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## Submission to the Royal Commission into Victoria's Mental Health System:

Support for people living with HIV

5 July 2019

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### Living Positive Victoria

Living Positive Victoria is a not for profit, community-based organisation representing all people living with HIV in Victoria since 1988. It is committed to the advancement of human rights and wellbeing of all people living with HIV. The organisation offers a wide variety of peer led services to both inform and connect people living with HIV. Living Positive Victoria also advocates for the rights of all people living with HIV through law reform as well as challenging stigma and discrimination.

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### Thorne Harbour Health

Thorne Harbour Health is one of Australia's largest community-controlled health service providers for people living with HIV and the lesbian, gay, bisexual, trans and gender diverse, and intersex (LGBTI) communities. Its services include general practice, health promotion, counselling, family violence, housing support, and alcohol and other drug rehabilitation and harm reduction programs. Thorne Harbour Health primarily serves the populations of Victoria and South Australia, but also leads national projects. Thorne Harbour Health works to protect and promote the health and human rights of LGBTI people and all people living with HIV.

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### Positive Women Victoria

PWV provides support, information and advocacy for women in Victoria living with HIV. For over thirty years PWV has responded to the changing needs of women living with HIV, recognising the impact gender has on the way women experience HIV and addressing the specific needs and emerging issues that affect women living with HIV in Victoria.

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# 1. Introduction

Living Positive Victoria, Thorne Harbour Health, and Positive Women Victoria welcome the opportunity to contribute to the Royal Commission into Victoria's Mental Health System, and would like to thank the Australian Research Centre in Sex, Health and Society for providing feedback and endorsing this submission.

While this submission deals in detail with mental health concerns for people living with HIV, we would like to begin by putting the submission in context. It is clear that Victoria's mental health system is beset by some significant structural and funding issues that affect service delivery and outcomes, with specific groups within the community more vulnerable to these shortcomings. Key areas of concern include:

- A lack of policy and systems compliance consistency between local, state, and federal levels of government;
- Patchy and inconsistent access and referral pathways to reliable evidence-based drug and alcohol services, including rehabilitation programs, particularly from general practice;
- A need to make mental health services physically and culturally safe and welcoming places for vulnerable and marginalised populations of people, including people living with HIV;
- A need for services that address the health and mental wellbeing of people who may not have access to services because of their immigration, visa or refugee status;
- Coordination of patient pathways and the patient journey; and
- A need to ensure that compliance with privacy legislation does not become a reason for poor coordination of care, by funding and encouraging services to invest in technologies that allow services to share patient information while safeguarding privacy.

A long history of constructive community action and government collaboration has made significant progress in the fight against the human immunodeficiency virus (HIV). Advances in biomedical treatment have made it possible to suppress HIV and prevent its progression to acquired immunodeficiency syndrome (AIDS), indeed they have made it possible for people living with HIV to live a normal lifespan, and to achieve an undetectable viral load, preventing the onward transmission of HIV.

Despite these advances, significant gaps in HIV care continue to exist. In particular, the mental health burden experienced by people living with HIV has a significant impact on individual and public health, as it affects every major aspect of the HIV response.

In 2017, there were an estimated 26,444 people living with HIV in Australia,<sup>1</sup> and that number has increased since then. Many people living with HIV experience poor mental

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<sup>1</sup> Australian Federation of Aids Organisations (AFAO), 'HIV in Australia, 2019', AFAO (Web Document) <[https://www.afao.org.au/wp-content/uploads/2018/12/HIV-in-Australia-2019\\_No-Bleed.pdf](https://www.afao.org.au/wp-content/uploads/2018/12/HIV-in-Australia-2019_No-Bleed.pdf)>

health outcomes, and evidence indicates a complex and bi-directional relationship between poor mental health and living with HIV.<sup>2</sup>

The Victorian and Commonwealth governments have committed to goals that are consistent with UNAIDS' 90-90-90 goals. Specifically, that by 2020, 90% of all people living with HIV will know their status; 90% of those diagnosed with HIV will be on treatment; and 90% of those on treatment will have an undetectable viral load.

One of the hurdles in achieving and maintaining our current goals is the mental health of people living with HIV. People with mental health issues are at an increased risk of acquiring HIV, and people living with HIV can have poorer mental health outcomes than the general population due to the anxiety and depression that can be associated with the condition itself and/or the stigma and discrimination they experience as a result of their HIV status.

Key to improving the mental health of people living with HIV is combatting HIV-related stigma and discrimination, which are strongly correlated with poor mental health outcomes.<sup>3</sup> Also necessary is the appropriate integration of evidence-based interventions and community-controlled HIV mental health and wraparound support services. This will address gaps in the HIV care continuum, and yield positive service delivery outcomes. It is essential that people living with HIV, or those who may be at risk of contracting HIV, are able to access person-centred, respectful and confidential mental health support when required.

Our organisations remain available to provide further evidence, consultation and testimony to support the efforts of the Royal Commission, as required.

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<sup>2</sup> Fiona Leh Hoon Chuah et al, 'Interventions and approaches to integrating HIV and mental health services: a systematic review' (2007) 32 *Health and Policy Planning* 27.

<sup>3</sup> Jason Appleby, 'HIV, mental health and stigma: a brief survey of current research' (2013) 11(2) *HIV Australia* 17.

## 2. Summary of recommendations

1. Invest in population-wide, community-controlled HIV awareness and anti-stigma campaigns to tackle HIV related stigma and discrimination.
2. Build on progress made with the repeal of section 19A of the *Crimes Act 1958 (Vic)*, and end other forms of HIV criminalisation that continue to hinder the HIV response in Victoria and stigmatise Victorians living with HIV.
3. Invest in program support to ensure that all health care workers have the skills to provide culturally safe and competent services for people from diverse communities, including understanding the specific needs of people living with HIV.
4. Develop and implement an intersectionality framework to identify multiple risks and disadvantages experienced by people with poor mental health, HIV status and other intersecting minority positions, and address barriers to inclusion through an integrated policy framework and associated organisational toolkits.
5. Endorse the proven mixed-model of mental health service provision that includes both mainstream and community-controlled HIV mental health and wraparound support services, and prioritise community-controlled services.
6. Increase ongoing funding for wraparound community-controlled HIV support services.
7. Endorse community-controlled vocational service providers that are capable of assisting people living with HIV assess employment-related risks, facilitate pathways and skill development, and address underlying barriers to employment through integrated service provision.
8. Increase funding for HIV peer support and navigation programs to allow for greater capacity, coverage and diversity.
9. Increase ongoing funding for community-controlled HIV organisations to provide alcohol and other drug services.
10. Increase ongoing funding for home care services for people living with HIV.
11. Fund the co-design of new, and expansion of existing, community-controlled family counselling, peer education programs, and other support services for families of people living with HIV to build stronger communication and relationships within families.

## 3. Mental health experiences of people living with HIV

### 3.1. Rates of mental health conditions

People living with HIV have higher rates of mental illness than the general population.<sup>4,5,6</sup> Anxiety and depression are associated with the HIV diagnosis itself, as well as with stigma and discrimination that can occur as a result of one's HIV status. Relationship difficulties, sexual exclusion and violence, issues with self-esteem, and anxiety disorders can present at key moments during the lifetime of someone living with HIV. This includes at the time of diagnosis of an opportunistic infection or AIDS defining illness, a declining CD4 count (cells that are killed by HIV) or transient viral increase ('blip') or any other reminder of ongoing HIV infection.<sup>7</sup>

#### 3.1.1. Suicidal Ideation

The stigma and discrimination experienced by people living with HIV can cause them to become withdrawn and isolate themselves. This is especially true for people living with HIV at vulnerable intersections, such as immigrants, men who have sex with men, people without familial connection and support, people with pre-existing mental health conditions, and people experiencing intimate partner violence.

While it is known that people living with HIV experiencing isolation can lead to suicidal ideation,<sup>8</sup> there is little available research about suicide rates of people living with HIV. It is possible that these rates have changed over time along with changes in the health and social impacts of HIV. Many risk factors for suicide are factors that are common in the lives of people living with HIV, including social isolation and marginalisation, chronic illness, depression and anxiety, unemployment or financial vulnerability, drug and alcohol use, and social stigma.<sup>9</sup>

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<sup>4</sup> Jennifer Power et al, 'HIV Futures 8: Health and Wellbeing of People Living with HIV' (The Australian Research Centre in Sex, Health & Society, La Trobe University: Melbourne, 2016) <[https://www.latrobe.edu.au/\\_data/assets/pdf\\_file/0006/766896/HIV-Futures-8-Broadsheet-1-on-Health-and-wellbeing.pdf](https://www.latrobe.edu.au/_data/assets/pdf_file/0006/766896/HIV-Futures-8-Broadsheet-1-on-Health-and-wellbeing.pdf)>

<sup>5</sup> Wendy Heywood and Anthony Lyons, 'HIV and elevated mental health problems: diagnostic, treatment, and risk patterns for symptoms of depression, anxiety, and stress in a national community-based cohort of gay men living with HIV' (2016) 20(8) *AIDS and Behavior* 1632.

<sup>6</sup> Anthony Lyons et al, 'Factors related to positive mental health in a stigmatized minority: An investigation of older gay men' (2013) 25(7) *Journal of Aging and Health* 1159.

<sup>7</sup> 'HIV and anxiety fact sheet', *American Psychiatric Association* (Web Page) <[www.psychiatry.org/psychiatrists/practice/professional-interests/hiv-psychiatry/resources](http://www.psychiatry.org/psychiatrists/practice/professional-interests/hiv-psychiatry/resources)>.

<sup>8</sup> Brian Kelly et al, 'Suicidal ideation, suicide attempts, and HIV infection' (1998) 39(5) *Psychosomatics* 405; Nina A Cooperman & Jane M Simoni, 'Suicidal ideation and attempted suicide among women living with HIV/AIDS' (2005) 28(2) *Journal of Behavioral Medicine* 149.

<sup>9</sup> Kelly, B., Raphael, B., Judd, F., Perdices, M., Kernutt, G., Burnett, P., ... & Burrows, G. (1998). Suicidal ideation, suicide attempts, and HIV infection. *Psychosomatics*, 39(5), 405-415; Cooperman, N. A., & Simoni, J. M. (2005). Suicidal ideation and attempted suicide among women living with HIV/AIDS. *Journal of Behavioral Medicine*, 28(2), 149-156.

### 3.2. Psychological side effects of antiretroviral medication

Some medications used to treat HIV can have side effects that cause anxiety, depression and other psychological symptoms.<sup>10</sup> There are potentially severe pharmacokinetic and pharmacodynamic interactions between HIV antiretroviral medication and psychotropic medications. There are specific contraindications to the use of some antipsychotic medications when protease inhibitors are prescribed as treatment for HIV. Drug interactions must be considered and monitored carefully when using psychopharmacotherapy in people living with HIV.<sup>11</sup>

### 3.3. Impact of mental health conditions

People living with HIV who also have a serious mental illness are less likely to adhere to antiretroviral medication.<sup>12</sup> Adherence to medication is important for both personal and community health. A low viral load is important for a person living with HIV to keep control of the virus and maintain a healthy immune system. It also affects the cognitive abilities of people living with HIV.<sup>13</sup> Also, a person with an undetectable viral load is not able to pass on HIV.<sup>14,15</sup> For these reasons, adherence to medication and suppressing the viral load in people living with HIV increases their mental health and quality of life.<sup>16</sup>

A person's health impacts their ability to enter the workforce and engage in sustained work; being asymptomatic or having an undetectable viral load are positively associated with successful labour force participation, and a strong sense of personal identity can also have facilitative effects for employment.<sup>17</sup>

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<sup>10</sup> American Psychiatric Association (n 7).

<sup>11</sup> Ibid.

<sup>12</sup> Buckingham E, Schrage E, Cournos F. 2013. Why the treatment of mental disorders is an important component of HIV prevention among people who inject drugs. *Advances in Preventive Medicine* 2013: 690386; Jeffrey S Gonzalez et al, 'Depression and HIV treatment nonadherence' (2011) *Journal of Acquired Immune Deficiency Syndromes*, online edition. DOI:10.1097/QAI.0bo13e31822d490a

<sup>13</sup> Chang, L., Ernst, T., Witt, M. D., Ames, N., Gaiefsky, M., & Miller, E. (2002). Relationships among brain metabolites, cognitive function, and viral loads in antiretroviral-naive HIV patients. *Neuroimage*, 17(3), 1638-1648.

<sup>14</sup> Rodger A. *Association between sexual activity without condoms and risk of HIV transmission in serodifferent couples when the HIV-positive partner is using suppressive antiretroviral therapy: the PARTNER study*. 21st International AIDS Conference, Durban, abstract TUAC0206, 2016.

<sup>15</sup> Rodger A et al. *Risk of HIV transmission through condomless sex in gay couples with suppressive ART: the PARTNER2 study expanded results in gay men*. 22nd International AIDS Conference, Amsterdam, abstract WEAX0104LB, 2018.

<sup>16</sup> Grace, D., Chown, S. A., Kwag, M., Steinberg, M., Lim, E., & Gilbert, M. (2015). Becoming "undetectable": Longitudinal narratives of gay men's sex lives after a recent HIV diagnosis. *AIDS Education and Prevention*, 27(4), 333-349.

<sup>17</sup> Catherine Worthington et al, 'Enhancing labour force participation for people living with HIV: a multi-perspective summary of the research evidence' (2012) 16 *AIDS and Behavior* 231.

### 3.4. Neurocognitive comorbidities

It is important to consider neuropsychiatric conditions when assessing anxiety and depression in people living with HIV, particularly HIV-associated neurocognitive disorders.<sup>18</sup> In Australia, an estimated 7% of people living with HIV are affected by HIV-associated dementia (the most severe of the HIV-associated neurocognitive disorders) while 30% are affected by a HIV-associated neurocognitive disorder.<sup>19</sup> Age, co-infection with hepatitis, methamphetamine use and a family history of dementia all increase the risk of people living with HIV developing a neurocognitive disorder.<sup>20</sup> Since the advent of highly active anti-retroviral therapy, and with a larger HIV positive population living longer, the incidence of HIV-associated dementia has fallen; however, its prevalence has increased.<sup>21</sup>

### 3.5. AIDS Survivor Syndrome

While the advent of effective medication for people living with HIV has greatly improved their quality of life, it has also created unique stressors on their mental health. The US-based Multicenter AIDS Cohort Study (MACS)<sup>22</sup> has investigated AIDS Survivor Syndrome and how it affects people who have lived through the HIV epidemic, prior to the development of highly effective antiretroviral therapies. As of 2013, the average age of people in the study was 56, and roughly half of the men surveyed (49%) were living with HIV. More than a quarter (27%) of men in the study had lost more than 10 people close to them to AIDS. Thirty-five percent of men reported that they “still grieve” for these lost people, 7% of men reported that they “still deeply grieve,” and 3% reported that they “grieve these losses nearly every day.”<sup>23</sup>

### 3.6. The Lazarus effect

Another side effect to the improved quality of life brought on by effective treatment for HIV is the Lazarus effect. Prior to the development of effective treatment, many people living with HIV lived their lives as if they were about to die; for example, by selling off assets and spending life savings.<sup>24</sup> Once effective treatments drastically increased the quality and longevity of the lives of people living with HIV, many who considered themselves terminally ill never fully recovered financially. These financial pressures add to all the other mental pressures which surround living with HIV, leading not only to poverty but also significant anxiety and depression. This has been seen anecdotally through the peer navigator program at Living Positive Victoria.

