



RECENT DIAGNOSIS & THE IMPACT OF SUPPORT ON THE EXPERIENCES OF HIV (RISE)

24 June 2022

This brief updates Australia's HIV sector on the RISE study – a Kirby Institute qualitative cohort study of 28 people recently diagnosed with HIV.¹ This report is comprised of in-depth interviews with participants, most of whom completed follow up discussions after the start of the COVID-19 pandemic.

The report also includes information from interviews with HIV community-controlled organisations to examine how COVID-19 affected service delivery. The RISE Study Partnership features AFAO, the National Associate of People with HIV Australia (NAPWHA), our state and territory-based members and other affiliates.

INTRODUCTION

The report captures information on the experience of being diagnosed with HIV. It also investigates the impact of accessing HIV support services on people's overall well-being and aims to better understand the contribution of community-led HIV support to treatment uptake. The study also aims to determine contemporary factors associated with HIV diagnoses, including prior awareness and experience of pre-exposure prophylaxis (PrEP), and changes in sexual activity following diagnosis.

POLICY CONTEXT

The eighth [National HIV Strategy 2018-2022](#) (the National Strategy) includes targets around diagnosis, treatment commencement, and the achievement of a sustained undetectable viral load (UVL) among people with HIV. AFAO renewed HIV treatment targets through *Agenda 2025* – a costed plan to eliminate HIV transmission by 2025.² These targets include:

- 98% of people with HIV are on treatment
- 98% of people with HIV have a UVL
- 90% of newly diagnosed people with HIV commence treatment within two weeks of diagnosis

The latest national HIV surveillance data show gaps in the realisation of these targets. For example, around one in five (19.5%) people with HIV in Australia have not reached a UVL.³ This figure is comprised of people who are undiagnosed, diagnosed but not yet on treatment, or on treatment but have not reached a UVL.

The project is now in its final stages. This brief notifies the sector of some of the study's key findings before the final report is released later in the year.

Findings from the RISE study will need to be taken into health service operations. One clear finding to date is the importance of formal referral pathways to peer-support services (including peer navigation) upon diagnosis. Such practices are not firmly in place - clinicians and other health-care providers often are unclear about how and when to refer people newly diagnosed with HIV to peer-based support. As such, there appear to be no standard protocols for this to occur. Peer-based support services are 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. It is expected that other findings and recommendations from the study will need to be brought into policy and implemented into practice.

1. Murphy, D., Philpot, S., Clifton, B., Brown, G., Ellard, J., Rule, J., Howard, C., Prestage, G. (2021). Experiences after HIV diagnosis: Report on findings from a qualitative cohort study of people recently diagnosed with HIV. Sydney: The Kirby Institute, UNSW Australia. ISBN: 978-0-7334-3996-4.
2. Grulich, A., Bavinton, B., Stoové, M., Wright, E., & Treloar, C. (2021). *Agenda 2025: Ending HIV Transmission in Australia*, Technical paper on science, trends and targets. Sydney: AFAO.
3. Kirby Institute. (2021). HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report 2021. Sydney: The Kirby Institute, UNSW Australia.



KEY POINTS

- HIV diagnosis remains a significant moment in people's lives. Participants' reactions to an HIV diagnosis are varied, but responses of shock or disbelief are common.
- Concerns surrounding career-related restrictions, living or working in other countries, and concerns surrounding the possibility of becoming a parent were more prevalent than health concerns at diagnosis.
- Participants were largely aware that the early commencement of treatment is suggested. However, many participants did not know a considerable amount about HIV before diagnosis. Treatment coverage, including linkage to and retention in HIV clinical care, is high.
- Having a UVL is an important consideration when commencing treatment. However, many participants had only a limited understanding of UVL before diagnosis.
- The COVID-19 pandemic has affected how HIV services are offered in Australia. In addition, COVID-19 related social distancing and lock-down restrictions had a negative impact on participants. Peer support is highly valued among people with HIV.

SUMMARY

Experience prior to HIV diagnosis

Accounts suggest that interactions with healthcare providers can impact experiences in accessing testing and prevention services. For example, many gay male participants had some experience taking or enquiring about PrEP before their diagnosis, and many had discontinued PrEP use before their diagnosis. Some participants reported adverse experiences in their interactions with clinical services when accessing an HIV test. Female participants report never being offered an HIV test due to assumptions based on their gender and ethnicity.

