



**LA TROBE**  
UNIVERSITY

AUSTRALIAN  
RESEARCH CENTRE  
IN SEX, HEALTH  
AND SOCIETY

# HIV FUTURES

**Research Impact and  
the Australian HIV Response**

Australian Research Centre in Sex, Health and Society  
2018



## INTRODUCTION

HIV Futures is a study of the wellbeing and life-experiences of people living with HIV (PLHIV) in Australia. The study has been running since 1997, having been initiated by community advocates who saw the need for research about how PLHIV were coping socially, emotionally and financially following the introduction of highly active combination antiretroviral therapy (ART) in 1996. HIV Futures involves periodic, cross-sectional surveys of PLHIV, exploring health, wellbeing, antiretroviral treatment use, sex and relationships. There have now been eight iterations of HIV Futures (1997-2016).

When the study began in 1997, highly active combination ART had only been available in Australia for 12 months. This meant that, while ill-health remained a major concern for many people living with HIV, other life issues were emerging (or re-emerging) as important – relationships, identity, employment and housing. Many people living with HIV returned to work as their health improved, while others remained in a precarious financial situation following extended periods of illness. While ART fundamentally changed the experiences of PLHIV and saved countless lives throughout the late 1990s and early 2000s, PLHIV often had to cope with significant side-effects from ART that reduced quality of life and made it difficult to engage in their everyday activities, like work and social lives.

The 1997 HIV Futures study was designed to identify and explore the needs of people living with HIV in the ‘new era’ of ART. The study aimed to be “an investigation of the various ramifications of the changed perception and experience of HIV on the ways that people living with HIV/AIDS lead their lives” (1). Tracking self-reported quality of life among

PLHIV in Australia – an indicator in the Australian National HIV Strategy – is the principal aim of HIV Futures. However, the study is also intended to build a body of evidence about factors that support quality of life among PLHIV as a tool to inform HIV-related policy, advocacy, research, clinical services and community-based support services (1).

In 2018, the HIV Futures study continues to explore issues related to the experience of living with HIV with a particular focus on factors that affect health-related quality of life among PLHIV. The major issues affecting PLHIV have changed substantially since 1997. For most people, modern ART has few side effects and simpler pill regimens, creating minimal life disruption. Health issues for PLHIV are now commonly related to ageing and chronic illness rather than HIV directly. Despite this, HIV-related stigma can still have an impact on the everyday life and wellbeing of PLHIV.

The study is run by the Australian Research Centre in Sex, Health and Society (ARCSHS), based at La Trobe University in Melbourne and is funded by the Australian Department of Health. Since its inception, community advocates and organisations have played a critical role in the success of the study. A range of PLHIV peer-based organisations and HIV advocacy/community agencies based in every state and territory of Australia are actively involved in the project – providing guidance on the survey instrument, facilitating participation through their membership and community networks, and input to analysis priorities. The project is officially endorsed by the National Association of People with HIV Australia (NAPWHA), The Australian Federation of AIDS Organisations (AFAO), and the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM).

## CASE STUDY AIMS AND METHOD

This case study report aims to describe the ways in which HIV Futures has been utilised by the HIV sector, especially the community-based HIV sector, in informing policy development, advocacy work and service delivery. In particular, we aim to identify the themes or topics within HIV Futures reporting that have had the most significant influence or been of the most use within the HIV sector. We also discuss the way that data gaps are understood and used by community and peer organisations, and describe the role of HIV Futures in the Australian HIV partnership response.

This project involved a desktop review and key-informant interviews. The desktop review involved analysis of Google Scholar citations, Australian HIV organisational websites, Australian HIV community publications, and key policy and strategy documents to determine the range and nature of publications in which data from HIV Futures had been used or cited.

Key informant interviews were undertaken with 12 people working within HIV community and peer organisations. Individuals from a range of agencies across Australia were invited to participate in an interview.

In particular, we aimed to speak to people who had been working in the HIV sector for several years or more in a range of specific roles. Discussions were held with people working in diverse roles including: peer support, policy, community programs, advocacy, prevention campaigns and support services. Two of the key informants were former directors of PLHIV organisations. Interviews were held over the telephone and lasted approximately half an hour. We asked about the ways that organisations had utilised findings from HIV Futures over the years, and about how HIV Futures had informed their work. Extensive notes were taken during each discussion.

