

Mental Health Inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Positive Life NSW Submission to the Productivity Commission Mental Health Inquiry

Positive Life NSW is please to be able to provide the Productivity Commission with a submission on the mental health of people living with HIV in NSW.

I can be contacted on 0422 509 200 or at craigc@positivelife.org.au if additional information or clarification is required.

Yours respectfully,



Craig Cooper
Chief Executive Officer

5 April 2019

POSITIVE LIFE NSW - SUBMISSION

Scope of this submission

Positive Life NSW is the state peak representing people living with HIV (PLHIV) in New South Wales (NSW). We thank the Productivity Commission for the opportunity to provide this submission on the social and economic benefits of improving mental health in PLHIV in NSW. Our submission addresses 1) the consequences of mental ill-health in NSW PLHIV and 2) the gaps in current programs and available supports. We are not in a position to provide comment on 3) the effectiveness and cost of current programs and support or, 4) the likely effectiveness of alternative programs and supports.

PLHIV are also experiencing HIV Associated Neurocognitive Disorder (HAND) and HIV Associated Dementia (HAD). While this has been identified as out-of-scope for this inquiry, Positive Life would like to put on the record that both HAND and HAD will continue to impact negatively on the social and economic participation of PLHIV into the future. We stand ready to provide the Commission with information on HAND and HAD in NSW.

Demographics of PLHIV in NSW

There are approximately 28,000 people living with diagnosed HIV in Australia. NSW has the largest population of PLHIV in Australia (41.2%). By 2020, it is estimated NSW will have a PLHIV population of 11,721, (Wilson 2011).

PLHIV in NSW are becoming increasingly diverse in background. In the 1980s, most PLHIV were gay or bisexual men living in Australian capital cities. This has changed and heterosexual PLHIV now account for approximately 20.0% of the NSW PLHIV population. The proportions of PLHIV from culturally and linguistically diverse backgrounds (CALD) is also increasing, due in part to trends in immigration, and to the allocation of 457 visas and student visas.

The majority of PLHIV in NSW live in the Sydney metropolitan area (77.5%). The remaining 22.5% live in regional cities and rural NSW. Heterosexual and Aboriginal and Torres Strait Islander PLHIV are more likely to live in regional and rural NSW while gay and bisexual male PLHIV are more likely to live in a metropolitan area. There is a slow but steady migration of older PLHIV from Sydney to regional and rural NSW. This is primarily due to cost of living pressures and low income (reliance on government welfare payments) (Wilson 2011).

Mental illness and HIV

Mental illness is strongly associated with being diagnosed with Human Immunodeficiency Virus (HIV). In a 2016 study of 895 PLHIV in Australia, more than half the participants (51.8%) indicated they had been diagnosed with a mental health condition at some point in their life, while 31.9% had taken medication for a mental health condition in the past six months (Power, Thorpe & Brown 2016).

Depression and anxiety are the most common conditions reported. 42.4% had 'ever' been diagnosed with depression, while 11.5% had been diagnosed since 2010. 28.5% had 'ever' been diagnosed with anxiety, while 9.7% had been diagnosed since 2010. Less prevalent conditions were reported by a smaller proportion of study participants. These conditions included bipolar disorder (4.3%), post-traumatic stress disorder (7.0%), psychosis (2.8%) (Power, Thorpe & Brown 2016).

Rates of depression are higher in female PLHIV. 41.7% HIV-positive women responding to HIV Futures 8 indicated they had been diagnosed with a mental health condition within their lifetime and 33.8% had received medical treatment for a mental health condition in the last six months. Anxiety and depression were the most common conditions which were diagnosed (Thorpe et al.

2017). As a point of comparison, in 2014-15 Australian National Health survey reported 19.2% of Australian women having a mental health or behavioural condition (ABS 2016).