<sup>18</sup> American Psychiatric Association (n 7); ‘Help Sheet 19: HIV associated dementia’, *Alzheimer’s Australia* (Web Document) <[https://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia19-HIVAssociatedDementia\\_english.pdf](https://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia19-HIVAssociatedDementia_english.pdf)>

<sup>19</sup> Ibid.

<sup>20</sup> ‘HIV and cognitive disorders fact sheet’, *American Psychiatric Association* (Web Page) <[www.psychiatry.org/psychiatrists/practice/professional-interests/hiv-psychiatry/resources](http://www.psychiatry.org/psychiatrists/practice/professional-interests/hiv-psychiatry/resources)>

<sup>21</sup> ‘What once was old is new again: the re-emergence of HIV-associated dementia’ (2009) 7 *HIV Australia* 20.

<sup>22</sup> Roger Detels et al, ‘The multicenter AIDS cohort study, 1983 to....’ (2012) 126(3) *Public health* 196.

<sup>23</sup> Emily Land, ‘What is AIDS Survivor Syndrome?’, *San Francisco Aids Foundation* (Web Page) <<https://www.sfaf.org/collections/beta/what-is-aids-survivor-syndrome/>>

<sup>24</sup> Stephen Klotz et al, ‘HIV Infection-Associated Frailty: The Solution for Now Is Antiretroviral Drugs: A Perspective’ (2019) 18 *Journal of the International Association of Providers of AIDS Care* 1.

## 4. Prevention

### 4.1. Combatting stigma and discrimination

The *Victorian HIV Strategy 2017-2020* commits Victoria to the ambitious goal of eliminating HIV stigma and discrimination by 2030.<sup>25</sup>

Stigma and discrimination are a large contributor to poor mental health outcomes for people living with HIV.<sup>26</sup> Stigma can prevent people from disclosing their HIV status and obtaining the support, treatment and care they need.<sup>27</sup>

While stigma is external to the individual, stigma becomes internalised and is often deeply diminishing to the person who experiences it.<sup>28</sup> Both external and internal stigma influence the mental and physical wellbeing of people living with HIV.<sup>29</sup> Stigma merely has to be perceived for it to have a significant impact on a person's mental health,<sup>30, 31</sup> and has been directly linked to depression.<sup>32</sup>

#### 4.1.1. Awareness and anti-stigma campaigns

Educational initiatives and community-controlled anti-stigma campaigns can combat HIV stigma, raise awareness, and build resilience in communities. Thorne Harbour Health's HIV Still Matters and Treat HIV Now, and Living Positive Victoria's U=U campaigns have raised awareness of HIV, contributing to HIV prevention and anti-stigma efforts. However, there exists a need for a dedicated, population-wide, community-controlled HIV anti-stigma campaign if Victoria is to make headway in achieving its ambitious goal of eliminating HIV-related stigma and discrimination. It is essential that any such campaign be based on the principles of the meaningful involvement of people living with and affected by HIV.

<sup>25</sup> 'Ending the AIDS Epidemic by 2030', Fast-track Cities, (Web Page) <[www.fast-trackcities.org/cities/victoria](http://www.fast-trackcities.org/cities/victoria)>

<sup>26</sup> Sean Slavin et al, 'The HIV stigma audit: community report' (National Association of People Living With HIV/AIDS, National Centre in HIV Social Research) <[http://napwha.org.au/files/napwa\\_stigma\\_audit\\_report.pdf](http://napwha.org.au/files/napwa_stigma_audit_report.pdf)>

<sup>27</sup> James Dennis Fortenberry D et al, 'Relationships of stigma and shame to gonorrhoea and HIV screening' (2002) 92(3) *American Journal of Public Health* 378.

<sup>28</sup> Elaine Brohan et al, 'Experiences of mental illness stigma, prejudice and discrimination: a review of measures' (2010) *BMC Health Services Research*.

<sup>29</sup> Peter Venable et al, 'Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment Among HIV-Positive Men and Women' (2006) 10(5) *AIDS and Behavior* 473.

<sup>30</sup> 'Beyondblue Information Paper: Stigma and discrimination associated with depression and anxiety', *BeyondBlue* (Web Document) <<https://www.beyondblue.org.au/docs/default-source/policy-submissions/stigma-and-discrimination-associated-with-depression-and-anxiety.pdf>>

<sup>31</sup> Anthony Lyons et al, 'Psychosocial factors associated with resilience in a national community-based cohort of Australian gay men living with HIV' (2016) 20(8) *AIDS and Behavior* 1658.

<sup>32</sup> Mary R Tanney et al, 'Depression and stigma in high risk youth living with HIV (YLH): A Multisite Study' (2012) *Journal of Pediatric Health Care* 26(4) 300; Michael Young et al, 'Interpersonal Discrimination and the Health of Illicit Drug Users' (2005) 31(3) *American Journal of Drug and Alcohol Abuse* 371.

### Recommendation 1

Invest in population-wide, community-controlled HIV awareness and anti-stigma campaigns to tackle HIV related stigma and discrimination.

#### 4.1.2. End legislative discrimination

In 2015, Victoria repealed section 19A of the *Crimes Act 19589* (Vic), which specifically criminalised the intentional transmission of HIV, labelling it an “outdated, discriminatory law” that was the only offence of its kind in Australia to single out people living with HIV.<sup>33</sup> However, people living with HIV can still face criminal charges for reckless HIV transmission, as well as reckless endangerment in cases where no such transmission or transmission risk occurs.

These laws do not take into account recent biomedical advances in HIV prevention. There is a need to clarify what constitutes ‘reasonable precautions’ taken to prevent the transmission of HIV, as reasonable precautions are not limited to condom use. Scientific evidence supports that a sustained *undetectable* viral load means HIV is *untransmittable* (U=U), and partners without HIV can protect themselves using pre-exposure prophylaxis (PrEP). Indeed, it has been demonstrated that an undetectable viral load is the most powerful HIV prevention method available.<sup>34</sup> It is not reckless for people living with HIV to have sex without a condom if other reasonable precautions (such as adherence to treatment and the maintenance of an undetectable viral load) to reduce the risk of HIV transmission have been taken.

The *Sex Work Act 1994* (Vic) prohibits people living with HIV from working as sex workers.<sup>35</sup> This discriminatory law is in breach of the right to non-discrimination, and fails to recognise both that sex workers have high rates of condom use, and that people with a sustained undetectable viral load cannot transmit HIV.

Based on evidence from the national HIV Stigma Indicators Project that many health care workers admit to having treated patients differently based on their HIV status. There is a need to ensure health care workers are adequately trained to provide culturally safe services to people from diverse communities, including people living with HIV and their specific needs.

<sup>33</sup> ‘Another Step Toward Equality for People Living with HIV’, *Premier of Victoria* (Web page) <<https://www.premier.vic.gov.au/another-step-toward-equality-for-people-living-with-hiv-2/>>

<sup>34</sup> Alison Rodger et al, ‘Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study’ (2019) 383(10189) *The Lancet* 2428.

<sup>35</sup> *Sex Work Act 1994* (Vic), ss 19-20.

**Recommendation 2**

Build on progress made with the repeal of section 19A of the *Crimes Act 1958* (Vic), and end other forms of HIV criminalisation that continue to hinder the HIV response in Victoria and stigmatise Victorians living with HIV.

**Recommendation 3**

Invest in program support to ensure that all health care workers have the skills to provide culturally safe and competent services for people from diverse communities, including understanding the specific needs of people living with HIV.

**4.2. Mental health and HIV risk**

Prevalence studies have shown that mental health is a risk factor for HIV acquisition and other blood borne viruses (BBV).<sup>36,37</sup> Multiple co-occurring conditions, such as substance abuse and depressive symptoms, contribute to an even higher risk.<sup>38</sup>

A US study of men who have sex with men found that the probability of acquiring HIV increases as the number of comorbid conditions increases,<sup>39</sup> and severe mental health problems (for example, disorders that are persistent, disabling, and require specialised psychiatric treatment) contribute an even higher risk.<sup>40</sup>

People living with serious mental illness and/or addictions experience much higher rates of physical ill health than the general population.<sup>41</sup> The mental health burden in this population widens health inequalities and contributes to disability, which affects access to care. This is further exacerbated by insufficient early intervention in primary care to people experiencing symptoms of mental illness, which is critical to reducing future adverse outcomes.<sup>42</sup> Of particular relevance to people living with a serious mental illness and HIV is the influence psychiatric illness may have on risk behaviours, medication adherence and disease progression.<sup>43</sup> Psychiatrists treating people living with HIV should ensure adequate support is provided either through up-skilling or appropriate referrals.

<sup>36</sup> Elizabeth Hughes et al, 'Prevalence of HIV, hepatitis B, and hepatitis C in people with severe mental illness: a systematic review and meta-analysis' (2016) 3(1) *The Lancet* 40.

<sup>37</sup> Christina S Meade & Kathleen J Sikkema, 'HIV risk behavior among adults with severe mental illness: a systematic review' (2005) 25(4) *Clinical psychology Review* 433.

<sup>38</sup> *Ibid.*

<sup>39</sup> Dale O'Leary, 'The syndemic of AIDS and STDS among MSM' (2014) 81(1) *Linacre Q* 12.

<sup>40</sup> *Ibid.*

<sup>41</sup> Royal Australian and New Zealand College of Psychiatrists, 'Keeping body and mind together: Improving the physical health and life expectancy of people with serious mental illness' (RANZCP Melbourne, Australia: 2015)

<sup>42</sup> Louise Farrer et al, 'Primary care access for mental illness in Australia: Patterns of access to general practice from 2006 to 2016' (2018) 13(6) *PLoS One* e0198400.

<sup>43</sup> Kurt Andersson-Noorgard, 'Mental illness and HIV' (2010) 18 *Social research briefs* 1.

Despite a higher incidence of HIV-related risk behaviours (e.g. sex without a condom, trading sex for money and drugs) among people living with mental illness, attention to HIV education and prevention for this group of people has been limited to date.<sup>44</sup> People with serious mental illness should be identified as a health priority population group. Psychiatrists should consider screening their patients for sexual and drug use risks during routine psychiatric assessments. HIV testing should be offered where indicated by risk histories or other relevant medical findings.

Some of the risk behaviours surrounding exposure to HIV have specific causes. For example, women, and men who have sex with men who experience intimate partner violence are more likely to engage in at risk behaviours for contracting HIV (such as unprotected sex and drug use).<sup>45</sup> While heterosexual men do not experience the same levels of intimate partner violence, they do also participate in risk behaviours.

### 4.3. Intersectionality framework

There are some specific communities or groups of people whose risk of HIV transmission, or of a poorer health outcome if diagnosed with HIV is related to cultural and other factors. Therefore, it is necessary to take an intersectional approach, to ensure that these factors, where relevant, are acknowledged.

These risks are related to factors including more general cultural or social isolation, as well as language, cultural differences, or the practising of behaviours that are stigmatised within the broader community. These can increase the vulnerability of people with HIV, including their vulnerability to poor health and mental health outcomes. There may be less support available to these people due to language or cultural barriers, health literacy, or appropriate health services.

One group of people at high risk of poor mental health outcomes from HIV is people who are seeking asylum or who are refugees, people who cannot access services because they do not have Medicare access, or people who may be concerned that seeking testing or treatment for HIV may affect their visa status.

The stigma associated with a HIV diagnosis may be great in certain communities. It is crucial to support the mental health of people living with HIV by supporting peer-led approaches that recognise the diversity of cultural background and life experience of people living with HIV.

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<sup>44</sup> Sandra C Thompson et al, 'HIV risk behaviour and HIV testing of psychiatric patients in Melbourne' (1997) 31 *Australian and New Zealand Journal of Psychiatry* 566; Andersson-Noorgard (n 37).

<sup>45</sup> Laura Bogart et al, 'The association of partner abuse with risky sexual behaviors among women and men with HIV/AIDS' (2005) 9(3) *AIDS and Behavior* 325.

**Recommendation 4**

Develop and implement an intersectionality framework to identify multiple risks and disadvantages experienced by people with poor mental health, HIV status and other intersecting minority positions, and address barriers to inclusion through an integrated policy framework and associated organisational toolkits.

## 5. Community-controlled services

Community-controlled organisations are governed and operated by and for affected communities, which enables them to deliver safe and culturally appropriate services that are trusted by the communities they serve.

Community-controlled health services, such as those provided by Living Positive Victoria, Thorne Harbour Health, and Positive Women Victoria, have a long history of mobilising community-led responses to health issues that are capable of overcoming access barriers posed by privacy concerns, stigma and discrimination experienced by people living with HIV.<sup>46</sup> Supportive environments facilitate people seeking the care they need, ultimately resulting in better health outcomes.

Peer led programs work best when integrated into the formal structure of the healthcare system. Providing knowledge and skills to the healthcare providers who work with people living with HIV is the best way of ensuring that these people will receive the best care possible. This includes the dissemination of information about available programs to any healthcare provider who may diagnose a person with HIV. All healthcare providers should be aware of issues relating to HIV, know where they might be able to access this information and/or feel confident enough to refer people living with HIV to another healthcare provider who is better equipped to deal with issues relating to HIV. This is especially true for any mental health professional, including acute and emergency responders to mental health (such as suicide helplines, general practitioners and psychologists, psychiatrists, and counsellors).

### Recommendation 5

Endorse the proven mixed-model of mental health service provision that includes both mainstream and community-controlled HIV mental health and wraparound support services, and prioritise community-controlled services.

### 5.1. Overview of services

#### 5.1.1. Living Positive Victoria's services

Living Positive Victoria delivers the following peer-led programs to better the mental health and quality of life for people living with HIV:

- Ongoing contact for people living with HIV with regular Cook and Chats for heterosexual men; Seaside retreats for people living with HIV and their families; and Planet Positive for all people living with HIV.

<sup>46</sup> Nous Group, 'Demonstrating the value of community control in Australia's HIV response: AFAO and Australia's State and Territory AIDS Councils' (24 June 2016).