Key informant interview notes were analysed alongside results of the desktop review to identify the ways in which HIV Futures data had been used to inform policy and advocacy documents and decision-making as well as service planning and delivery.

# FINDINGS

## POLICY AND ADVOCACY DOCUMENTS

It is difficult to assess the impact of a study like HIV Futures from citations in published material alone, as study findings may be used to inform policies, programs and practice that do not appear in publications. Nonetheless, analysis of published data provides some insight into the topic areas where HIV Futures data has informed policies and programs.

Google Scholar indicates the number of times the official reports of findings from HIV Futures 1-8 have been cited in published documents. An analysis of Google Scholar citations indicates HIV Futures reports have been cited in Australian and international published documents over 350 times since 1998. The citations on Google Scholar reflect the changing nature of the Australian HIV epidemic. In the late 1990s and early 2000s, HIV Futures data was most often cited in publications about:

- HIV treatment (2-4)
- Managing treatment breaks (5)
- Caring for people with HIV or AIDS (6, 7)
- Understanding HIV as a chronic illness (8-10)
- Use of complementary therapy (11-13)
- Sexual practice among gay and HIV positive men (14, 15).

More recently, HIV Futures data has been used to inform, or provide background to, publications on:

- Aging with HIV (16-20)
- HIV-related stigma (21-25)
- Tobacco use among PLHIV (26-29)
- Drug and alcohol use among PLHIV
- ART uptake and treatment as prevention (30-33)
- HIV testing (34)

A review of online HIV community and peer based strategy, policy, projects and community publications indicates that HIV Futures data about HIV-related stigma and discrimination, unwanted disclosure, and the impact of HIV disclosure laws have been most widely used in these types of publications. HIV Futures data has been used to inform law reform advocacy and community support programs. In addition, data about smoking from HIV Futures is cited in a wide range of smoking cessation and cancer prevention policies and programs across the HIV sector. HIV Futures data about women's experiences of HIV, as well as financial barriers to treatment/ poverty have been widely used in submissions and advocacy documents, as well as community publications.

## PRIORITISING POSITIVE VOICES

Key informant interviews revealed that HIV Futures is recognised within the Australian HIV-sector as the principal data set relating to experiences of living with HIV in Australia, complementing other datasets, such as the Gay Community Periodic Surveys, which provide information on the sexual health and sexual practices of gay and bisexual men (35). Within HIV community organisations, HIV Futures data is highly regarded for its technical quality, as well as its ability to show change over time. It is also considered to be a study that reliably reflects the voices of Australian PLHIV – a means by which the needs and concerns of PLHIV are documented and made visible.

If we want data on the lived experience [of PLHIV], of all the research that refers to people with HIV, HIV Futures is the go-to (Research/policy practitioner, community HIV organisation).

The most important thing for me is that [HIV Futures] paints a comprehensive picture of PLHIV across Australia (Head of community based HIV organisation).

Key informant interviews also showed that HIV Futures has guided some agencies in their organisational governance and PLHIV representation. For example, during the restructure of one PLHIV organisation, there was growing recognition that the board did not reflect the cultural, gender or age makeup of the contemporary population of PLHIV. HIV Futures provided evidence of the changing demographic of PLHIV over time, and helped this agency to inform and build the consensus decision to change board composition to better represent breadth of HIV affected communities.

We rely on Futures data as a key source of strategic planning and decision making. (Head of PLHIV organisation).

## HIV COMMUNITY AND PEER ORGANISATIONS: SUPPORTING PROGRAMMATIC RESPONSES

HIV Futures was described by interview participants as being the only source of data about the quality of life of Australian PLHIV, which makes the study fundamental to the understanding of the social and health determinants of living well with HIV in Australia. As advances in biomedical treatment have significantly changed what it means to be living with HIV and the factors that impact on health and wellbeing for PLHIV, understanding and improving the quality of life of PLHIV has become increasingly central to the Australian HIV response. HIV Futures has played an important role in keeping the spotlight on PLHIV at a time when much HIV policy and practice has focused to pre-exposure prophylaxis (PrEP) and other prevention efforts. Several interview participants commented that HIV Futures data assists to position the needs and wellbeing of PLHIV as central to HIV prevention. Ensuring that PLHIV are living well on treatment, and are linked with services and care, is essential to achieving Australian national and state/territory targets of eliminating HIV transmission.