Despite the improved efficacy and tolerability of modern combination antiretroviral therapy to control HIV disease progression and sexual transmission (NSW Ministry of Health 2015), infection with HIV remains a highly stigmatised condition and has long been recognised as a serious and debilitating feature of the HIV epidemic (Slavin et al. 2012). There are many reasons why HIV is stigmatised, including the fact that it is a serious communicable disease, it disproportionately affects groups who are already marginal in society and it is linked to behaviours such as drug taking and homosexual sex (Herek 1999; Herek and Capitanio 1999). There have been numerous studies of HIV stigma internationally and many attempts to combat it, yet it stubbornly persists. HIV stigma is particularly endemic and difficult for PLHIV who come from CALD, Aboriginal and Torres Strait Islander or heterosexual communities where HIV and the behaviours that enable transmission are less tolerated.

There are also many additional factors that contribute to depression and anxiety in PLHIV. These issues include receiving an HIV diagnosis and having to tell a partner, friend or family member you have been diagnosed with a highly stigmatised health condition (HIV); contacting a sexual partner or multiple partners who you may have infected with HIV and advising them to get tested; having transmitted HIV to a child; commencing lifetime daily medication to control HIV disease progression and transmission; physical illness, for example, seroconversion illness (when the body biologically adapts to being infected with HIV); death of a significant other from AIDS or another health condition; survivor guilt – “why did I survive when others didn’t”; the breakdown of a relationships because of a negative reaction by a partner, family or friends after an HIV diagnosis; having to stop work because of illness associated with HIV, other infections and/or treatment related side-effects; poverty; and being reliant on welfare.

Receiving an HIV Diagnosis

People who are faced with receiving an HIV diagnosis report feeling stressed, fearful and overwhelmed (Prestage et al. 2015). There are many new technical and personal issues with which newly diagnosed PLHIV need to come to terms. These include learning about HIV and AIDS and coming to terms with a regimen of lifelong clinical monitoring, pathology testing and treatment; finding a HIV specialist to manage clinical care; starting treatment and managing induction and longer-term side-effects; telling or not telling family and friends about an HIV diagnosis; learning about HIV prevention; and learning about legal responsibilities and not infecting others. The combination of all these factors can result in a newly diagnosed PLHIV needing to take time off work to physically and emotionally adjust to the diagnosis. It often also results in a period of acute depression and anxiety post-diagnosis. In some cases, acute depression/anxiety does not resolve and becomes intractable chronic depression, panic attacks and/or anxiety.

Not all PLHIV are diagnosed early. In 2018, there were 26 people diagnosed with advanced stage HIV infection (NSW Health, 2018). Advanced stage HIV infection is categorised by a CD4 cell count of less than 200 or an AIDS defining illness. PLHIV who are diagnosed with advanced stage HIV infection often experiencing serious AIDS-related health conditions such as tuberculosis, pneumocystis carinii, Kaposi’s sarcoma, oesophageal candidiasis, mycobacterium avium complex, toxoplasmosis and cytomegalovirus (Hoy & Lewin, 2003). In fact, in many cases it is one of these opportunistic infections which precipitates hospital admission and HIV testing. The treatment and recovery time required to bring these singular/multiple conditions under control can take many months and in some cases years. In addition to controlling opportunistic infections, the immune system of PLHIV has to be reconstituted with antiretroviral therapy. This takes time. Depression often accompanies hospitalisation and an AIDS diagnosis along with loss of employment and career prospects. While some PLHIV eventually manage to regain physical health and get back-on-track, others experience

chronic mood disorders and become reliant on continuous treatment with antidepressants and/or anti-anxiety medication.

Living with long-term HIV and the causal factors leading to depression and anxiety

Living long-term with HIV increases the risk of developing other health conditions. The combination of living with HIV and other chronic health conditions increases the risk of mental ill-health. A recent study of Australian PLHIV reported that respondents aged 50 years and over were diagnosed with the following conditions: hypertension (27.2%); arthritis (26.6%); hepatitis B (20.8%); cardiovascular disease (17.7%); asthma (17.1%); hepatitis C (13.2%); respiratory disease (12.0%); osteoporosis (11.8%); diabetes (8.9%); kidney disease (5.8%); and cancers other than breast or prostate (14.6%) including anal cancer (Power, Thorpe & Brown 2016). Younger PLHIV also report increased risk of these chronic conditions.