- Gen Next, an empowering program which allows young people living with HIV to connect and build knowledge about the social and health issues relating to HIV;
- The Positive Leaders Development Institute, which builds leadership skills in people living with HIV.
- Positive Self-Management program; a capacity building program designed to allow people aging with HIV to maintain their health independently
- Volunteer participation and community events delivery which promote acceptance, validation, visibility and community connection.

### 5.1.2. Thorne Harbour Health's services

Thorne Harbour Health provides the following services to support the mental health of people living with HIV:

- Counselling Services for people affected by or at risk of HIV
- Alcohol and Drug Counselling, Care Coordination and therapeutic group services
- Family/Intimate Partner Violence programs
- General Practice with specialist care for people living with HIV/Hep C, and specific bulk billing General Practice services to the trans and gender diverse community;
- The Positive Living Centre, a drop-in centre providing practical, social and peer support for people living with HIV;
- The Community Support Program, which provides staff and volunteer support to people living with HIV, including medical transport and group activities, and home care from attendant care workers; and
- Housing Plus, a state-wide program supporting people living with HIV who are homeless or at risk of homelessness to seek appropriate and stable accommodation.

### 5.1.3. Positive Women Victoria's services

Positive Women Victoria services include:

- Individual support for women and girls living with and affected by HIV;
- Support and referral for women living with HIV from diverse cultural and social backgrounds;
- Peer support leadership and development programs for women to increase the visibility of women living with HIV in the community; and
- Advocacy and peer-led education, including education for health care and other service workers, to increase understanding of the specific health and mental health needs of women living with HIV in the community.

## 5.2. Wraparound support

In addition to medical treatment, wrap-around HIV support services are essential, because when people's basic needs are met they adhere better to treatment.<sup>47</sup> Treatment adherence is of fundamental importance because it improves the health of people living with HIV, while also reducing HIV transmission through the maintenance of an undetectable viral load.

Examples of wrap-around support services include low cost meal programs, recreational and physical activities, housing support, home care, and employment services. Home care is of particular importance in the context of an ageing population of people living with HIV; residential aged care can cause many people who had been living openly with HIV to feel they have to hide their HIV status.<sup>48</sup> As people living with HIV are living longer due to the advancements in treatments they will be needing to access supports through the aged care system and in aged care facilities. There are unique challenges to providing mental health support in an aged care context. Conditions such as HIV-related neurological complications<sup>49</sup> may add to the already complex care needs associated with ageing. Aged care workers need to have the skills and training to care for PLHIV, stigma in the aged care setting is something many people fear..

### Recommendation 6

Increase ongoing funding for wraparound community-controlled HIV support services.

### Recommendation 7

Endorse community-controlled vocational service providers that are capable of assisting people living with HIV assess employment-related risks, facilitate pathways and skill development, and address underlying barriers to employment through integrated service provision.

### 5.2.1. Peer support

Key to the success of peer support is that it is delivered by peers with a shared lived experience with those they support. The empathy and connection to community ensures a safe space for people to work through issues that impact their mental health such as internalised stigma, depression and coping with the diagnosis itself.

<sup>47</sup> Gonzalez (n 11).

<sup>48</sup> Catherine Barrett, 'My people: Exploring the experiences of gay, lesbian, bisexual, transgender and intersex seniors in aged care services' (Report, Matrix Guild Victoria Inc and Vintage Men Inc, June 2008).

<sup>49</sup> Clifford, D. B., & Ances, B. M. (2013). HIV-associated neurocognitive disorder. *The Lancet. Infectious diseases*, 13(11), 976–986. doi:10.1016/S1473-3099(13)70269-X

### 5.2.1.1. *Living Positive Victoria's peer support*

Living Positive Victoria's peer navigation program is designed to help people who have been newly diagnosed with HIV and/or are struggling with the day to day realities of living with HIV. This is achieved by connecting them with other people living with HIV who can help them navigate their way through difficult times. The diverse team of peer navigators aims to be able to cater to a wide variety of shared experiences with and around HIV including gender, sexuality and culture.

Living Positive Victoria also runs Phoenix, a peer facilitated workshop designed for people who have yet to come to terms with their HIV diagnosis. This program connects people living with HIV with each other, and provides health literacy around HIV, including treatments, health concerns and strategies to prevent transmission of HIV. There are three different Phoenix workshops which are tailored for different demographics; men who have sex with men, heterosexual men, and women living with HIV.

An evaluation of Phoenix showed statistically significant improvements for participants in social, psychological and health concern indicators at two months follow up.<sup>50</sup> As the following testimonials make clear, Phoenix provides psychosocial support to people living with HIV at a time when they need it most:

***"I went to Phoenix years ago and still have friends I made at these groups. Phoenix is very professionally run, and they pack a lot of good information into the time. It's a good way of learning about the diversity of experience from others in the group, and quietly busting a few self-generated myths. I appreciated just being able to express myself in front of peers."***

### 5.2.1.2. *Thorne Harbour Health's peer support*

Thorne Harbour provides HIV peer support through the Community Support Program and the Positive Living Centre.

Community Support peer staff work regularly in the ID clinics of major HIV hospitals, with a focus on talking to people who are newly diagnosed and ensuring that they are connected to other appropriate Community Support services. This includes referral for support from peer volunteers, medical transport and on-going support from a volunteer team to combat social isolation and connect clients to their community. Peer staff train and support the peer volunteers, and also facilitate small group social gatherings for peer support.

Peer staff at the Positive Living Centre provide one-on-one peer support for new and existing clients and refer them to other services as required. Trained peer volunteers also facilitate HIV peer support groups that run weekly for up to eight weeks and provide a safe and supportive environment for exploring key topics about living with HIV.

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<sup>50</sup> Graham Brown and James Dunne, 'PozQoL PLHIV Quality of Life implementation and evaluation trial' (Australian Research Centre in Sex, Health and Society, La Trobe University: Melbourne, 2019).

An evaluation of Thorne Harbour Health's community support at the Positive Living Centre showed statistically significant increases in social, psychological and health concern indicators over two to three months.<sup>51</sup>

Thorne Harbour Health and Living Positive Victoria are collaborating on a peer-led, HIV & Ageing Project. The project includes the Positive Self-Management Program for HIV and also a monthly Peer Support Network gathering offering sessions covering a variety of topics relating to HIV & Ageing in a social setting.

### **Recommendation 8**

Increase funding for HIV peer support and navigation programs to allow for greater capacity, coverage and diversity.

#### 5.2.2. Alcohol and other drug treatment services

The concurrence of mental health conditions and substance use is often referred to by people working for Victorian alcohol and other drug treatment services as a 'dual diagnosis'. The term emerged when the Victorian mental health and drug systems were deinstitutionalised between 1988 and 1998, and in the process re-conceptualised as two separate systems, and large psychiatric hospitals were closed in favour of community-based services.<sup>52</sup> Victoria differed to other states in that it adopted a less medicalised model and a wholly non-government specialist AOD workforce; one that lacked funding for addiction medicine and psychiatry support.<sup>53</sup>

Dual diagnosis presents as clients self-medicating to alleviate the symptoms of poor mental health or to help cope with feelings and self-worth that is impacted by stigma and discrimination. This is particularly relevant to people living with HIV who are struggling with their HIV status as well as any other stressors present in their lives.<sup>54</sup>

A 2012 study of Victorian AOD treatment services found that study participants believed, consistent with dual diagnosis program evaluations,<sup>55</sup> that dual diagnosis discourse has positively influenced AOD service screening, assessment and treatment.<sup>56</sup> In addition, the study found that notable barriers to quality improvement included high expectations that the

<sup>51</sup> Ibid.

<sup>52</sup> Bridget Roberts and Rebecca Jones, 'Dual Diagnosis Narratives and Their Implications for the Alcohol and other Drug Sector in Australia' (2012) 39(4) *Contemporary Drug Problems* 663, 666.

<sup>53</sup> Ibid.

<sup>54</sup> De Hert, M., Correll, C., Bobes, J., Cetkovich-Bakmas, M., Cohen, D., Asai, I., et. al. (2011). Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care. *World Psychiatry* 10(1), 52–77.

<sup>55</sup> Australian Healthcare Associates, 'Evaluation of the Victorian Dual Diagnosis Initiative' (Australian State and Territory Peak Alcohol and Other Drugs (AOD) 2011); National Improved Services Initiative Forum, 'Outcomes from the National Improved Services Initiative Forum: A Tale of Two Systems' (Australian State and Territory Peak Alcohol and Other Drugs (AOD) Non-Government Organisations. Adelaide, 2011)

<sup>56</sup> Roberts and Jones (n 45) 678.

sector provides professional services with specialist expertise, as well as more general support from a low funding base.<sup>57</sup>

### **Recommendation 9**

Increase ongoing funding for community-controlled HIV organisations to provide alcohol and other drug services.

#### 5.2.3. Housing support

Housing Plus is a state-wide Victorian program operated by Thorne Harbour Health that supports people living with HIV who are homeless or at risk of homelessness to seek appropriate and stable accommodation. Homelessness and inappropriate public housing can cause a lot of stress for people living with HIV. These stressors include but not limited to the fear of stigma and discrimination from an unwanted or unplanned disclosure of their HIV status and/or not being able to look after their physical health without an appropriate place to store and take medication.

Housing Plus streamlines client referrals to Thorne Harbour Health's mental health and other health and support services, which improves efficiencies and data integration between services. This emphasises the importance of community-controlled health service delivery and the integration of mental health and wraparound support services.

#### 5.2.4. Home care

Home care supports people living with HIV to continue living independently for longer than would otherwise be possible. Home care provides attendant care workers to assist with cooking, cleaning and shopping, and is targeted at people with complex physical or mental health conditions who may otherwise need to move out of their home into a supported living facility. Home care also assists people recovering from a serious hospital admission in their transition back to independent living and supports palliative clients to stay at home for as long as practicable. Home care complements clinical services, promotes HIV and mental health treatment adherence, and improves the physical and mental health of people living with HIV.

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<sup>57</sup> Ibid 679.

**Recommendation 10**

Increase ongoing funding for home care services for people living with HIV.

### 5.2.5. Support for families

Caring for people with mental health conditions can be a burden for families, and a lack of support from family or community can lead to negative impacts for people with poor mental health.<sup>58</sup> Family support structures can be less accessible to people living with HIV due to the stigma associated with HIV.<sup>59</sup> As families are a key support structure for people with poor mental health, it is important that families, both biological and chosen, are knowledgeable about the mental health and wellbeing issues that can affect someone living with HIV.<sup>60</sup>

Not only should families of HIV positive people be knowledgeable about what struggles may be experienced by those living with HIV, but they need to be supported to deal with issues that arise for them in caring for those individuals. Community-controlled family counselling, peer education programs and support services will help families reduce the stigma surrounding HIV and create a supportive environment to allow for better mental health outcomes for themselves and those they care for.

**Recommendation 11**

Fund the co-design of new, and the expansion of existing, community-controlled family counselling, peer education programs, and other support services for families of people living with HIV to build stronger communication and relationships within families.

<sup>58</sup> Ajit Avasthi, 'Preserve and strengthen family to promote mental health' (2010) 52(2) *Indian journal of psychiatry* 113.

<sup>59</sup> Tllhalefi Tlhowe et al, 'Strengths of families to limit relapse in mentally ill family members' (2017) 22(3) *Health SA Gesondheid* 28.

<sup>60</sup> Asha Persson et al, 'Families Living with Blood-Borne Viruses: The Case for Extending the Concept of "Serodiscordance"' (2017) *Interdisciplinary perspectives on infectious diseases* 1.

## 6. Conclusion

This submission has outlined measures to improve the mental health and wellbeing of Victorians living with HIV, including improved prevention and bolstered community-controlled mental health and wraparound support services.

Key community-controlled HIV organisations have collaborated on this submission to outline a range of recommendations to combat stigma and discrimination, and build on existing funded services and programs.

We must never forget that the HIV response is not just about ending new HIV transmissions and getting people living with HIV on treatment; it is also about ensuring people living with HIV are supported by high quality, culturally safe mainstream and community-controlled mental health and wraparound support services, and can live free of the impact of HIV-related stigma and discrimination. By doing this, and by adopting the recommendations in this submission, we can work towards a Victoria where people living with HIV maintain the good mental health and high quality of life that they deserve.



20 August 2019

Royal Commission into Victoria's Mental Health System

By email: [contact@rcvmhs.vic.gov.au](mailto:contact@rcvmhs.vic.gov.au)

**Re: Implementing respectful and appropriate mental health care for people living with HIV**

Thorne Harbour Health, Living Positive Victoria, and Positive Women Victoria welcome the opportunity to contribute to the Royal Commission into Victoria's Mental Health System.

In addition to the recommendations made in our joint submission dated 5 July 2019, we further recommend the full implementation of the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) *Standards for psychological support for adults with HIV* (ASHM guidelines). In short, the ASHM guidelines detail eight standards that prioritise the promotion of mental and psychological wellbeing through care that is sensitive to the unique and full range of needs of people living with HIV. They seek to encourage:

- Positive service and treatment uptake;
- Peer support and community engagement;
- Open and supportive clinical communication to facilitate referral;
- Effective service integration and coordination; and
- Early and timely access to evidence-based psychological interventions, of various levels of complexity.

We recommend that the Royal Commission endorse the ASHM guidelines in its findings. The full implementation of the ASHM guidelines across all sectors of the healthcare system will ensure that people living with HIV receive a consistently high standard of care that is safe, affirming and supportive.

The formal endorsement of the ASHM guidelines will have a significant impact in promoting mental health and wellbeing, the early detection of psychological difficulties, and the provision of appropriate interventions for people living with HIV.

This must be supported by training so that mental health professionals have an adequate understanding of living with HIV. Greater investment is also needed in peer navigation programs to assist people living with HIV to navigate the mental health system.

Yours sincerely

Richard Keane  
CEO, Living Positive Victoria

Simon Ruth  
CEO, Thorne Harbour Health

Kirsty Machon  
EO, Positive Women Victoria

STANDARDS FOR  
PSYCHOLOGICAL  
SUPPORT FOR  
ADULTS WITH HIV



**ashm**

Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine



# Standards for psychological support for adults with HIV

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## Foreward

The Australian *Standards for psychological support for adults with HIV* are based on the United Kingdom's (UK's) *Standards for psychological support for adults living with HIV*. The UK standards are produced by the British Psychological Society, British HIV Association and Medical Foundation for HIV & Sexual Health and were published in November 2011.

People with HIV (PWHIV) experience significantly higher rates of psychological difficulties than the general population [1-3]. This has a major impact on quality of life, complicates clinical care, adversely affects physical health outcomes and increases the risk of HIV transmission. Evidence shows that psychological care can improve mental health outcomes for PWHIV.

The document sets out standards for psychological support that should be available for all adults with HIV in Australia. The aim is to promote mental health and wellbeing, early detection of psychological difficulties and the provision of appropriate interventions for those who need them.