NAPWHA's 2017 national campaign to improve quality of life was informed by HIV Futures data that showed a link between social isolation and comorbidities. The 'Good Quality of Life' project team engaged in a deeper analysis of the data from HIV Futures, resulting in a program focusing on happiness, healthiness and connectedness, and underpinned by the role of treatment. Another recent example is ACON's 2015 'Drop Your Load' early HIV treatment campaign. While HIV Futures was certainly not the only source of data used to develop this project, it was fundamental to creating the project brief, the funding submission, the campaign materials and the broad understanding how to communicate the information.

Many programs and campaigns in the HIV sector incorporate aspects of the social determinants of health for PLHIV into their program logic. HIV Futures data on poverty, employment, stigma and discrimination, connectedness, and service utilisation is critical to using these frameworks. Interview participants reported that HIV Futures data on poverty has been used to inform client services, such as financial support, material aid and financial planning services. Data on service use, access and relationships with doctors was described as being critical to informing programmatic work around treatment uptake and decision making.

HIV Futures has also informed support programs for people across all ages and stages of living with HIV. For example, ACON highlighted that their support program for newly diagnosed people, Genesis, has drawn on HIV Futures at every stage: building a case for the funding submission; supplying evidence for the content; informing the approach to key issues and ways of delivering content. Similarly, interview participants stated that programs, services and workforce development activities that address the needs of people aging with HIV have emerged from the way that the HIV sector has used HIV Futures data over time.

Epidemiology is important, but Futures adds so much more to the surveillance picture. Futures provides quality data that provided reassurance in the planning and targeting of our activities. (Former head of PLHIV organisation).

Data from HIV Futures has been used to support applications for funding from HIV agencies by demonstrating that there is an ongoing need for services to support PLHIV. In one case, data from HIV Futures relating to stigma and discrimination, treatment uptake and viral load was used by an agency to successfully acquire funding to integrate dedicated HIV clinics and testing facilities into their community-based support and prevention services. This occurred in a period when funding for HIV services had been decreasing.

Futures shows us that some things have changed, and some things have not. It shows to governments that we need to do more, and when we might need to use different strategies if we are to effect change (Head of community based HIV organisation).

## SUPPORTING POLICY, ADVOCACY AND RESEARCH

An important message that came through key informant interviews was that HIV Futures plays an important role in identifying issues and providing direction for research, advocacy and policy within the Australian HIV sector.

We go to [HIV] Futures when we are dealing with policy issues relating to positive people (Research/ policy practitioner, community based HIV organisation).

For example, HIV Futures 8 (in 2015/16) showed that 30% of respondents were living in poverty. Similar figures had been shown in previous years indicating that poverty was an enduring problem for many Australian PLHIV, even decades after the introduction of combination ART. HIV Futures data provided evidence that was used

by NAPWHA to initiate further research on financial barriers to treatment access. This led to a successful advocacy campaign for a change to co-payments in New South Wales (NSW) in 2013.

HIV Futures tells us where we need to put our attention (Head of PLHIV organisation)

As evident in the above example, HIV Futures is also a key reference point for the development of research priorities and questions relating to communities affected by HIV in Australia, and for policy work that addresses the social determinants of the health of PLHIV.

Futures is a go-to document as somewhere you can get data that's recent, regular, [and] change can be seen over time (Research/ policy practitioner community based HIV organisation).

## AUSTRALIAN WOMEN LIVING WITH HIV

HIV Futures has been a vital source of data about the experiences of women living with HIV in Australia. Women involved in the community response to HIV have been involved with HIV Futures as advisors, supporters and promoters since the early days of the study. One interview participant described the first HIV Futures report on women, entitled 'Standing on Shifting Sand', as having a tremendous impact on framing the response to HIV among women. The report drew attention to how women's needs were different to men's, and that, despite being a minority of the affected population, there was a very clear and compelling need for specific services, programs and approaches to meet the needs of women living with HIV.

The women's data that is drawn out from each HIV Futures is incredibly important for us, it has helped us formulate our ongoing work and programs as well as provided solid research on disparities faced by women living with HIV, particularly in relation to poverty and care responsibilities (Former head of PLHIV organisation).

