with which they work. Skills development to support staff to deliver online support should also be considered to ensure they effectively meet the needs of communities of PLHIV.

### Negotiating the digital divide

As HIV community organisations adapt models of service, with increasing numbers of programs offered online, health and digital literacy of community members is a consideration when developing programs and services digitally. The 2016 Shanghai Declaration articulates the ethical challenges that must be considered by health promoters. The declaration recognises 'health literacy as a critical determinant of health which empowers citizens and enables engagement in collective health promotion' and states that 'health literacy is founded on inclusive and equitable access to quality education and life-long learning. It must be an integral part of the skills and competencies developed over a lifetime'. Health literacy (7) is complementary to the goals of the Ottawa Charter, particularly to the goal to strengthen personal and community skills, however if there is to be a proliferation of digital services to PLHIV, ethical considerations specific to social determinants of health need to be assessed.

Online health promotion, as discussed, has been an unexpected opportunity presented by

COVID-19 restrictions. However, the capacity of individuals and a group of PLHIV to equitably access these services is an issue. Below are some key factors which have impeded or facilitated equitable access and built health literacy.

*It's also highlighted that there is quite a digital divide as well, those who have and those who don't have a means to engage online. You know, things like Zoom and whatnot, those vehicles quickly chew up data, [...] so we are finding a lot of people might pop on for one and then we'll get a text message from them saying, 'you know I chewed up half my data just on that one call'.*  
(Kyle)

As indicated by this quotation, socio-economic factors such as income, employment status, and income discrepancy have influence on an individual's capacity to afford the tools necessary to engage with online health promotion interventions. Similarly, prior opportunities to engage with and understand these platforms are likely to be influenced by a person's background.

According to the service providers, some PLHIV with limited income have find this mode of communication difficult to navigate as they may not be able to afford the cost of cellular data or have had prior opportunities to learn how to use online platform in the same way as a person with a higher income: *'Online content just will not reach them. We'll help them to send emails. We have to help them log on to Zoom'* (Marcel).

Factors such as age, gender, ethnicity, and literacy, education level, reading and arithmetic skills (competences) are all important when considering the skills required to build an individual's health literacy. Older PLHIV are more likely to be unemployed and face challenges engaging with technology. Participants often said that responding to these challenges through the lens of health promotion necessitates that HIV community organisations address these social factors by create supportive environments and developing personal skills.

*Being able to engage online or have access to that sort of equipment, particularly now that libraries have shut down and things like that as*

*well, it's been quite important for the [partner org] to be able to make sure that the technology is there for people to be able to use.* (Ben)

Despite these challenges, participants nonetheless stated that online social spaces were frequently used by older PLHIV through mediums like Facebook.

Directly improving the health literacy of PLHIV was not seen to be the only task of HIV community organisations. Attaining good health literacy goes beyond addressing only proximal factors of the individual. Secondary factors such as government policy, health, and education systems, as well as social mobilisation and advocacy are antecedents which impact on health literacy. However, when planning online health promotion activities into the future, equity and access challenges need to be addressed so all PLHIV within the community can improve their health literacy and address the individual and community needs.

### Policy Implications

Some state governments implemented policies that provided accommodation to people experiencing or at risk of homelessness, and some participants said that these state government policies together with federal government initiatives such as JobKeeper and JobSeeker had temporarily resolved clients' immediate needs, thereby also reducing the level of contact with both the support worker and the organisation. One interviewee was concerned that after these temporary arrangements reduced or stopped, clients would again be facing the same issues they had beforehand. The intersectionality of HIV with other social determinants of health, including regional geography homelessness, and Indigenous background, remain a key consideration for organisations, as does the type of support or intervention offered to different communities.

Some service providers noted that although Indigenous PLHIV had benefited from temporary accommodation and income support, federal and state government policies had reduced the frequency of contact with

their Indigenous clients. It is therefore essential that community organisations are in a position to reconnect with clients who may need their services once these supports are discontinued. In addition, there were differing experiences between Indigenous and non-

Indigenous PLHIV in regional areas during COVID-19, and Indigenous PLHIV in regional and remote areas in particular require culturally appropriate interventions to ensure they remain linked to services.

## Points for consideration

These analyses of interviews with participants living with HIV and service providers raise some key points for consideration for people working in peer-based HIV support, research, policy, and clinical practice:

- Receiving an HIV diagnosis is still a significant life event in the contemporary era.
- Although people diagnosed with HIV since 2016 are generally positive about their health outcomes – in terms of HIV treatments and clinical management – they have significant concerns around the social implications of living with HIV (which has an ongoing effect on their emotional well-being).
- Many people still experience concerns about rejection by potential sexual and/or relationship partners (i.e. sexual exclusion).
- Formal referral to peer-support services (including peer navigation) does not always take place. Referral to peer navigation, in particular, would be beneficial to newly diagnosed people in the period prior to accessing HIV clinical care.
- Achieving an undetectable viral load (UVL) was an important goal for participants (including ensuring that there was no risk of transmission to sexual partners).
- Many participants – including gay men – had only a limited knowledge about UVL prior to their diagnosis. Despite the significant attention that has gone into promoting UVL, treatment-as-prevention (TasP), and U=U, confidence in this strategy still remains quite low among HIV-negative men.
- Moving between jurisdictions and/or cities can lead to HIV-negative gay men becoming disconnected from sexual-health care in the period prior to acquiring HIV – even among men who had previously been regular consumers of sexual-health services (including for example, PrEP users).
- Over time, concerns about the risk of COVID-19 for PLHIV decreased, due to information accessed from different sources. However, concerns decreased mostly in relation to risk of infection with SARS-CoV-2 (i.e. COVID-19), rather than about the likelihood of poorer health outcomes if diagnosed with COVID-19.
- Most participants indicated their intention to receive a COVID-19 vaccination.
- Online peer support has been adopted and developed by community organisations, often in response to urgent need, but with varying models for implementation, without the opportunity or resources to systematically assess their effectiveness, sustainability, or impact.
- Clinicians and other health-care providers often are unclear about how and when to refer people newly diagnosed with HIV to peer-based support, and there appear to be no standard protocols for this to occur. Peer-based support services are, however, location-specific and protocols would need to be drafted in consultation with the services responsible for delivery of peer-support programs, and local health departments.

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