A wide range of service providers – across public, private and nongovernment sectors – play a critical role in the provision of psychological support for PWHIV. These standards are intended to apply to all services providing psychological support for adults with HIV in Australia. The editorial committee of this guideline notes that although the term *psycosocial* is more widely used in Australia, the term psychological was kept because substantial changes would have been needed to have made the change from psychological to psycosocial, and such changes were outside of the scope of this project.

These standards are intended to provide a guideline for the optimum development, planning and provision of HIV services. Meeting all standards may be difficult, particularly in areas that are remote, are under-resourced or have limited contact with PWHIV. Nevertheless, the purpose of these standards is to inform service providers about how effective psychological support adds value to HIV prevention, treatment and care services.

The committee involved in the development of these standards acknowledges the principles of the Ottawa Charter [4], *The greater involvement of people living with HIV (GIPA)* [5] and the *Declaration of rights of people living with HIV/AIDS* [6].

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# Abbreviations and Acronyms

<b>AHPRA</b>	○ —	<b>Australian Health Practitioner Regulation Agency</b>
<b>ART</b>	○ —	<b>antiretroviral therapy</b>
<b>ASHM</b>	○ —	<b>Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine</b>
<b>BHIVA</b>	○ —	<b>British HIV Association</b>
<b>CALD</b>	○ —	<b>culturally and linguistically diverse</b>
<b>CBT</b>	○ —	<b>cognitive behaviour therapy</b>
<b>CPD</b>	○ —	<b>continuing professional development</b>
<b>GIPA</b>	○ —	<b>greater involvement of people living with HIV</b>
<b>HAND</b>	○ —	<b>HIV-associated neurocognitive disorder</b>
<b>HARP</b>	○ —	<b>Hospital Admission Risk Program</b>
<b>HIV</b>	○ —	<b>human immunodeficiency virus</b>
<b>HQIP</b>	○ —	<b>Health Quality Improvement Partnership</b>
<b>MEDFASH</b>	○ —	<b>Medical Foundation for HIV &amp; Sexual Health</b>
<b>NAPWHA</b>	○ —	<b>National Association of People with HIV Australia</b>
<b>NSW</b>	○ —	<b>New South Wales</b>
<b>PLHIV</b>	○ —	<b>people living with HIV (or person living with HIV)</b>
<b>PWHIV</b>	○ —	<b>people with HIV</b>
<b>RCT</b>	○ —	<b>randomised controlled trials</b>
<b>UK</b>	○ —	<b>United Kingdom</b>
<b>UNSW</b>	○ —	<b>University of New South Wales</b>
<b>WHO</b>	○ —	<b>World Health Organization</b>

## Executive summary

**People living with HIV are at increased risk of psychological distress and cognitive impairment; hence, they need effective, psychological support services. Being diagnosed with HIV continues to have a strong influence on psychological coping and lifestyle choices for many people.**

The dominant theme of psychological wellbeing is unashamedly present in these national guidelines because of the psychologically distressing impacts of living with HIV. This recognition is vital in reminding us that there is always a person present behind the diagnosis of HIV. Of course, people are more than their HIV, and we need to develop ways of reducing psychological distress wherever possible as people come into contact with our health systems and related care systems. These guidelines are notable for their recognition of the primacy of the role of the person with HIV in the development, implementation and evaluation of the psychological support services meant for them. The meaningful involvement of people with HIV provides a robust mechanism that insures the suitability and sustainability of the service, and addresses the unique and diverse environments and communities of Australia, including the diverse demographic and geographic nature of this constituency. These guidelines mean that people with HIV in Australia can expect the highest standard of psychological care, no matter where they are in Australia. The guidelines are framed as eight standards. They provide clear and purposeful benchmarks for better practice that will continue to shape and inform treatments and support mechanisms. Existing and newer services and agencies working to prevent and treat HIV can use the opportunity offered by these standards to develop appropriate and respectful approaches for care and prevention. Standard 1 sets the scene, stating unequivocally the need to promote mental and psychological wellbeing, particularly in regards to the prevalence of stigma and discrimination.

The other seven standards deliver a comprehensive, coordinated framework of professionally supported, evidence-based service provision. Particularly important are:

- Standard 3 (Meaningful involvement of people with HIV), which specifically mandates a role for people with HIV in the development, implementation and evaluation of psychological support services
- Standard 4 (Support at the time of diagnosis), which articulates the importance of well-trained practitioners in the delivery of a confirmation of HIV transmission, but also mandates referral pathways to voluntary and peer-based services for emotional support.

The guidelines describe a true partnership between service planners and service providers (both professional and non-professional) and the people they seek to serve. They prescribe a high standard of service planning and delivery, training and development, and the inclusion of affected populations. This is the perfect environment to enhance the agency of the person with HIV to:

- contribute to the system of support
- engage in the management of their own psychological wellbeing and, where that engagement is beyond their capacity, to trust that their particular sensibilities, vulnerabilities and control over their reality will be recognised, prioritised and dignified.

The standards will offer the opportunity to assess and monitor the effectiveness of clinical and service approaches to those living with HIV. Auditable indicators offered for service improvement for each standard will assist in guiding action.

It is hoped that these national standards will influence and support psychological wellbeing as we continue to prevent and reduce the burden of disease associated with HIV. Of greatest importance, however, is the recognition that psychological support sits equally beside physical wellbeing and prevention strategies in the HIV response.

## Part A: Introduction

---

### 1.1 What are the standards?

This document sets out standards for psychological support that should be available for all adults with human immunodeficiency virus (HIV) in Australia. The Australian standards are an adaptation of the United Kingdom (UK) document, Standards for psychological support for adults living with HIV [1]. The UK standards were developed through a partnership between the British Psychological Society, the British HIV Association (BHIVA) and the Medical Foundation for HIV & Sexual Health (MEDFASH).

#### 1.1.1 Definition of psychological support

For the purposes of this document, psychological support is defined as 'any form of support that is aimed at helping people with HIV to enhance their mental health and their cognitive, emotional and behavioural wellbeing'.

Psychological support is provided at different levels of complexity by a wide range of professional groups, peers and informal providers, both in clinical settings and in the community. Examples of such support include emotional support and the provision of a variety of talking therapies, cognitive assessment and interventions, and appropriate medication.

### 1.2 Who should use the standards?

The standards represent current best practice and are intended to apply to all services providing psychological support (as defined above) for adults with HIV. These services may be provided by the public, private or nongovernment sectors. The standards do not make recommendations for specific professional groups.

This document should be a key resource for the following groups:

- service providers – to help them to provide a high standard of psychological care to people with HIV (PWHIV)
- PWHIV – to help them to understand what they can expect from services
- HIV program planners – to ensure that psychological support services for PWHIV are adequately resourced.

The standards are intended to apply to all parts of Australia. Although the systems and structures for planning and funding services differ between states and territories, all PWHIV are entitled to expect a consistently high standard of care. In cases where services providing psychological support are not currently meeting these standards, the standards should act as a catalyst to improve the psychological care provided to PWHIV.

### 1.3 Scope of the standards

The focus of these standards is the psychological support PWHIV should receive. The standards recognise that various factors other than psychological support influence psychological outcomes in PWHIV. Examples of such factors are social and economic circumstances, life experiences (e.g. immigration), community attitudes and stigma, medical care and medication (including antiretroviral therapy, ART). Although these standards recognise the impact of these additional factors, addressing them is outside the scope of the standards.

### 1.4 Why is psychological support for people with HIV important?

#### 1.4.1 HIV in Australia

At the end of 2015, there were about 25,313 people with HIV in Australia, of whom an estimated 10% were not aware of their HIV-positive status. The number of people with HIV in Australia has remained stable over the past 4 years, with over 1000 new notifications each year. The rate of new notifications is proportionally higher among Aboriginal and Torres Strait Islander populations than among Australian-born non-Indigenous populations. In Australia, HIV



prevalence is highest among men who have sex with men [2]. Patterns of late presentation have been noted in certain populations of Australians; for example, culturally and linguistically diverse (CALD) communities, heterosexual men and women, and people from high-prevalence countries [2].

#### **1.4.2 High prevalence of psychological problems**

The prevalence of mental health problems among PWHIV is substantially higher than in the general population [3-5]. For example, PWHIV are about twice as likely to be diagnosed with depression as matched controls in the general population. Similarly, people with visible symptoms of HIV are more likely to experience depression, stress, anxiety and HIV-related stigma than those without such symptoms [6].

Psychological difficulties can result from receiving an HIV diagnosis and the challenges of living with HIV [7]. In Australia, the introduction of highly active ART (HAART), which is more effective than ART, has changed HIV from being a fatal disease to a chronic condition [8]. Yet despite increased longevity and improved physical health, HIV continues to be a difficult and stressful condition for many people. Recent research with PWHIV identified a complex array of concerns about quality of daily life and other personal, social and medical issues, with widespread reports of discrimination and social isolation. Such experiences, together with the other psychosocial factors noted above, can have a negative effect on health outcomes [6, 9, 10].

HIV is often concentrated in vulnerable and stigmatised populations who are already at greater risk of mental health problems than the general population [11], and HIV exacerbates this mental health inequality [12, 13]. For example, the rate of mental health issues is higher among Aboriginal and Torres Strait Islander people than among non-Indigenous people [14]. Also, experiences of discrimination reported by gay men with HIV are associated with poorer mental health outcomes in this population [15].

#### **1.4.3 Impact on clinical management and worsening health outcomes**

Psychological problems complicate the care and clinical management of people with HIV by decreasing rates of adherence to ART, increasing loss to follow-up, reducing quality of life and leading to poorer health outcomes, including clinical decline and mortality [16-19]. Such outcomes result in longer and more frequent hospital admissions and other costly interventions.

Experiences of stigma in the context of health care can have a negative influence on treatment adherence for HIV [20, 21]. In contrast, satisfaction with health-care professionals' service tends to increase adherence to medication and treatment in adult PWHIV [22, 23].

#### **1.4.4 Higher prevalence of cognitive impairment and its outcomes**

Cognitive impairment is more common among PWHIV than in the general population [24] and is an independent risk factor for earlier death [25]. It can contribute to poor adherence to medication [26], poorer functioning in daily life and loss of employment [27]. Cognitive impairment can occur at any stage of HIV disease, and even subtle impairments can affect an individual's wellbeing.

#### **1.4.5 Increased risk of HIV transmission**

Psychological difficulties can be associated with lower rates of adherence to ART. This can increase viral load and the risks of onward HIV transmission.

## 1.5 Effectiveness of psychological support

### 1.5.1 Psychological support improves mental health

Interventions, particularly cognitive behaviour and stress management interventions, whether delivered through individualised or group methods, can improve coping among PWHIV [28]. A range of approaches – in particular, psychological interventions (especially those incorporating a cognitive behavioural component) – have been effective in reducing anxiety and depression in PWHIV [29, 30].

### 1.5.2 Psychological support improves health outcomes and reduces risk of HIV transmission

There is evidence that a range of psychological interventions can make a considerable difference to the long-term health and wellbeing of a person with HIV, including how well they manage their HIV and maintain treatment [30]. Psychological interventions leading to improved adjustment can improve neuroendocrine regulation and immune functioning [31].

By improving mental health outcomes, psychological support can reduce the risk of HIV transmission associated with psychological difficulties. More specifically, psychological interventions that address self-efficacy and behavioural skills training are important [32].

These guidelines are based on a stepped care model that makes the most of resources at all levels of expertise to provide comprehensive psychological support. The model is described in Appendix A.

### 1.5.3 Cognitive rehabilitation improves adherence and functioning

Cognitive rehabilitation can improve adherence to ART and day-to-day functioning in those with HIV-related cognitive impairment [33, 34].

## 1.6 Why are standards needed?

These are the first Australian standards for the provision of psychological support for PWHIV. The extent and quality of psychological support for PWHIV appears to vary across jurisdictions. Psychological and cognitive difficulties are often underestimated by health-care practitioners; as a result, many PWHIV may not be offered access to the services they need [35-37]. These standards provide evidence-based recommendations to guide service provision; the aim is to ensure that appropriate psychological support is available to meet the needs of PWHIV.

## 1.7 HIV-specialist psychological support

Frameworks developed for psychological support for the general population or for those with other long-term conditions may be relevant for PWHIV. However, particular aspects of HIV and its care mean that different assessment and intervention methods may be appropriate. Although not currently available in all areas, there are pragmatic reasons why HIV-specialist provision for people who have psychological or cognitive difficulties should be considered, to augment generic mental health services.

Services providing psychological support for PWHIV in Australia need to recognise the impact of the stigma associated with HIV, and understand the experience of the priority populations most affected by HIV. Also, services need to be able to provide appropriate, culturally sensitive and effective support in relation to sexual behaviour and reducing the risk of transmission. HIV-specialist psychological care can be highly responsive to these multifaceted needs of PWHIV.

Practitioners require an understanding of the physical impact of HIV infection and HIV therapy, how this may affect psychological and cognitive functioning, and the implications of this for the use of assessment and intervention methods. Specifically, neuropsychological assessment in HIV is a specialist area for which the skills and materials are usually only available in HIV-specialist services or at major hospitals.



## 1.8 Implementing the standards

As with any standards, the standards given here will only have an impact on quality of care if they are implemented. Evaluation and audit can be used to measure whether the standards are being implemented by services providing psychological support for PWHIV. This exercise may be undertaken on an individual service basis as a part of quality improvement processes; alternatively, the evaluation and audit can be included as key performance indicators in organisational reporting frameworks.

Evaluating and auditing services involves a systematic process of looking at current practice and comparing it to standards of best practice. This is a proven method of quality improvement that can highlight problems, identify gaps and assist in developing solutions.

The auditable outcomes sections of the standards (summarised in Appendix B) set out suggested indicators to measure practice against the standards and their effect on outcomes.

## 1.9 Language and terminology

Except in specific contexts where it is necessary, the term 'person with HIV', abbreviated to PWHIV, is used in preference to 'patient'. Also, the term 'practitioner' is used in the standards to describe anyone providing psychological support. This term has been chosen as an inclusive one that encompasses a wide range of health-care and social-care professionals, as well as others, such as community sector volunteers and peer support workers.

## 1.10 Development of the standards

The Australian standards are an adaptation of the UK document, Standards for psychological support for adults living with HIV [1]. The UK standards were developed through a partnership between the British Psychological Society, BHIVA and MEDFASH. The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) thanks the above organisations for their permission to adapt the UK standards into a document for use in Australia.

The consideration and advocacy for the production of Australian standards was initiated by community organisations in Victoria, led by Living Positive Victoria, which identified a need for a document of this nature. A Victorian committee under the auspices of the Ministerial Advisory Committee on Gay, Lesbian, Bisexual, Transgender and Intersex Health and Wellbeing was formed to adapt the UK document for use in Victoria. ASHM took over this process when the need for a national set of standards was identified.