The data from HIV Futures was described by interviewees as strengthening women's resolve to continue to fight, to advocate, to unite, and to gather. The impact is perhaps most notable in Victoria, the only state with a dedicated PLHIV organisation for women. Positive Women Victoria used this report in its early years to better understand the experiences of women living with HIV in Australia, and to make decisions about the type of services, supports and advocacy activities needed. Positive Women Victoria have shaped and been shaped by HIV Futures data. They have used it to determine the most important areas for their support and advocacy work, as well as to advocate for their position as an independent organisation.

The 2017 Futures women's report informed every single piece of policy and advocacy work we did that year, including our submissions and advocacy in relation to the next National HIV Strategy (Former head of PLHIV Organisation).

Positive Women Victoria also used HIV Futures data in their submission to the Victorian Gender Equality Strategy and their 2015 submission to Victoria's Royal Commission into Family Violence.

## GAPS IN THE DATA

One of the weaknesses of HIV Futures is that not all PLHIV are proportionally represented in the data. Consistently, the HIV Futures sample has under-represented people from migrant communities, particularly people who have low English proficiency. In addition, people who are well connected to HIV services tend to be over-represented because they are most likely to know about the study. PLHIV who are living well and not accessing services are less likely to hear about the study.

Interviewees described these gaps in the data as representing more than just an academic limitation. Many people and communities with HIV have existed at the periphery of the HIV response. The 'gaps' in HIV Futures data possibly also reflect gaps in service delivery. Interviewees from community organisations conveyed a sense of shared responsibility for

addressing these gaps, and collectively increasing value and validity of HIV Futures data.

HIV Futures is a platform to start conversation about engagement with people we are not reaching (Head of PLHIV Organisation)

Positive Women Victoria used the gaps in the HIV Futures data to demonstrate a need for a stronger research focus on women from cultural backgrounds that are underrepresented in the sample. This scoping work translated into a small research project undertaken by Positive Women Victoria, as well as an engagement strategy targeting these specific communities.

The gaps in HIV Futures were seen as providing insight and clarity about the challenges, successes and direction of the broader HIV sector. Several people told us that the changes over time to these data gaps offer a very real indicator of program and organisational reach. For those organisations that are reorienting to reach more diverse HIV affected communities, HIV Futures will be important to inform changes in strategic direction, to guide formal collaboration, and to demonstrate the impact of these changes.

## HIV FUTURES CHARACTERISES THE HIV PARTNERSHIP RESPONSE

HIV Futures has always been there, it seems, it adds to our body of work with PLHIV and informs *how* we work. (Head of community based HIV organisation)

The Australian response to HIV is characterised by an active partnership between PLHIV, the community sector, researchers, clinicians and government. HIV Futures exemplifies this partnership as a study that is reliant on the active involvement of all contributors to the partnership, while also informing and supporting the work of the HIV partnership. HIV Futures demonstrates a sustained commitment to the principles of the greater and meaningful involvement of PLHIV (UNAIDS, 2007) that strengthens the rigour and quality of the research. HIV Futures is funded as part of the Australian Government commitment to the HIV response, and in turn the study helps to inform the achievements of this response by providing publicly available statistics on the quality of life of PLHIV. HIV Futures relies on the active participation of a large number of community organisations and PLHIV to promote and participate in the study. The work that community agencies do to improve the lives of PLHIV is supported and informed by HIV Futures.

HIV Futures was described in interviews as being a tool for many HIV peer and community organisations to engage and build meaningful involvement of HIV-affected communities. It is incorporated into several HIV sector organisations' engagement strategies and activities, particularly in relation to engaging with communities that haven't previously been reached. We heard how HIV Futures is used to start community conversations about the importance of all voices being heard, and about what it might take to have more voices included. It was noted that it was often easier and safer engage with communities about research participation and issues of representation than it was to try to engage people to access HIV peer and community services.

We are still passionate about Futures; we rely on data as a key source of strategic planning and decision making. We are passionate about engaging a broader group of people with HIV into the HIV Futures study (Head of PLHIV organisation).