Rates of comorbidity/multimorbidity are significantly higher in PLHIV than people without HIV, or the Australian general population. In an Australian study of HIV-positive and HIV-negative Australian gay and bisexual men, those infected with HIV were more likely to have comorbidity. Unsurprisingly, rates of comorbidity increased with age. For example, HIV-positive men reported a significantly higher mean number of comorbidities compared to HIV-negative men of a similar age. 85% of HIV-positive men reported one or more comorbidities, and just over half (56%) reported two or more comorbidities (Petoumenos 2017). The issue of age-associated comorbidity is further exacerbated by the fact that the Australian PLHIV population is ageing. It is estimated that by 2020, 44.4% of Australian PLHIV will be aged 55 years and older (Wilson 2011). The burden of disease is therefore highly significant in older PLHIV and is often associated with increased rates of psychological distress and mental ill-health. In the APPLES study (Petoumenos 2017), depression was reported by 35% of HIV-positive respondents and anxiety by 19%.

Illicit drug use by PLHIV and mental health

While methamphetamine use among the general Australian population is low (2%) (NDSHS 2013), HIV-positive men are much more likely to report recent methamphetamine use compared to HIV-negative men (27.4% vs. 9.9%) (Lea 2016). In addition, HIV-positive men are more likely to report recent injecting drug use (53.8% vs. 21.9%), (Lea 2016). In 2017, 11% of HIV-positive men reported using methamphetamine weekly and 4.6% daily. People who occasionally use methamphetamine can experience paranoia, hallucinations, memory loss and difficulty sleeping. More frequent use can cause psychosis with paranoid delusions, hallucinations, strange, aggressive and socially unacceptable behaviour. The “come-down” can take days. Mental health professionals consulted for this submission reported young PLHIV being referred to their services who were “partied out”, chaotic, depressed and homeless. Getting these PLHIV back-on-track can take years and stretch the capacity of social workers and mental health professionals in HIV specialist and generalist services.

The association between HIV, poverty and poorer physical and mental health outcomes

Financial security is key to people’s health, wellbeing and quality of life. A reasonable income enables access to safe housing and other basics such as food and clothing; which are necessary for survival. It also allows for greater choice in how people live their lives, which in turn, supports psychological and social wellbeing. By contrast, unemployment and poverty can be intensely stressful and isolating. Poverty can be, and often is, disempowering and limiting of people’s capacity to demand quality in services and healthcare. All of this can have a significant negative impact on physical health, mental health, wellbeing and quality of life of PLHIV.

For PLHIV in Australia, access to an adequate and secure income, supports quality of life by facilitating greater security and choice in the places where people live, services they utilise, and

healthcare providers with whom they interact. Capacity to choose and demand quality services is most important for good healthcare, and PLHIV are wholly reliant on healthcare to monitor and treat HIV as well as a range of other chronic health conditions.

PLHIV are vulnerable to poverty. This is due to a combination of poor physical health and/or mental health and stigma associated with HIV. In particular, people who have been living with HIV for a long time are likely to have experienced living with untreated HIV and sickness from AIDS-related conditions and physically disfiguring side-effects from early (pre-1996) crude treatments. They also endured the loss of partners, family, friends and peer networks from AIDS. These factors all contributed and interfere with the capacity to work.

Australian HIV research has found around half of Australian PLHIV are living on household incomes substantially lower than the average Australian income. One in four have experienced significant financial stress in the past two years. For example, 27.9% of respondents to the 2017 Futures 8 reported an annual income less than \$30,000 per year, and 16.0% reported an annual income between \$30,000 and \$49,999 (Power et al. 2018).

In the 2017 Future 8 study (895 Australian PLHIV), PLHIV who experienced financial stress had poorer health, more experiences of HIV-related stigma/discrimination and lower levels of resilience. The study did not enable differentiation between cause and effect (for example, the place that mental-ill health plays in determining low income and the place that low income plays in influencing poor mental health), but irrespective of this, it can be said that many Australian PLHIV are living on low incomes and that PLHIV on low incomes are likely to face greater challenges when it comes to accessing health services and quality of life.