ASHM convened a working group, which included representatives of key professional bodies and other experts from across Australia, to oversee the development of the standards (Appendix C). The document was reviewed by a number of key stakeholders (Appendix C).

## 1.11 Structure of the document

This introduction (Part A) is followed by the actual standards of care (Part B). There are eight standards, and each one includes:

- recommendations
- rationale
- implications for HIV program planning
- auditable indicators.

Where relevant, the standards also list further supporting documents and guidance.

# Introduction

The document also includes three appendixes:

- Appendix A describes the stepped care model, which is referenced throughout the document and designed to complement the standards
- Appendix B summarises the auditable outcomes from each of the standards
- Appendix C lists those who contributed to the document and those who reviewed it.

## Part B: Standards of care

### Summary of standards

<b>Standard 1</b>	<b>Promotion of mental and psychological wellbeing</b> People with HIV (PWHIV) should receive care that promotes their emotional, cognitive and behavioural wellbeing (psychological wellbeing), and is sensitive to the unique aspects of living with HIV.
<b>Standard 2</b>	<b>Comprehensive psychological support services</b> People with HIV (PWHIV) should have access to a range of psychological support services appropriate to their needs.
<b>Standard 3</b>	<b>Meaningful involvement of people with HIV</b> People with HIV (PWHIV) should be meaningfully involved in the planning, delivery and evaluation of psychological support services.
<b>Standard 4</b>	<b>Support at the time of diagnosis</b> People with HIV (PWHIV) should have timely access to information and appropriate emotional support following the diagnosis of HIV.
<b>Standard 5</b>	<b>Identifying psychological support and treatment needs</b> People with HIV (PWHIV) should regularly have their psychological support needs assessed as part of a holistic care model.
<b>Standard 6</b>	<b>Competence to provide psychological support</b> People with HIV (PWHIV) should have their psychological support provided by competent practitioners who are qualified to provide ethical and effective treatment and care.
<b>Standard 7</b>	<b>Coordination of psychological support and treatment</b> People with HIV (PWHIV) should have access to appropriate psychological support services that are coordinated within a managed framework.
<b>Standard 8</b>	<b>Evidence-based practice</b> All psychological assessment and interventions for people with HIV (PWHIV) should be based on the best available evidence.

# Standard 1 – Promotion of mental and psychological wellbeing

**People with HIV (PWHIV) should receive care that promotes their emotional, cognitive and behavioural wellbeing (psychological wellbeing), and is sensitive to the unique aspects of living with HIV.**

## S1.1 Recommendations

### S1.1.1 Psychological wellbeing as a priority

PWHIV should be given the opportunity to discuss their psychological wellbeing with all practitioners providing their health care and social care (including peer support workers and community care providers).

### S1.1.2 HIV-sensitive care

PWHIV should receive confidential, non-stigmatising care that is informed by an understanding of the unique HIV-related factors affecting psychological wellbeing, and of how these factors affect people differently, depending on their gender, sexuality and cultural backgrounds.

### S1.1.3 Information to promote psychological wellbeing

During their contact with health-care and social-care services, PWHIV and their support networks should be provided with information and resources promoting their psychological wellbeing. Such information should include pamphlets, online resources and referrals to social networks. Access to patient or service user representatives and peer support should be provided as a priority.

## S1.2 Rationale

### S1.2.1 Psychological wellbeing as a priority

A large body of evidence shows a high prevalence of psychological difficulties associated with HIV infection. Difficulties include depression, stress and anxiety [6, 7, 29, 30, 38, 39]; social isolation, including rejection by potential sexual partner [8, 10, 40, 41]; and HIV-associated neurocognitive disorder (HAND) [42, 43].

### S1.2.2 HIV-sensitive care

PWHIV report experiencing HIV-related stigma from health-care and social-care professionals, especially from those not specialising in HIV [6, 8, 44].

PWHIV face challenges similar to those of people living with other long-term conditions. According to the 2013 HIV Futures Seven report [45], 48% of respondents had at some time been diagnosed with a mental health disorder, 42% had been diagnosed with depression and 25% had been diagnosed with an anxiety disorder.

PWHIV may also face social issues and challenges specific to HIV, including stigma and discrimination [46, 47], and the risk or experience of criminal prosecution [46] for HIV transmission or exposure (either as complainant or accused), which can exacerbate fears relating to disclosure of HIV-positive status [48]. In Australia, HIV has typically affected marginalised communities (primarily men who have sex with men) who are already subjected to high levels of stigma and discrimination, which can also exacerbate mental health problems and isolation. Assuring the confidentiality of services caring for PWHIV is of high importance, as is publicising this confidentiality to service users – and potential users – to encourage service uptake and open communication.

PWHIV may also have conditions that are a direct result of HIV infection, such as HAND [49], neuropathic pain and (less commonly since the advent of the new antiretroviral treatments) physiological changes such as lipodystrophy.

# Standard 1

The promotion of psychological wellbeing through engagement in care is most effective when it is built on social networks that are already in place, and uses a combination of methods focusing on individuals, families and communities. Support for self-management strategies can benefit from the involvement of carers, partners and others affected by HIV. When people have a limited personal support network, interventions such as peer support (see S3.2.2) can be helpful in addressing problems of isolation. Facilitating linkages to relevant support networks and ensuring access to culturally sensitive information can also be important in reducing isolation and stigma for PWHIV from diverse backgrounds, such as lesbian, gay, bisexual, transgender, queer, intersex (LGBTQI) groups; Aboriginal and Torres Strait Islander people; culturally and linguistically diverse (CALD) populations; people moving in and out of custodial settings; and people travelling to and from high-prevalence countries.

### **S1.2.3 Information to promote psychological wellbeing**

PWHIV may not wish to talk to their clinicians about their psychological wellbeing. The provision of written, as well as verbal, information and the promotion of other resources such as online materials and websites can facilitate a discussion about psychological wellbeing, or can be an opportunity to provide information about how to access psychological support and the options available. Contact with patient representatives or peer support provides a different way to convey information and may also facilitate access to further psychological support. Account should be taken of gender, culture, language and literacy needs, to ensure that all PWHIV have equitable access to information.

## **S1.3 Implications for HIV program planning**

### **S1.3.1 Implication 1.1**

Services providing health care, social care or any other support to PWHIV should be explicitly required to promote the psychological wellbeing of PWHIV and that of other individuals affected. Such support should include interventions that enhance social inclusion and combat stigma and discrimination.

### **S1.3.2 Implication 1.2**

Services providing health care, social care or any other support to PWHIV should be required to ensure that their staff understand the HIV-specific factors that can affect psychological wellbeing, and know how to apply this understanding in their work. For workers from regional, remote and very remote settings, appropriate professional support pathways and online courses should be considered.

### **S1.3.3 Implication 1.3**

The planning of services for PWHIV should include provision for the availability of information resources, and space for their display (e.g. leaflets in clinics, information on websites, waiting room monitors, social media support and posters in waiting rooms). Peer support or expert health consumer programs should also be engaged.

## **S1.4 Auditable indicators**

### **S1.4.1 Indicator 1.1**

Proportion of service users who report that:

- a) their service providers give them sufficient opportunity to discuss their psychological wellbeing
- b) their service providers understand the experience of living with HIV
- c) they have experienced stigma from health-care practitioners in the last year
- d) they have received information about HIV and their care that has included psychological wellbeing.  
(Measurable through surveys of service users.)

### **S1.4.2 Indicator 1.2**

Evidence that accurate, evidence-based information is provided within services for PWHIV, including information in languages and formats that meet local needs, and information materials from accredited providers.  
(Measurable through observation and surveys of service users.)

## Standard 2 – Comprehensive psychological support services

**People with HIV (PWHIV) should have access to a range of psychological support services appropriate to their needs.**

### S2.1 Recommendations

#### S2.1.1 Assessment for psychological support

All PWHIV should be assessed for the appropriate level of psychological support to meet their needs.

#### S2.1.2 Stepped care model

The stepped care model (see Appendix A) should be used to plan and enable access to the psychological support services needed by each individual at levels 1, 2, 3 or 4 (see Appendix A and Standard 7).

#### S2.1.3 Access to interventions

All PWHIV should be provided with level 1 psychological support that includes supportive communication, referral information and referral options. They should also be provided, according to agreed referral criteria, with subsequent levels of more complex intervention when indicated through psychological and cognitive screening and assessment.

#### S2.1.4 Timely access

Access to interventions should be timely, according to identified need. Where screening or clinical observation identifies a serious and immediate risk of harm to self or others, PWHIV should be referred immediately to emergency mental health services (level 4). A pathway needs to be locally defined for access to these services. PWHIV referred less urgently for specialist psychological support (level 3) should be seen within a maximum of 3 months.

### S2.2 Rationale

#### S2.2.1 Assessment for psychological support

PWHIV and their support networks are likely to benefit from some form of psychological support, whether they experience mild and transient emotional symptoms, or more severe problems such as depression, anxiety, trauma or suicidal ideation [50]. Problems may recur, change in intensity and lead to other problems such as anxiety or depression, problematic substance use, relationship breakdown, isolation and suicidal behaviours [49, 51]; also, problems may impede treatment for HIV [16] (e.g. reduced adherence to antiretroviral therapy, ART).

The appropriate psychological support intervention will depend on the nature and severity of the person's problems, protective factors such as social support and resources, and the person's individual preferences. Therefore, assessment is required to identify the appropriate intervention (or interventions) for each individual.

All PWHIV should have access to assessment for psychological support, whether through referral by practitioners or through self-referral. Referral for assessment may follow a positive screen or identification of psychological or cognitive difficulties by practitioners.

#### S2.2.2 Stepped care model

The stepped care model described in Appendix A provides a framework for comprehensive assessment and provision of psychological support to meet the full range of needs of PWHIV. Although the particular services available locally may determine how such support is provided and by whom, all aspects of assessment and support provision described in the model should be available, regardless of geographical location.

# Standard 2

## S2.2.3 Access to interventions

Some practitioners who identify psychological distress may not know how to deal with emotional issues or where to turn for advice or support for distressed PWHIV [52-54]. Nevertheless, practitioners offering frontline care can give general psychological support to PWHIV, their carers and those directly affected by the presence of HIV in their relationships. Practitioners can play a key role in psychological screening, distress reduction, HIV prevention, the management of other health risks and the provision of referral options to promote a good quality of life. All PWHIV should have access to this level of support (level 1 in the stepped care model).

Some practitioners may have particular skills in counselling that give them the competence to manage mild or transient psychological difficulties. This type of psychological support may be provided in specialist HIV treatment centres, hospital settings, social-care settings and community-based services, within or outside the area covered by the HIV service.

Specialist services for more complex and chronic psychological problems include clinical or counselling psychology, liaison psychiatry and psychotherapy. These may be available as an integrated part of the HIV service; as part of local clinical health psychology services or generic mental health services; or through private practitioners under the Medicare Better access scheme [55] and the Access to allied psychological services (ATAPS) initiative [56].

Interventions for cognitive impairment in PWHIV are provided in acute hospital settings and by community teams. They may be embedded within HIV-specialist services, but in most parts of the country are accessed through general or neurological support services.

## S2.2.4 Timely access

To support PWHIV in managing their condition and adhering to ART, access to interventions at all levels should be timely [16]. Waiting times and delays may cause further psychological difficulties and associated health problems, including non-adherence to ART. Therefore, PWHIV should not experience delays in referral to services at levels 2, 3 and 4 when needed.

If the problem is urgent or has potential health risks (e.g. suicidal intent), immediate referral for further assessment with a mental health practitioner (level 4) and appropriate treatment should occur. Suicide, attempted suicide and suicidal thoughts are all more common in PWHIV [57]. Prompt referral minimises the risks associated with psychological distress.

## S2.3 Implications for HIV program planning

### S2.3.1 Implication 2.1

All agencies and organisations involved in the provision of HIV care need an understanding of the nature and extent of the psychological support needs of PWHIV in their area. They also need to ensure that appropriate services are available at adequate levels to meet the comprehensive range of psychological support needs identified (see Standard 7).

### S2.3.2 Implication 2.2

HIV program planners should ensure that clear and defined pathways exist between services at different levels according to the stepped care model (see Appendix A).

### S2.3.3 Implication 2.3

HIV program planning should consider the professional support and development arrangements for practitioners who are providing psychological support to PWHIV sporadically.



### S2.3.4 Implication 2.4

HIV programs should link up with related services (e.g. mental health and chronic condition management), to ensure the provision of comprehensive psychological support services. They should also work with local clinical or service networks where these exist. Such planning may be across a wider geographical area than simply focusing on areas where HIV prevalence is highest.

## S2.4 Auditable indicators

### S2.4.1 Indicator 2.1

When psychological support needs have been identified, the proportion of PWHIV who have been referred on to appropriate psychological support.

(Measurable through occasional fixed-period audit of service user records in HIV treatment centres and community support organisations.)

### S2.4.2 Indicator 2.2

Proportion of PWHIV in whom a serious and immediate risk of harm to self or others has been identified through screening or clinical observation, who are referred to emergency mental health services on the same day.

(Measurable through audit of service user records.)

## S2.5 Further supporting documents and guidance

- Barr, VJ, Robinson, S, Marin-Link, B, et al. 2003, The expanded chronic care model: an integration of concepts and strategies from population health promotion and the chronic care model. *Hosp Q*. 7(1): 73–82. [58]
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# Standard 3

## Standard 3 – Meaningful involvement of people with HIV

**People with HIV (PWHIV) should be meaningfully involved in the planning, delivery and evaluation of psychological support services**

### S3.1 Recommendations

#### S3.1.1 Engagement in service planning and development

PWHIV should be consulted about the psychological support services they may wish to access as well as those they have accessed.

PWHIV should be consulted in the design, redesign, development, implementation and evaluation of all psychological support services intended for them.

Inclusive frameworks to engage PWHIV, reflecting their diversity, should be developed across all services providing psychological support.

#### S3.1.2 Engagement in service delivery

As part of psychological support service delivery, PWHIV should play a role in the provision and dissemination of information about HIV and HIV services to other PWHIV. They should also be involved in providing peer support, advice, advocacy and means of engagement.

#### S3.1.3 Engagement in service evaluation

PWHIV should be provided with opportunities for feedback on psychological support services as part of service evaluation, to inform future service development.

PWHIV should be involved in the development, collection and reporting of outcome measures for psychological support services, to ensure that these capture both clinical outcomes and user experiences.

#### S3.1.4 Support for engagement of PWHIV

PWHIV who are involved with service user activities should be provided with opportunities to update and develop their knowledge and skills, in order to maintain effective involvement with professional services and to ensure a consistent approach to psychological support.