One PLHIV community organisation described a symbiotic relationship between HIV Futures research and their organisation, which had emerged more recently. The online community The Institute of Many (TIM) has contributed significantly to HIV Futures' engagement with PLHIV who aren't linked in with other HIV sector organisations, which has directly resulting in HIV Futures achieving better participation across younger age groups. At the same time, the meaningful inclusion of TIM in the list of community/ referral/ connection organisations in the HIV Futures survey meant that this unfunded grassroots organisation was able to not only demonstrate its reach and impact using high quality data, but contribute

to broader understanding of the value and impact of online and grassroots communities of PLHIV.

ARCSHS engagement in community beyond the sector is admirable and wonderful. The meaningful inclusion of TIM in HIV Futures 8 gave us evidence to prove that we were really doing what we said we were doing, but also generated great data around the impact and effect of peer led platforms (Founder of PLHIV Organisation).

Perhaps the most striking aspect of these interviews was the incredible commitment and connectedness to HIV Futures that has been built over many years. Interview participants conveyed very strongly that HIV Futures data, and the HIV Futures research process over time, sustains and is sustained by the Australian HIV Partnership Response.

## HIV FUTURES IN SELECTED POLICY AND ADVOCACY DOCUMENTS: EXAMPLES OF HOW HIV FUTURES DATA HAS BEEN USED

Table 1 illustrates some of the ways that HIV Futures data has been used by organisations in reports, submissions for funding, program development and academic research and publications. Entry one in the table illustrates the reach of HIV Futures data being used to inspire a parallel project in Japan.

Table 1. Table Futures Impact

PROJECT/REPORT	REFERENCE TO HIV FUTURES
Yousuke Takaku, BEc. "HIV-Related Health Status, Adherence, and Stress Coping Capacity among Men Living with HIV in Japan." <i>population 2</i> (2018): 5.	Modeled on the HIV Futures project in Australia, the [HIV Futures Japan] project is intended to help individuals living with HIV lead a healthier personal lifestyle and to create livable conditions for those individuals. Many individuals living with HIV in Japan have been surveyed on various scales, but those surveys were all conducted through medical facilities and they covered information of interest to medical personnel. The distinct QoL and needs of individuals living with HIV have yet to be ascertained.
Cameron, S (2015) <i>Measuring HIV-based discrimination and human rights abuses: why bother?</i> HIV Australia, 13(1), <a href="https://www.afao.org.au/article/measuring-hiv-based-discrimination-human-rights-abuses-bother/">https://www.afao.org.au/article/measuring-hiv-based-discrimination-human-rights-abuses-bother/</a>	Data driven commentary on discrimination in Australia has largely relied on the findings of the HIV Futures survey. Conducted every two to three years since 1997, it routinely attracts more than 1000 responses from people living with HIV all over Australia. The survey has a broad focus, but also includes questions on discrimination and the environment in which that discrimination occurred. Although not often used in this way, the staying power of the HIV Futures survey allows consideration of progress since the previous survey, but also over a long period.
Positive Life NSW (2013). <i>Antiretroviral co-payments for people with HIV in NSW</i> . Sydney, Positive Life NSW, available at <a href="https://www.positivelife.org.au/images/PDF/2013/SB13-ATimeForReview.pdf">https://www.positivelife.org.au/images/PDF/2013/SB13-ATimeForReview.pdf</a>	Higher rates of multi-morbidity are experienced by people with HIV when compared to the general population. Nearly half (46.1%) of respondents to Futures Six indicated that they had a major health condition other than HIV. The most common conditions were mental health [anxiety/depression (44.6%) with 28.6% having taken prescribed medication in the last six months], hepatitis C (13%), cardiovascular disease (10%) and diabetes (4%).