Barriers to accessing health services may mean PLHIV on low incomes have less choice of healthcare provider, which could explain their greater likelihood of experiencing HIV-related stigma and discrimination in healthcare settings and mental ill-health. PLHIV experiencing financial stress may also be socially isolated, which could be a consequence of low income as well as poorer health or limited mobility. These factors are well documented in being causal factors for exacerbating depression and anxiety.

Suicide, Accidental or Violent Death in Australian PLHIV

In the era of effective HIV treatment, more than half the causes of death in PLHIV are non-AIDS related (Bonnet, 2004; Chiao, 2003; Petoumenos, 2006) the most common being non-AIDS defining cancers, cardiovascular disease and liver disease. High rates of suicide and accidental or violent death have also been described in PLHIV receiving effective treatment. In the D:A:D study, Suicide was reported as the cause of death in 4% of cases, with a further 2.5% attributed to overdose and 1.5% to accident (Smith, 2010). In the CASCADE study, suicide was reported in 6.4% of deaths violence in 3.3% and 5.7% of deaths were attributed to substance abuse (Martin, 2009). In the Swiss HIV Cohort Study, the majority (>75%) of patients who committed suicide (post 1996) had a diagnosis of mental illness with depression being the most common (>80%). A significant proportion (23%) of PLHIV who died by suicide had untreated mental illness. In an Australian study of suicide and accidental or violent death in Australian PLHIV, there was an association between increased risk of suicide and accidental or violent death in PLHIV and employment and accommodation status as well as immunological status where a CD4 cell count of >500 cells was a significant predictor of increased risk of suicide. The number of psychiatric/cognitive diagnoses also contributed to the level of risk. The findings indicate a complex interplay of factors associated with risk of suicide and accidental or violent death in PLHIV (McManus, 2014).

Gaps in current programs and supports

HIV mental health professions in NSW report the mental health system is critically under resourced and exceeding capacity. There are difficulties getting mental health services involved unless the

PLHIV is subject to a community health treatment order or has a psychotic illness that impacts significantly on their day-to-day functioning and adherence to HIV antiretroviral therapy (and hence transmission). Even for those PLHIV who have mental health case management support, this support is often just for administration of HIV and other essential stabilising medication and not for therapeutic processes. There are many PLHIV who remain un-serviced or fall between the service cracks due to them being not quite unwell enough to be prioritised by mental health services. Further, if the person living with HIV is engaged and retained in specialist HIV care, we are told mental health services will not take on the referral and leave the mental health treatment, care and support to another specialist service provider. We were told that mainstream mental health services have a policy of exclusion before inclusion with only the most serious cases prioritised. Psychosocial issues are de-prioritised, even though many of these issues are causal factors in the PLHIV's ongoing mental ill-health.

There is disparity in access to mental health service in metropolitan Sydney versus regional and rural NSW. While PLHIV in metropolitan Local Health Districts have access to multidisciplinary tertiary bulk-billing services such as St Vincent's Hospital, Royal Prince Alfred Hospital and Prince of Wales Hospital, as well as other HIV specialist services in metropolitan Sydney, PLHIV in regional NSW report experiencing long waiting and travel times for access to mental health services. In many cases PLHIV who live in regional and rural NSW are required to use general nursing staff and visiting medical officers at sexual health centres to diagnose and treat both their HIV and mental health conditions. For more serious cases, travel to Sydney becomes necessary. The cost of travel and accommodation for regional and rural PLHIV presents a further barrier to clinical care and improved mental health outcomes.

REFERENCES

Australian Institute of Health and Welfare, 2014, 'National Drug Strategy Household Survey detailed report:2013', no. 28,

Australian Government Department of Health, 2019, 'Healthdirect', viewed 2 April 2019, <<https://www.healthdirect.gov.au/>>.

Bonnet, F., Lewden, C., May, T., Heripret, L., Jouglu, E., Bevilacqua, S., Costagliola, D., Salmon, D., Chêne, G., Morlat, P. 2004, 'Malignancy – related cause of death in human immunodeficiency virus-infected patients in the era of highly active antiretroviral therapy'. *American Cancer Society*, vol. 101, no. 2, p.317-324.