### S3.2 Rationale

#### S3.2.1 Engagement in service planning and development

PWHIV play a central role in the response to the HIV epidemic. Being most affected, they will have a uniquely valuable insight into how services, programs and policies, including psychological support services, should be designed.

PWHIV are active health-care consumers, receiving care from multiple health-care and social-care professionals [8].

The need to involve PWHIV has also been endorsed in the internationally adopted 'greater involvement of people living with HIV principle' (GIPA principle). The Joint United Nations Programme on HIV and AIDS (UNAIDS) defines GIPA as a principle that:

*aims to realize the rights and responsibilities of people with HIV, including their right to self-determination and participation in decision-making processes that affect their lives [65].*



The guiding principle of partnership that underpins Australia's Seventh National HIV Strategy [66] requires that clinical care be provided in partnership between clinicians, researchers, community organisations and health organisations. This entails the involvement of PWHIV in the planning, design, implementation and evaluation of services. Service user forums, networks and representatives are examples of how such engagement can be facilitated.

This approach improves quality, ensures accountability and is cost effective.

### **S3.2.2 Engagement in service delivery**

The engagement of PWHIV in the development and delivery of HIV services has provided a model for user engagement in many other areas of health care. There are numerous benefits of engaging PWHIV in all aspects of service delivery; for example, increased effectiveness, relevance and acceptability of services. The engagement of PWHIV in the delivery of services can be important in enhancing PWHIV's self-efficacy; it also enables outreach to groups that might otherwise be hard to reach [67].

Peer support services represent a key aspect of the engagement of PWHIV. Peer support (i.e. support provided by PWHIV for PWHIV) can take many forms including emotional support, advice, advocacy, information, workshops, forums and courses. Such support forms an integral part of good HIV care; therefore, it is recommended that clinical service providers actively foster access to peer support.

### **S3.2.3 Engagement in service evaluation**

Service user experience of treatment and care is a major indicator of service quality. User experience can be captured through mechanisms such as satisfaction surveys, qualitative interviews, focus groups, and rating scales that measure states of health and illness from the perspective of the service user.

Surveying PWHIV is a way to gain insight into how they perceive their health and the impact that treatments or adjustments to lifestyle have on their quality of life. Health status information collected from PWHIV through surveys before and after an intervention can provide an indication of the outcomes or quality of care.

Surveys designed to measure outcomes should examine, for example, access, communication, interaction with professionals, coordination, care and respect, privacy and dignity, information about mental health and wellbeing, involvement in decisions and overall experience (see also Standard 8).

### **S3.2.4 Support for engagement of PWHIV**

PWHIV may wish to participate in planning, delivering and providing feedback on psychological support services but lack the confidence or skills to do this effectively. The process of engagement should therefore include the provision of information, training and support on an ongoing basis to empower and enable PWHIV to develop the relevant skills.

## **S3.3 Implications for HIV program planning**

### **S3.3.1 Implication 3.1**

Those tasked with the planning of services should engage with representatives of PWHIV organisations in the development of programs for psychological support as part of strategies for HIV treatment and care. Engagement of PWHIV should be clearly expressed in strategy implementation plans.

### **S3.3.2 Implication 3.2**

Specifications for services providing psychological support for PWHIV should include arrangements for the involvement of PWHIV representatives in the planning of such services, and of PWHIV in their monitoring and evaluation. Providers should consider ways to measure both self-perceived health outcomes and the experience of using services among PWHIV.

# Standard 3

### S3.3.3 Implication 3.3

HIV program planners should require providers to involve PWHIV appropriately in the delivery of psychological support. They should also require providers to make available training, supervision and support, to enable the participation of PWHIV to meet consistent quality standards.

### S3.3.4 Implication 3.4

The resourcing of local planning and provision of services for PWHIV should include allocations to support the engagement of PWHIV in planning, delivering and evaluating services.

## S3.4 Auditable indicators

### S3.4.1 Indicator 3.1

Evidence from providers of HIV-specialist psychological support that they have:

- a) developed a plan for engaging PWHIV
- b) implemented the plan
- c) taken action in response to PWHIV input.

### S3.4.2 Indicator 3.2

Inclusion of surveys in audits and evaluations of psychological support provision.

## S3.5 Further supporting documents and guidance

- Flickinger, TE, Saha, S, Moore, RD, et al. 2013, Higher quality communication and relationships are associated with improved patient engagement in HIV care. *J Acquir Immune Defic Syndr.* 63(3): 362–6. DOI:10.1097/QAI.0b013e318295b86a. [68]
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## Standard 4 – Support at the time of diagnosis

**People with HIV (PWHIV) should have access to a range of psychological support services appropriate to their needs.**

### S4.1 Recommendations

#### S4.1.1 Support and information at the time of diagnosis

At the time of their HIV diagnosis, all PWHIV should be offered one-to-one emotional support by the practitioner giving them their test result. If, after the initial post-test discussion, more in-depth counselling or other support is urgently needed, rapid referral to an appropriate provider should be offered if this is beyond the competence or capacity of the testing provider.

Immediately relevant information about HIV and its implications should be given verbally at the time of diagnosis. This information should be backed up by the provision of written information and referral options as appropriate.

Regardless of where testing takes place, all practitioners providing test results and emotional support at the time of diagnosis should have the competence to do this, with access to relevant training and professional support.

#### S4.1.2 Referral for psychological support following diagnosis

Clear local policies and pathways for post-diagnostic support and referral should be in place and should apply to all settings offering HIV testing. All newly diagnosed PWHIV should be offered psychological support from practitioners with expertise in HIV at the earliest possible opportunity, preferably within 48 hours and certainly within 2 weeks of receiving the test result.

HIV home testing kits should contain comprehensive information about out-of-hours support services.

### S4.2 Rationale

#### S4.2.1 Support and information at the time of diagnosis

Diagnosis with HIV or AIDS can initially evoke strong feelings including fear, helplessness, disbelief, anger, guilt and numbness. Some people display symptoms that are similar to post-traumatic stress disorder (PTSD) [7, 74, 75]. Provision of accurate written information (e.g. in leaflets or online materials) can help to reinforce messages that may be hard to retain at this stage.

People may develop an acute stress reaction following an HIV diagnosis. Being provided adequate emotional support when receiving a positive HIV test result increases retention in care and reduces loss to follow-up. Health-care professionals and other practitioners offering HIV testing should follow the Australian National HIV testing policy [76] and should obtain informed verbal consent before testing. They should also be prepared for the possibility of giving a positive result, and ensure that they have the competence to do this, and to manage the conversation that follows. This may include helping the newly diagnosed person to plan the next 24–48 hours and the offer of a follow-up appointment within that period if necessary.

People from culturally and linguistically diverse (CALD) communities, including asylum seekers and refugees, can face additional challenges and threats as a result of an HIV diagnosis. Such challenges include insecure residency status, language difficulties, lack of familiarity with health-care systems and past trauma (including HIV experiences in country of origin) [77, 78]. Furthermore, HIV-positive status can interfere with social relations with family in the country of origin and with their local cultural community. People from minority cultural communities, including

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Indigenous Australians, can be reluctant to access services, including interpreters, because of concerns about confidentiality [79, 80]. Practitioners offering HIV services to people from CALD backgrounds, and to people from Aboriginal and Torres Strait Islander backgrounds, should seek training in cultural competency. They should also be familiar with appropriate services and resources to link their clients with additional support and assistance around coping with their HIV diagnosis.

All practitioners giving HIV test results should be fully competent in enhanced communication skills and in delivering a challenging diagnosis. For many, such as those in general practice or hospital settings, delivering challenging diagnoses will already be part of their professional remit. Access to appropriate professional support and guidance from a specialist in providing psychological support should also be available to practitioners when needed.

As HIV testing is increasingly undertaken in non-traditional or non-HIV-specialist settings – whether in the community, hospitals or the home – the ability of testing providers to offer more in-depth support will vary. If further immediate post-test support is needed at the time of diagnosis, beyond that which the service giving the test result has the competence or capacity to provide, this should be arranged with a sexual health, peer-based HIV support organisation or other appropriate service, using links that should already be in place. If needed, a 24-hour crisis support telephone number can be provided; this is especially relevant in the case of home testing.

## **S4.2.2 Referral for psychological support following diagnosis**

An HIV diagnosis can cause an adverse psychological impact [7, 74, 75]. Therefore, all newly diagnosed PWHIV should be offered psychological support from practitioners with expertise in HIV at the earliest possible opportunity, preferably within 48 hours and certainly within 2 weeks of receiving the test result.

Before giving a positive test result, practitioners should have knowledge of local HIV-specialist and support services (including peer-based organisations). Also, they should have established a clear referral pathway for assessment and care, including rapid access for those who need urgent psychological support.

As part of these recommended arrangements and within the same timeframes, early access to psychological support at levels 1 and 2 from practitioners with expertise in HIV (see stepped care model, Appendix A) should be available to PWHIV following diagnosis, whether within the HIV-specialist centre or other settings. Pathways should also be in place for timely referral after diagnosis for psychological support at levels 3 or 4 as needed (see also Standards 5 and 7).

All workers responsible for giving a new HIV diagnosis should be familiar with the National HIV testing policy [76], associated guidelines, relevant legislation and local policy directives.

## **S4.3 Implications for HIV program planning**

### **S4.3.1 Implication 4.1**

HIV program planners should ensure that services offering HIV testing provide information and emotional support at the time of diagnosis, and offer referral within the timescales set out in these standards for all people diagnosed with HIV.

### **S4.3.2 Implication 4.2**

HIV program planners should ensure that local pathways are in place for psychological support following diagnosis, including access to rapid support for those who need it urgently.

### **S4.3.3 Implication 4.3**

Specifications for HIV testing services should require practitioners giving positive results to have appropriate competencies, with access to funded training and professional support as needed.



#### **S4.3.4 Implication 4.4**

Where HIV testing services are provided in the community or non-HIV-specialist medical settings, HIV program planners should be clear about the roles and responsibilities of different organisations or teams involved. For example, it is possible that clinical staff providing testing will give the results but staff from a voluntary sector partner or peer-based organisation (if in the community) or in a hospital would provide immediate emotional support.

#### **S4.3.5 Implication 4.5**

Strategies should exist for providing support for people who have had a reactive result from an HIV home test, or a positive HIV result in a setting where counselling was not provided.

### **S4.4 Auditable indicators**

#### **S4.4.1 Indicator 4.1**

Proportion of people newly diagnosed with HIV who are offered appropriate psychological support. Of those who accept a referral, the proportion who receive it a) within 48 hours and b) within 2 weeks of diagnosis. (Measurable, where possible, through audit of records of services providing testing or through service user feedback.)

#### **S4.4.2 Indicator 4.2**

Evidence of a clear and agreed pathway for post-diagnostic psychological support from services providing HIV testing.

#### **S4.4.3 Indicator 4.3**

Evidence of a clear and agreed pathway for the provision of support to people who have had a reactive result from an HIV home test, or a positive HIV result in a setting where counselling was not provided.

### **S4.5 Further supporting documents and guidance**

- Baggaley, R, 2008, HIV for non-HIV specialists: diagnosing the undiagnosed. Medical Foundation for HIV & Sexual Health, London. Available from: <http://www.medfash.org.uk/uploads/files/p1b2t3peg4vsvoni6rec2eccd3.pdf>. [81]
- Madge, S, Matthews, P, Singh, S, et al. 2011. HIV in primary care. Medical Foundation for HIV & Sexual Health, London. Available from: <http://www.medfash.org.uk/uploads/files/p17abjng1g9t9193h1rsl75uuk53.pdf>. [82]

# Standard 5

## Standard 5 – Identifying psychological support and treatment needs

**People with HIV (PWHIV) should regularly have their psychological support needs assessed as part of a holistic care model.**

### S5.1 Recommendations

#### S5.1.1 Assessment and screening for psychological difficulties

PWHIV should be screened for symptoms of depression, anxiety, drug and alcohol issues, trauma, adjustment difficulties and risk of self-harm within the first 3 months of receiving an HIV diagnosis, and thereafter annually. It is essential for pathways to be in place for further assessment following screening for those identified as needing additional care.

#### S5.1.2 Screening for cognitive difficulties

PWHIV should be assessed for cognitive difficulties within the first 3 months of receiving an HIV diagnosis, and thereafter annually, unless symptoms indicate the need for earlier assessment.

Outside of clinical settings, practitioners should be alert to the potential for cognitive difficulties, and should be competent to refer people for further assessment when necessary.

#### S5.1.3 Repeat screening

PWHIV should have access to repeated screening following events that are known to trigger or exacerbate psychological distress or cognitive difficulties; otherwise, they should have access to screening on an annual basis.

#### S5.1.4 Referral following screening

PWHIV whose screen suggests significant difficulties should be offered referral to a suitably competent practitioner for further assessment.

### S5.2 Rationale

#### S5.2.1 Assessment and screening for psychological difficulties

Many individuals are able to adjust to living with HIV with little need for psychological support. However, some people experience difficulties and may struggle to seek out or access further support. PWHIV have high rates of psychological distress and mental health difficulties; these are under-recognised by providers and are sometimes underreported by PWHIV [6, 38, 83, 84]. The impact of psychological and cognitive difficulties on overall wellbeing should not be underestimated; it can have a negative impact on retention in care, quality of life and mortality [20, 85].

Services should have a process for systematically identifying those individuals who need psychological support. Screening usually entails asking individuals a set of structured questions to identify whether referral for a more in-depth assessment is needed. It should be distinguished from formal psychological assessment, which is a more thorough and comprehensive process of gathering information for the purpose of making a diagnosis or identifying a person's psychological problems. In some settings (e.g. peer-based and support network settings) it may be appropriate to use less structured tools and instead engage PWHIV in conversations about their general quality of life and feelings about their diagnosis.



Screening on its own does not improve outcomes – it must be part of a framework or process of ongoing holistic care, and must be provided by staff with appropriate competencies [86] (see Standard 6). If screening is used diagnostically without a referral pathway for further assessment or multidisciplinary team discussion, there is a risk of over-identification of psychological problems.

Screening for psychological difficulties should be offered and delivered with sensitivity and care, to avoid further stigmatising those already living with HIV-related stigma (see Standard 1). Gathering information about the current circumstances of PWHIV, their psychosocial history and previous use of mental health services provides a context for the interpretation of the screening results.

The early detection and treatment of psychological difficulties in people living with chronic conditions can improve health outcomes and psychological wellbeing, and reduce the need for more frequent and costly medical interventions [61, 87]. Screening for particular mental health problems and drug and alcohol use is a recommended part of routine clinical care for individuals at higher risk. Screening PWHIV for psychological difficulties can help practitioners to target resources cost effectively [52], which is important given the high prevalence rates of depression and psychological distress in this population [29, 30, 57, 74].