Australian Federation of AIDS Organisations (2012). Submission to the National Tobacco Strategy. Sydney, AFAO, available at <a href="http://www.nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/public-sub-afao-nts">http://www.nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/public-sub-afao-nts</a>	The experience of living with HIV is a social determinant of health that can have a profound effect on many aspects of the life of an HIV-positive person, including risks associated with smoking. Data from the HIV Futures 6 study of Australians living with HIV showed that about half of respondents smoked (42.3%) - representing more than twice the rate of the general Australian population. This figure is concerning as many of the conditions associated with smoking are much more likely to occur in people who are HIV-positive whether or not they smoke, and smoking further weakens overall immune response.
<b>Boughey, A, Pierce, A and Wesley, M (2015)</b> How can we set targets without the evidence? Achieving recognition for all women living with HIV in Australia. HIV Australia, 13(1), <a href="https://www.afao.org.au/article/can-set-targets-without-evidence-achieving-recognition-women-living-hiv-australia">https://www.afao.org.au/article/can-set-targets-without-evidence-achieving-recognition-women-living-hiv-australia</a>	The Futures survey is highly regarded as one of the most comprehensive pictures of life with HIV in Australia; however, when looking at the most recent survey data (HIV Futures Seven, 2013), the sample size of HIV-positive women who participated does not reflect the percentage of women living with HIV in Australia. Out of the 1058 survey participants in HIV Futures Seven, only 6.7 percent were women, whereas the percentage of women with HIV within Australia's overall population of people with HIV is estimated to be around 10 percent. Optimistically, promising changes are underway. For the first time, the HIV Futures team, which is scheduled to commence data collection for the Futures 8 survey in the second half of 2015, has designed a parallel data-collection approach targeted at women. This will enable examination of issues specific to women with HIV and, it is hoped, produce gender-segregated HIV data that will allow services to more appropriately target their offerings to women's needs. Clearly, a more targeted recruiting approach is required to increase the number of women respondents and improve the applicability of the findings.
Savage J, Crooks L, McLean S. Models of Access and Clinical Service Delivery for People with HIV in Australia: final report. Australasian Society for HIV Medicine. Sydney, NSW, 2009. Available at: <a href="http://www.ashm.org.au/default2.asp?active_page_id=168">http://www.ashm.org.au/default2.asp?active_page_id=168</a>	Service demand varies across different groups of people with HIV. A minority of people with HIV (25% in the Futures 5 study) are not currently on treatment - although 40% had been (Grierson 2006). One third of respondents in the Futures 5 study (Grierson 2006) described unmet needs for services such as peer support groups, financial assistance and services beyond the inner suburban areas of capital cities. While socio-economic disadvantage may not be an issue for everyone at the time of diagnosis (apart from late presenters in CALD or Indigenous populations), there is evidence that it may become so over time (Grierson 2006, 2007). Stress over financial issues also compounds the adverse health effects of HIV (Grierson 2006, 2007).