Chiao, E.Y. & Krown, S.E. 2003, 'Update on non-acquired immunodeficiency syndrome-defined malignancies', *Cur Opin Oncol*, vol.15, issue 5, p. 389–397.

Herek, G.M., & Capitanio, J.P., 1999, 'Aids Stigma and Sexual Prejudice', *American Behavioural Scientist*, vol. 42, no. 7, p. 1130-1147.

Hoy, J., Lewin, S., 2003 'HIV Management in Australia: a guide for clinical care', *Australasian Society of HIV Medicine*.

Mao, L., Adam, P., Treloar, C., & de Wit, J., 2016, *HIV/AIDS, hepatitis and sexually transmissible infections in Australia: annual report of trends in behaviour 2016*, Centre for Social Research in Health, University of New South Wales.

Marin, B., Thiébaud, R., Bucher, H.C., Rondeau, V., Costagliola, D., Dorrucchi, M., Hamouda, O., Prins, M., Walker, S., Porter, K., Sabin, C., Chêne, G., 2009, 'Non-AIDS defining deaths and immunodeficiency in the era of combination antiretroviral therapy', *AIDS*, vol. 24, no. 13, p.1743-1753.

NSW Ministry of Health, 2015, *NSW HIV Strategy 2016-2020*, viewed 2 April 2019, <<http://www.health.nsw.gov.au/endinghiv/Publications/nsw-hiv-strategy-2016-2020.PDF>>.

NSW Ministry of Health, 2018, *NSW HIV Strategy 2016-2020; Quarter 4 and Annual 2018 Data Report*, viewed 2 April 2019, < <https://www.health.nsw.gov.au/endinghiv/Publications/q4-2018-and-annual-hiv-data-report.pdf>>.

Power, J., Thorpe, R., Brown, G., Lyons, A., Dowsett, G.W., Lucke, J., 2016, *HIV Futures 8: Health and Wellbeing of People Living with HIV*, Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.

Power, J., Thorpe, R., Brown, G., Lyons, A., Dowsett, G.W., Lucke, J., 2016, *HIV Futures 8: Financial Security Among People Living with HIV in Australia*, Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.

Petoumenos, K., Huang, R., Hoy, J., Bloch, M., Templeton, D.J., Baker, D., Giles, M., Law, M.G., Cooper, D., 2017, *Prevalence of self-reported comorbidities in HIV positive and HIV negative men who have sex with men over 55 years – The Australian Positive & Peers Longevity Study (APPLES) 2017*, Kirby Institute, University of New South Wales, Sydney.

Petoumenos, K. & Law, M.G., 2006, 'Risk factors and causers of death in the Australian HIV Observational Database', *Sexual Health*, vol. 3, no. 2, p. 103-112.

Prestage, G, et al. Experiences of HIV: The Seroconversion Study Final Report 2007–2015, Kirby Institute, University of New South Wales, 2016

Slavin, S., Brener, L., Callander, D., de Wit, J., 2012, 'The HIV Stigma Audit, National Association of People Living with HIV/AIDS', viewed 4 April 2019, <http://napwha.org.au/files/napwa_stigma_audit_report.pdf>

Smith, C., Sabin, C.A., Lundgren, J.D., Thiebaut, R., Weber, R., Law, M., Monforte, A.D., Kirk, O, Friis-Moller, N., Phillips, A., Reiss, P., El Sadr, W., Pradier, C., Worm, S.W., 2010, 'Factors associated with specific causes of death amongst HIV-positive individuals in the D:A:D Study', *AIDS*, vol. 24, no. 10, p. 1537-1548.

Wilson, D. 2011, *Mapping HIV Outcomes; geographical forecasts of numbers of people living with HIV in Australia*, UNSW, Sydney.

Acknowledgement

This submission was authored by Lance Feeney – Consultant and Special Representative to Positive Life NSW.

Positive Life would like to thank the following Mental Health professionals who assisted with the development of this submission:

Mike Smith, HIV Community Outreach Team, Sydney Local Health District

Ronald Tripp, Psychologist, Sydney Sexual Health

Dee Holland, Adahps (formally, the AIDS Dementia and Psychiatry Service) Sydney Local Health District.