Baseline screening of all people newly diagnosed with HIV, for a specific range of problems that most commonly occur in PWHIV, enables the rapid identification of individuals:

- with pre-existing or current psychological and lifestyle difficulties who require fast-tracked referral for further assessment
- whose mental health is at risk of deteriorating due to a negative psychological reaction (e.g. acute stress or severe depression) following diagnosis
- who can benefit from low-intensity interventions, as in levels 1 and 2 of the stepped care model (see Appendix A)
- who require onward referral for specific assistance (e.g. alcohol or substance problems)
- who require assistance in living circumstance (e.g. housing or financial assistance).

Certain screening tools can be administered and scored by practitioners who do not have any formal mental health training. Some can also be self-administered, depending on language skills and cognitive abilities. Screening can take place in multiple settings, ranging from HIV clinics to community settings. However, screening of certain individuals should only be undertaken by appropriately qualified and competent staff. Such individuals include those who are known to be cognitively impaired; have learning disabilities, language or literacy problems, or sensory difficulties; it also includes those who are known survivors of trauma.

In Australia there are valid and freely available mental health screening tools that are already being applied to the HIV setting; for example, depression anxiety stress scales (DASS) [88, 89] and the anxiety and depression checklist (K10) [90].

### **S5.2.2 Screening for cognitive difficulties**

Screening for cognitive difficulties is recognised as an area that needs increased attention because HIV can result in neuropsychological impairment [7, 42] (referred to as HIV-associated neurocognitive disorder, HAND). Cognitive difficulties are often underestimated by clinicians, even more so than by PWHIV self-reporting. Although more effective therapies have reduced the proportion of people with more severe cognitive impairment (HIV-associated dementia), mild neurocognitive disorder remains prevalent, even in individuals treated with combination antiretroviral therapy (ART) [24].

Screening for cognitive difficulties should occur within 3 months of engaging with a service or diagnosis. Because the time of diagnosis may not coincide with the time of transmission, any baseline cognitive screening can help to indicate whether there are changes over time, providing a reference point for when further specialist assessment is warranted. There are a range of efficient methods to screen for cognitive difficulties, including brief screening questions [91, 92] that help to identify the need for more in-depth assessment.

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Tools used should be appropriate for the population served. Non-HIV specialists, such as general practitioners, should be aware that cognitive screening tools used in general populations may not be appropriate for use in PWHIV [93]. Screening tools should include activities that assess cortical and subcortical functions (e.g. the Montréal Cognitive Assessment). However, there are limitations to cognitive screening tools, with various tools being less sensitive to mild impairment or cognitive change in higher functioning individuals; therefore, underlying cognitive change may be missed if depending solely on screening tools [94].

### **S5.2.3 Repeat screening**

Psychological difficulties are more common in people living with chronic health conditions [95-98]; hence, it is recommended that PWHIV are re-screened at relevant points that are known to potentially trigger or exacerbate mental distress. These trigger points may or may not be directly related to HIV infection and its treatment. Examples of trigger points are:

- significant changes in physical health status or disease progression
- initiation or change of medication
- change of treatment centre
- after a period of non-attendance and loss of contact with treatment centre
- treatment failure
- varying adherence
- significant medication side effects
- at times of coinfection, such as with hepatitis B or C, or tuberculosis (TB)
- changes in psychosocial status, including relationships, support networks, and welfare issues such as housing, financial and employment changes
- distressing psychosocial problems (e.g. immigration and legal issues)
- experience of stigma, trauma, violence or abuse
- bereavement or relationship problems
- family problems including those arising from children's HIV status
- disclosure and sexual relationship concerns.

In the absence of trigger points, psychological screening once a year should form part of routine monitoring for PWHIV. There should also be regular monitoring of cognitive function, at least on an annual basis, because cognitive impairment can manifest at any time in the lives of PWHIV [24].

### **S5.2.4 Referral following screening**

If screening indicates significant psychological or cognitive difficulties, a referral to a suitably qualified specialist for a more in-depth assessment should be initiated. The outcome of the in-depth assessment will allow for a joint treatment decision to be made according to the stepped care model (see Appendix A).

Pathways to, or provision of, low-intensity support should also be available for PWHIV whose screen demonstrates this level of need. This includes psycho-education (the provision of information about the likely causes and maintaining factors of current difficulties), peer support, self-help and community support.

## **S5.3 Implications for HIV program planning**

### **S5.3.1 Implication 5.1**

HIV program planners should ensure that a regular screening program for new and existing service users is included in specifications for HIV-specialist services. Such a program should include provision for non-mental-health-trained staff to be trained to administer screening tools, and to be aware of the psychosocial symptoms and markers for psychological distress.



### S5.3.2 Implication 5.2

If screening is to occur in non-HIV-specialist settings (e.g. primary care), non-HIV specialists require an awareness of the complex care needs that PWHIV can present with and the high prevalence of psychological difficulties in PWHIV. They also need an understanding of the social impact of living with HIV and associated issues such as sexual diversity, marginalisation, cultural diversity, and the impact of migration and asylum seeking.

### S5.3.3 Implication 5.3

Clear pathways for onward referral for more in-depth assessment of identified psychological and cognitive need must be developed. These pathways should take into consideration patient choice and preference.

## S5.4 Auditable indicators

### S5.4.1 Indicator 5.1

Proportion of PWHIV receiving screening for a) psychological and b) cognitive difficulties at least once a year.

### S5.4.2 Indicator 5.2

Among PWHIV whose screen suggests significant psychological or cognitive difficulties, the proportion referred for further assessment by a suitably competent professional. The uptake of referrals and engagement in care could also be useful indicators. Surveys of PWHIV may be helpful in evaluating the effectiveness of referrals provided; however, surveyors are advised to be mindful of survey fatigue and should strive to minimise effort and maximise data.

## S5.5 Further supporting documents and guidance

- Grierson, J, Pitts, M, and Koelmeyer, R, 2013, HIV Futures Seven: the health and wellbeing of HIV-positive people in Australia. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne. Available from: <http://www.acon.org.au/wp-content/uploads/2015/04/HIV-Futures-7-report-2013.pdf>. [45]
- Lyketsos, CG, Hanson, A, Fishman, M, et al. 1994, Screening for psychiatric morbidity in a medical outpatient clinic for HIV infection: the need for a psychiatric presence. *International Journal of Psychiatry in Medicine*. 24(2): 103–13. DOI:10.2190/urtc-aqvj-n9kg-0rl4. [99]
- New York State Department of Health, AIDS Institute, 2007, HIV clinical resource: screening tools for completing mental health assessments in HIV primary care settings. New York State Department of Health, AIDS Institute, New York. [100]
- New York State Department of Health, AIDS Institute, 2009, Mental health standards of care. An integrated approach to serving communities in New York State. New York State Department of Health, AIDS Institute, New York. [101]
- Pence, BW, 2009, The impact of mental health and traumatic life experiences on antiretroviral treatment outcomes for people living with HIV/AIDS. *Journal of Antimicrobial Chemotherapy*. 63(4): 636–640. DOI:10.1093/jac/dkp006. [102]
- Pence, BW, Gaynes, BN, Whetten, K, et al. 2005, Validation of a brief screening instrument for substance abuse and mental illness in HIV-positive patients. *J Acquir Immune Defic Syndr*. 40(4): 434–44. [103]
- Power, C, Selnes, OA, Grim, JA, et al. 1995, HIV Dementia Scale: a rapid screening test. *J Acquir Immune Defic Syndr Hum Retrovirol*. 8(3): 273–8. [104]
- Sacktor, NC, Wong, M, Nakasujja, N, et al. 2005, The International HIV Dementia Scale: a new rapid screening test for HIV dementia. *AIDS*. 19(13): 1367–74. [105]
- Whetten, K, Reif, S, Whetten, R, et al. 2008, Trauma, mental health, distrust, and stigma among HIV-positive persons: implications for effective care. *Psychosom Med*. 70(5): 531–8. DOI:10.1097/PSY.0b013e31817749dc. [106]

# Standard 6

## Standard 6 – Competence to provide psychological support

**People with HIV (PWHIV) should have their psychological support provided by competent practitioners who are qualified to provide ethical and effective treatment and care.**

People with HIV (PWHIV) should have their psychological support provided by competent practitioners who are qualified to provide ethical and effective treatment and care.

### S6.1 Recommendations

#### S6.1.1 Competence to provide psychological support

All individuals requiring psychological support should have this provided by skilled practitioners who have been appropriately trained and have demonstrated the necessary competencies. All registered health practitioners are governed by the Australian Health Practitioner Regulation Agency (AHPRA), which determines and regulates professional competencies [107]. Registered and non-registered health professions also have professional societies that regulate competencies [108].

#### S6.1.2 Assessment of competence

Required standards, roles and competencies should be defined for all practitioners providing assessment and interventions across the spectrum of psychological support for PWHIV. Agreed mechanisms should be in place for the assessment of competence according to these benchmarks.

#### S6.1.3 Maintaining competence

Services providing psychological support for PWHIV should ensure that their practitioners can demonstrate competence on an ongoing basis. They should also make provision to support the maintenance of competence through training, continuing professional development (CPD) and supervision (see Accreditation under the Health Practitioner Regulation National Law Act [109]).

Individual practitioners have a responsibility to ensure that they have received training and attained the required competencies before undertaking an assessment or interventions to meet psychological support needs. They are also responsible for maintaining their competence on an ongoing basis, but should be supported in this by their employing organisation (e.g. through workforce professional development). Services should include workforce development in their budget planning.

#### S6.1.4 Training

Practitioners should receive training, supervision and CPD as appropriate to their role and profession, in order to develop and maintain competencies at that level. Access to training and supervision can be face-to-face or virtual (e.g. through Skype, telehealth or other online platforms).

Training courses in communication skills should be available for all practitioners who are working with PWHIV. Advanced communication skills training should be undertaken by those who frequently have to break significant news including HIV test results, assist PWHIV with disclosure and negotiating sexual practices, or discuss distressing issues.

Training for the skills and competencies to deliver psychological support to PWHIV should be provided, as should generic training for psychological screening, assessment and interventions.



### S6.1.5 Required competencies

Competencies are required by practitioners providing psychological support at levels 1, 2, 3 and 4 in line with the stepped care model (see Appendix A).

In addition to generic competencies, all practitioners providing psychological support for PWHIV should have a demonstrable minimum set of competencies comprising awareness and understanding about HIV and its impact on PWHIV. These competencies should include the cultural competence to engage with Aboriginal and Torres Strait Islander people, culturally and linguistically diverse (CALD) communities, gender and sexuality diverse people, people who use drugs, sex workers, people who move in and out of custodial settings, and other communities that are often stigmatised and marginalised.

## S6.2 Rationale

### S6.2.1 Competence to provide psychological support

Effective psychological and cognitive screening, assessment and interventions require practitioners to be trained and competent in supporting PWHIV and to have access to expert advice as necessary. A variety of health-care professionals, social workers and other practitioners may be involved in the delivery of psychological support. Although such practitioners can be from different disciplines, and competent in providing various aspects of psychological support to different levels, all should be trained, competent for their roles and provided with ongoing supervision, or should be working within an appropriate clinical governance framework [109]. In a survey, PWHIV placed a significant value on providers' competence, knowledge and communication skills, as well as nonjudgemental attitudes, friendly behaviours and a sense of humour [88].

Where specific and relevant competency frameworks exist for different professions and roles, these should be used as the basis for workforce development planning and assessment of competencies.

### S6.2.2 Assessment of competence

Whatever their role or profession, practitioners who will provide psychological support should have their competencies assessed to ensure that they are fit to practise. Professional groups have different ways of assessing competence. Generic competencies will often be demonstrated by professional qualifications, and professional vocational training will identify specific knowledge and skills against which competency can be assessed. Assessment should be evidence-based; for example, by observation of practice, verbal feedback and a practitioner's portfolio of work [110].

### S6.2.3 Maintaining competence

Service providers have a responsibility to ensure that the practitioners they employ receive training and other appropriate education and support to maintain and increase their competencies. Practitioners are responsible for maintaining their own competence and for ensuring that they do not practice beyond their competence. Training and competence levels should be reviewed on a regular basis.

### S6.2.4 Training

Psychological support should be an integral part of the role of every health-care and social-care practitioner working with PWHIV; however, for most, such support is not the focus of their practice. Many will require training in communication skills, delivering distressing news, and recognising or screening for psychological distress [111].

Good communication skills underpin all elements of care, and will enable practitioners to discuss the needs and preferences of PWHIV and those at risk of HIV (e.g. people testing for HIV or accessing post-exposure prophylaxis or pre-exposure prophylaxis). Those who must communicate particularly complex or distressing information should have good communication skills. Practitioners should also be mindful of personal attitudes and beliefs that may influence their verbal and non-verbal interactions, and that may interfere with the establishment of rapport and trust. It is essential for practitioners working with PWHIV or those at higher risk for HIV to be culturally sensitive in their work.

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There is some evidence that the communication skills of health-care professionals can be improved by training [112]. Specialists who are experienced in the provision of psychological support services to PWHIV can be a useful resource in the development of communication skills through teaching and training of less experienced practitioners. Cultural competency in working with PWHIV can be accomplished through education about HIV, as well as increased understanding about the perspectives of PWHIV and people at higher risk of infection. HIV-positive speakers' presentations to practitioners can be an effective way to challenge negative perceptions and stereotypes about PWHIV [113].

Practitioners whose primary role is psychological support may not be familiar with the specific needs of PWHIV. Such practitioners should have access to training on working with PWHIV if their role requires it.

### S6.2.5 Required competencies

To provide high-quality care for PWHIV, all practitioners providing psychological support to PWHIV should, in addition to the generic competencies for their role, have the following minimum competencies:

- awareness of the diversity of needs that PWHIV may have – especially men who have sex with men, Aboriginal and Torres Strait Islander people, people from CALD backgrounds, women, and people who use drugs – so that they can promote effective engagement
- awareness of the cultural dimensions of face-to-face communication, cultural sensitivities relating to HIV and its treatment, and cultural norms such as those relating to sexual practices
- an understanding of HIV including prevention, progression, symptoms, treatment regimens (current and emerging) and a changing epidemic
- an understanding of the presentation of cognitive difficulties in HIV disease and its functional consequences
- an understanding of the psychological impact of HIV and associated factors, including gender differences, diverse sexual populations and sensitivities
- an understanding of the ethical and legal issues relating to HIV transmission
- an understanding of the implications of confidentiality and disclosure for PWHIV, including between health practitioners, and recording of status within and between services
- knowledge of the range and diversity of local HIV service provision and related access and referral criteria
- an understanding of holistic care encompassing all aspects of health and the complex interplay of psychological needs on health and wellbeing.

## S6.3 Implications for HIV program planning

### S6.3.1 Implication 6.1

The expertise of experienced practitioners should be used to support the delivery of education, training and governance across the range of providers within HIV psychological support provision.