<p>Lake, R, Cogle, A, Parkhill, N and Cooper, C (2015), AFAO, NAPWHA, ACON, Positive Life NSW: Joint submission responding to the Senate Legal and Constitutional Affairs Committee Inquiry on the Regulator of Medicinal Cannabis Bill 2014, <a href="https://www.positivelife.org.au/images/PDF/2015/SB15-MedicinalCannabisBill.pdf">https://www.positivelife.org.au/images/PDF/2015/SB15-MedicinalCannabisBill.pdf</a></p>	<p>Research has shown that cannabis has been effective in assisting people to deal with HIV related pain, loss of appetite, neuropathy and nausea. People living with HIV, like many people with chronic illness, utilise cannabis to alleviate such symptoms - or would do so if cannabis purchase, possession and use were not illegal. 16.5% of PLHIV surveyed for HIV Futures Seven, a national cross-sectional survey of Australian PLHIV, reported using cannabis as a complementary therapy, with this number being separate to recreational use.</p>
<p>Queensland Health (2016), Queensland Government HIV Action Plan 2016 - 2021. Brisbane, Queensland Health, available at <a href="https://www.health.qld.gov.au/__data/assets/pdf_file/0032/601889/qh-hiv-action-plan.pdf">https://www.health.qld.gov.au/__data/assets/pdf_file/0032/601889/qh-hiv-action-plan.pdf</a></p>	<p><b>Priority outcome:</b> Increase awareness of HIV transmission and address stigma and discrimination  <b>Indicator number 5:</b> Proportion of PLHIV who report their general health status and wellbeing as excellent or good  <b>Source:</b> HIV Futures Study, La Trobe University</p>
<p>Bobby Goldsmith Foundation (2016). Strategic Plan 2016-2020. Sydney, BGF, available at <a href="http://www.bgf.org.au/bgf/images/assets/BGF_Strategic_Plan_2016-2019.pdf">http://www.bgf.org.au/bgf/images/assets/BGF_Strategic_Plan_2016-2019.pdf</a></p>	<p>Nearly 60% of people with HIV are currently in paid employment; while nearly 30% are living below the poverty line.</p>
<p>Living Positive Victoria (2017). Submission to the Victorian Parliament Law Reform, Road and Community Safety Committee, Inquiry into Drug Law Reform, <a href="https://www.parliament.vic.gov.au/images/stories/committees/lrrcsc/Drugs/Submissions/213_2017.03.28_-_Living_Positive_Victoria_-_submission.pdf">https://www.parliament.vic.gov.au/images/stories/committees/lrrcsc/Drugs/Submissions/213_2017.03.28_-_Living_Positive_Victoria_-_submission.pdf</a></p>	<p>HIV Futures is a cross-sectional survey conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) on people living with HIV since 1997. HIV Futures 8, published in 2016, surveyed 895 people living with HIV in Australia. Data show the most commonly used drugs for non-medical purposes in the past 12 months were:</p> <ul style="list-style-type: none"> <li>• pain killers/analgesics (22.4%, n=192),</li> <li>• tranquilisers/sleeping pills (13.7%, n=116),</li> <li>• marijuana (10.6%, n=90) and</li> <li>• methamphetamine (7.1%, n=60).</li> </ul> <p>11.2% of respondents reported injecting meth/amphetamine and 1.2% had injected heroin in the previous 12 months.</p> <p>Despite the high prevalence of use of illicit drugs and the illicit use of prescription medication within some populations of PLHIV, there remains only a small group for whom their use is problematic, including harms as a result of misuse, dependence and frequent use that affects other aspects of their lives. For example, in Futures 8, 4% of respondents indicated that their non-medical use of drugs affected their ability to work, while 3.4% of respondents had been diagnosed with a substance dependence disorder in previous 12 months. The interaction between mental health conditions, living with HIV and drug use needs to be further explored. Futures 8 data shows that “more than half the participants... had been diagnosed with a mental health condition at some point in their life,” with depression and anxiety being listed as the two most prevalent mental health conditions. Data also shows that “PLHIV may experience poorer mental health than the general population.”</p>
<p>Department of Health, National Centre in HIV Epidemiology and Clinical Research (2009) Return on investment 2: Evaluating the cost-effectiveness of needle and syringe programs in Australia. Canberra, Commonwealth of Australia, University of NSW (Appendix D: Productivity losses and gains, available at <a href="https://www.health.gov.au/internet/main/publishing.nsf/content/A407CF4FECBDC715CA257BF0001F98B2/\$File/retapd.pdf">https://www.health.gov.au/internet/main/publishing.nsf/content/A407CF4FECBDC715CA257BF0001F98B2/\$File/retapd.pdf</a>)</p>	<p>Data on the workforce participation of people who inject drugs is limited. Studies from the early 1990s reported participation rates of around 30% for injection drug users with and without HCV attending clinics and participating in a coordinated care program.... On the other hand, in the HIV Futures 5 study (n=982) carried out in 2005/6...47 to 50% of the 271 current or previous injection drug users living with HIV were currently employed compared to 62% of those who did not inject drugs with HIV.</p>

## CONCLUSION

This case study report demonstrates clearly that data from the eight HIV Futures surveys has played an important role in shaping the Australian responses to the HIV from 1998 to the present. The desktop analysis showing that HIV Futures has been cited in publications no less than 350 times since 1998, indicates the importance of the data set across a range of areas, including political and law reform agendas, the development of health and wellbeing programs, and in identifying, understanding and combatting HIV-related stigma and discrimination. The 12 key informant interview participants quoted in this study show that HIV Futures has provided a trusted, reliable, rigorous and ongoing data set that has been used not only to respond to pressing contemporary concerns for PLHIV but also to a source of comparison data over time - including highlighting gaps in knowledge around the needs of culturally and linguistically diverse communities and showing that work must continue to ensure broader representation of these groups in research. Finally, the reach and use of HIV Futures data over time - and indeed, the very HIV Futures survey itself - demonstrates the unique and world-leading Australian response to HIV from the very beginning, a model of collaboration and consultation between PLHIV, the community sector, researchers, clinicians and government.

## SUGGESTED CITATION

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