Experience of HIV diagnosis

HIV diagnosis remains a significant moment in people's lives. Participants were diagnosed across several settings, often outside sexual health and s100-prescriber networks. While reactions to an HIV diagnosis are varied, feelings of shock and disbelief are common. Some gay and bisexual

men reported a sense of inevitability when receiving their diagnosis, which could provide insight into the historical association between HIV and gay/queer sexuality.

HIV clinical care

While referrals to HIV specialists occurred promptly across all diagnosis settings, many participants reported uncertainty and a lack of information to describe the period before receiving specialist care. Likewise, most participants did not have a great deal of knowledge on HIV at diagnosis, suggesting HIV literacy can be improved. Most participants began treatment within a few weeks of their diagnosis, but not all were offered immediate treatment when seroconverting. Despite this, almost all were aware that early commencement of treatment is important. Achieving a UVL was another critical consideration. Despite this, many (including gay men) had limited knowledge about UVL before diagnosis.

Experience of peer-based HIV support

A private Facebook group of the Institute of Many was the most accessed peer-support service among participants. Around a third of participants had experience with official peer navigation. The experience of people accessing workshops, one-on-one support, social support groups, and peer navigation was positive, allowing participants to find others with similar experiences. Many peer-support activities were transitioned online due to the COVID-19 pandemic.

Living with HIV

Participants were aware that HIV was highly manageable but were also aware of social stigma. While there were few health-related concerns, other concerns included career-related restrictions, living/working restrictions overseas, concerns about becoming a parent, and concerns about their health-related data. Many felt that HIV continues to be associated negatively with others. Despite this, participants felt that effective treatment and reaching a UVL can contribute to a new narrative and identity about being HIV-positive. One participant reported that U=U messaging was changing societal understandings of HIV. These understandings may be limited within networks with heightened HIV awareness, such as within LGBTQ communities.



Accounts on disclosure varied across different participants. For example, female participants reported minimal sexual relationships since diagnosis. Many gay men felt that HIV biomedical prevention strategies had made decisions to disclose to partners easier to approach. While smartphone applications can facilitate disclosure, they are also being used to open up discrimination against people with HIV. Some participants were unsure whether they had a responsibility or legal obligation to disclose, especially in the context of having a UVL. Positive disclosure experiences were common among social networks, and there were few examples of social exclusion and negative emotional responses.

COVID-19 IMPACT

Participants

Follow up interviews were completed with most participants to investigate the impact of COVID-19 and other changes to their lives. COVID-19 significantly impacted participants, mainly through changes to working and employment, decreased physical and mental health and well-being, and reduced sexual partners. In the early months of the pandemic, many wondered whether they would be at increased risk of acquiring COVID-19 and whether they would experience poorer health comes. Over time, these concerns decreased as more health information on COVID-19 was made available.

Clinical care remained largely unaffected, and several spoke in favour of telehealth appointments due to their convenience and reduced need to travel for specialised care. However, there were a few notable changes to experiences of testing for HIV clinical markers. There was a trend towards less frequent monitoring of HIV clinical markers and a delinking relationship between clinical care consultations and antiretroviral therapy (ART) prescribing with CD4 and viral load testing.

Community-led HIV support services

In addition, RISE aimed to understand the economic and social implications of COVID-19 on the support services provided to people with HIV. Providers identified psychosocial concerns, including anxiety, thoughts of loneliness, and isolation due to restrictions, as the primary issues experienced by people who seek HIV support. Providers also signalled concern for those who were socially isolated before COVID, had comorbidities or were older.

COVID-19 also heavily impacted HIV service delivery, as the work provided by HIV community-controlled organisations was not deemed essential in all jurisdictions, and many offices were vacated as people began working from home. Video conferencing platforms offered opportunities and challenges for HIV organisations. For example, increased accessibility to services online provided connectivity to people who may not have utilised services before the pandemic. At the same time, one provider believed there was less control in online workshops, potentially threatening the confidentiality of participants. Providers report that connectivity, belonging and shared experience, the most valued elements of workshops, were challenging to recreate virtually. Due to this, almost all workshops ceased running through the pandemic. A hybrid service delivery model will likely become standard for HIV community organisations moving forward.