### S6.3.2 Implication 6.2

HIV program planners and service providers should ensure that:

- local education and training provision is adequate to ensure that the workforce is appropriately skilled to meet the demands of all four levels of psychological support for PWHIV (described in Appendix A)
- resources for adequate education and training are costed and included in planning agreements.

### S6.3.3 Implication 6.3

Contracts for all services to provide psychological support for PWHIV should state requirements relating to education, training and assessment, and maintenance of competencies.



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## S6.4 Auditable indicators

### S6.4.1 Indicator 6.1

Proportion of practitioners delivering psychological support to PWHIV who have successfully completed competency-based training according to their scope of practice and fulfilled relevant CPD requirements.

(Measurable through audit across local providers of psychological support.)

### S6.4.2 Indicator 6.2

Evidence of satisfactory assessment of competencies and appropriate professional registration of practitioners at levels 1 to 4 of the stepped care model.

(Measurable through audit across local providers of psychological support.)

### S6.4.3 Indicator 6.3

Education and training budgets are included in service delivery agreements.

## S6.5 Further supporting documents and guidance

- Shaw, L, 2004, Good practice guidelines for the training and consolidation of clinical psychology practice in HIV/sexual health settings. British Psychological Society Division of Clinical Psychology, London. Available from: [https://www.bps.org.uk/system/files/user-files/Division%20of%20Clinical%20Psychology/public/good\\_practice\\_guidelines\\_for\\_the\\_training\\_and\\_consolidation\\_of\\_clinical\\_psychology\\_practice\\_in\\_hiv\\_sexual\\_health\\_settings.pdf](https://www.bps.org.uk/system/files/user-files/Division%20of%20Clinical%20Psychology/public/good_practice_guidelines_for_the_training_and_consolidation_of_clinical_psychology_practice_in_hiv_sexual_health_settings.pdf). [114]

# Standard 7

## Standard 7 – Coordination of psychological support and treatment

**People with HIV (PWHIV) should have access to appropriate psychological support services that are coordinated within a managed framework.**

### S7.1 Recommendations

#### S7.1.1 Service design

Psychological support should be included in the design, development and implementation of all HIV treatment and care services. A coordinated range of psychological support interventions should be offered across the spectrum of providers.

#### S7.1.2 Pathways of care

Clear pathways should be developed between services providing HIV clinical treatment and care, and those offering psychological support. Pathways should be explicit, agreed and adopted by all HIV clinical services.

Psychological support should be delivered through a network of providers with different levels and types of expertise in psychological issues for PWHIV (see stepped care model, Appendix A).

Coordination, collaboration and communication among general practitioners, HIV clinicians, other specialists and patients is crucially important for effective management of HIV-related care and services, including mental health services for PWHIV [115, 116]. Services should aim to provide seamless integration across levels of psychological support and across providers, including transitions from services for families and young people to those for adults.

A pathway enabling PWHIV to self-refer into psychological support services should be established. Services should be provided free of charge where possible to allow equitable access, and to recognise the impact of HIV on marginalised and vulnerable communities. Pathways should also be in place to ensure the availability of psychological support at all levels from practitioners with specialist expertise in HIV.

Pathways should be established to ensure that PWHIV can access specialist level 3 and level 4 support as and when they need it. Emergency psychiatric services should be available when required for PWHIV with severe mental health problems, in and out of normal working hours. Particularly where there is limited access to services (e.g. in rural and remote regions), other avenues of support and treatment should be considered, such as telehealth assistance and consultation with specialist professional networks.

#### S7.1.3 Leadership and collaboration

The provision of psychological support for PWHIV should be strategically planned and coordinated across all relevant local providers. Such coordination requires collaboration across organisational and professional boundaries, with clearly defined and accountable leadership and management arrangements. This may be achieved through HIV service networks or clinical networks where these are in place.

Clinical leadership of psychological support for people who use HIV treatment services should be provided by practitioners who are appropriately trained and experienced in this area. Clinical leads should be part of the multidisciplinary clinical and management teams of services providing HIV care, should collaborate with the professional leads of other local services providing psychological support for PWHIV (e.g. social care and community support) and should work closely with HIV program planners.



### **S7.1.4 Service provision**

All people involved in HIV service provision should work together to ensure that high-quality psychological support services based on the needs of local PWHIV are available, are delivered and are effectively coordinated.

## **S7.2 Rationale**

### **S7.2.1 Service design**

Psychological support for PWHIV should be given equal priority with other aspects of their care, and should be fully integrated with HIV diagnosis and treatment. Where HIV service networks or clinical networks are in place, consideration should be given to including psychological support for PWHIV within their scope. Networks can facilitate equity of access and quality of care across providers; they can also foster multidisciplinary working and professional development.

### **S7.2.2 Pathways of care**

The psychological support needs of PWHIV can be complex; hence, appropriate psychological support for an individual may involve a variety of practitioners within health-care, social-care and other community settings. The full range of psychological support should be available for PWHIV, regardless of the level of provision available within the services where they normally receive their HIV care. This should include access, when necessary, to local mental health services including psychiatric and community support, as well as to social and legal services.

Coordination of all aspects of care is imperative, with effective pathways agreed and in place between providers, so that PWHIV can move between services as needed and receive psychological support that is seamless from their perspective.

### **S7.2.3 Leadership and collaboration**

Although HIV services should be implemented in line with state and Commonwealth strategies, their work needs to be informed by needs assessments, frontline experience and the professional knowledge of expert practitioners.

HIV program planners should work closely with service providers to understand local needs and plan the provision of high-quality care through coordinated services. Collaborative arrangements, through formal networks or other frameworks, should be centred around the needs of PWHIV, to ensure that these needs are met wherever PWHIV access psychological support in health-care, social-care or community support services.

Experience and training in psychological support for PWHIV is required to provide effective clinical leadership for psychological support services. Clinical leads should maintain close contact with clinical practitioners who are actively involved in the care or support of PWHIV, and ensure they are enabled to provide psychological support at an appropriate level as part of their role. Supervision, consultation and training by clinical leads can be an effective way to support practitioners.

### **S7.2.4 Service provision**

Where coordination of service provision at strategic and operational levels is missing, PWHIV may be denied access to appropriate services for a variety of reasons. These include:

- a failure to assess, recognise or actively investigate the psychological support needs of PWHIV
- a failure of PWHIV to access existing services due to their lack of familiarity with or difficulty in accessing such services
- a failure of accessed services to fully meet the psychological support needs of PWHIV because of inadequate communication skills and competencies
- a lack of appropriate services due to limitations in planning, funding or workforce capacity.

# Standard 7

To overcome these risks, it is important to ensure strategic and operational coordination, which will lead to PWHIV having a better quality of life and greater satisfaction with services.

For the provision of coordinated and high-quality psychological support services, HIV program planners, clinical leads and other relevant stakeholders should ensure that services include the following:

- population-centred care – the demographic profile of the local population of PWHIV should be understood in order to ensure that its needs are adequately met
- diversity – the diversity of the needs of PWHIV should be taken into consideration when developing network protocols
- equity – strategies should be in place to identify and meet the needs of local PWHIV who have difficulty accessing services or require assistance to access services
- consumer engagement – PWHIV should be involved as equal partners with professionals in the development and provision of psychological support (see Standard 3)
- evidence-based best practice – decisions on service configuration and on developmental priorities should be informed by needs assessment and clinical expertise
- appropriate resourcing – resources available should be age and gender appropriate, and available in languages used by the local community, with specific attention paid to issues affecting Aboriginal and Torres Strait Islander people, ethnic minority groups, young people, gender and sexuality diverse people, asylum seekers and refugees, survivors of trauma, and those with sensory impairment, learning disabilities or mental health problems
- continuing professional development – resources should be available for education and training sufficient to maintain required competencies
- service partnerships – mechanisms should be established to support effective partnerships between the government, nongovernment and community sectors to ensure PWHIV receive coordinated and cost-effective care
- referral networks – operational policies, care pathways and referral guidelines should be developed in partnership between providers of psychological support in health-care, social-care and other community settings, including those in the voluntary sector
- holistic approach – effective multidisciplinary and multiagency communication and collaboration should be employed to allow the HIV-specific psychological support needs of PWHIV to be met.

## S7.3 Implications for HIV program planning

### S7.3.1 Implication 7.1

HIV program planners should consult with those involved in the delivery of psychological support services in the planning and implementation of coordinated psychological support for PWHIV. Ensuring a comprehensive range of services to meet the varied psychological support needs of PWHIV may require cooperation across health district boundaries.

### S7.3.2 Implication 7.2

HIV program planning of high-quality psychological support will require:

- assessment of the local need in terms of the prevalence, complexity and diversity of psychological and cognitive problems in PWHIV, and of the resources, competencies and training required to meet these needs
- assessment of existing service provision in terms of resources, psychological support, and HIV-specialist workforce and competencies
- mapping of available psychological support provision to the established psychological need
- development of strategies for comprehensive provision of psychological support based on the results of the mapping procedure
- development of care pathways including definitions of provider roles, referral criteria, protocols, capacity, clinical governance and performance outcomes, and an understanding of more specialist services for onward referral



- regular appraisal and determination of training requirements for all those providing psychological support
- access to training, supervision or other effective means of ongoing support for all practitioners providing psychological support
- regular audits of the availability and appropriateness of psychological support to ensure that the required standards are met and to inform workforce development
- a seamless interface between psychological support providers and other providers of HIV care through regular communications where appropriate.

## S7.4 Auditable indicators

### S7.4.1 Indicator 7.1

Evidence of inclusion of psychological support at levels 1, 2, 3 and 4 in agreed care pathways at each HIV treatment centre.

### S7.4.2 Indicator 7.2

Supporting documents and policies that demonstrate coordination and integration across multiple agencies.

## S7.5 Further supporting documents and guidance

- New York State Department of Health, AIDS Institute, 2009, Mental health standards of care. An integrated approach to serving communities in New York State. New York State Department of Health, AIDS Institute, New York. [101]
- Savage, J, Crooks, L, and McLean, S, 2009, Models of access and clinical service delivery for people with HIV in Australia: final report. Australasian Society for HIV Medicine, Sydney, NSW. Available from: <http://napwha.org.au/files/MACSD%20-%20Final%20Report.pdf>. [117]

# Standard 8

## Standard 8 – Evidence-based practice

**All psychological assessment and interventions for people with HIV (PWHIV) should be based on the best available evidence.**

### S8.1 Recommendations

#### S8.1.1 Evidence-based assessment and interventions

All psychological assessment methods and psychological support interventions used across the four levels of stepped care should be selected and delivered according to the best available evidence of effectiveness.

#### S8.1.2 HIV-appropriate assessment and intervention methods

Methods used for psychological and cognitive assessment and psychological support interventions for PWHIV should have been developed, standardised and evaluated for use with HIV or other life-threatening chronic medical conditions.

### S8.2 Rationale

#### S8.2.1 Evidence-based assessment and interventions

Evidence-based practice is decision-making based on sound research evidence that is combined with individual practitioner expertise. It also takes into consideration the needs of the individual service user. The goal of evidence-based practice is to improve outcomes for the service user, enhance quality of care, and provide some standardisation of treatment and other interventions. Using evidence-based interventions also improves cost effectiveness, by avoiding expenditure on interventions that do not work or work less well than others.

The scientific and health-care community grades the strength of evidence for the effectiveness of interventions into three or four levels, according to the robustness of the research methodology used. Level 1 refers to randomised controlled trials (RCTs) that are generally accepted as the gold standard, providing the most reliable evidence. However, this level of evidence for psychological support interventions in HIV is relatively rare.

The most prevalent types of evidence for psychological support interventions in HIV include nonrandomised clinical trials, observational case studies and general consensus from experts.

Existing evidence-based guidelines should be used to inform practice in psychological assessment, support and intervention for PWHIV. To create realistic and relevant best practice guidelines for psychological assessment and support for PWHIV, all levels of evidence need to be considered. Given the limited availability of RCT evidence, other research designs such as qualitative and outcomes research are becoming recognised as meaningful ways of providing evidence. However, clinical or other service provision experience and judgement will always be needed to inform practice, especially where relevant evidence is scarce, absent or not directly relevant to the needs of an individual PWHIV.

No assessment method or intervention can be described as evidence-based for all populations, cultural groups and key populations (e.g. men who have sex with men). Most studies have been conducted with white American or British populations, so their applicability to other communities is questionable; therefore, more diverse and robust sample sizes are needed [28, 118, 119]. A number of experts have recently called for 'culturally modified' psychological interventions, including cognitive behaviour therapy (CBT) [120-122]. Comprehensive, holistic, psychosocial and welfare support should be provided involving all types of stakeholders in the provision of care [79]. Culturally relevant and appropriate mental health services need to be provided to Aboriginal and Torres Strait Islander people [123].

There has been no adequate evaluation of the adjustments or modifications needed. Therefore, an evidence base for CBT and other psychological therapies across all communities affected by HIV is not currently available. Given these limitations, involving service users from all communities affected by HIV in the evaluation of assessment methods and interventions is recommended.



### S8.2.2 HIV-appropriate assessment and intervention methods

Assessment takes place at all levels within the stepped care model (see Appendix A). Regardless of the provider and that person's level of expertise in HIV, assessment should be performed in a way that has been shown through research and evaluation to be effective with PWHIV. This will help to ensure that PWHIV receive appropriate referrals for psychological support interventions.

## S8.3 Implications for HIV program planning

### S8.3.1 Implication 8.1

HIV program planners should involve public health, clinical and community experts to ensure that planning and provision of psychological assessment, support and intervention is informed by up-to-date evidence of effectiveness and current evidence-based guidelines.

### S8.3.2 Implication 8.2

Local health-care and social-care needs assessments relevant to HIV and mental health should include consideration of the psychological support and intervention needs of PWHIV.

### S8.3.3 Implication 8.3

Adequate resources should be made available for the continual evaluation and development of assessment methods and psychological support interventions for PWHIV.

## S8.4 Auditable indicators

### S8.4.1 Indicator 8.1

Adherence by services providing psychological assessment, support and intervention for PWHIV to evidence-based guidelines of best practice, as set by organisations such as Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) and the Australian Psychological Society [124].

### S8.4.2 Indicator 8.2

Evidence that services providing psychological support for PWHIV are using assessment and intervention methods that have been developed, standardised and evaluated for use with HIV or other chronic medical conditions.

## S8.5 Further supporting documents and guidance

- Bravo, P, Edwards, A, Rollnick, S, et al. 2010, Tough decisions faced by people living with HIV: a literature review of psychosocial problems. *AIDS Rev.* 12(2): 76–88. [9]
- Burgess, R, 2010, *New principles for best practice in clinical audit.* Radcliffe Publishing Ltd: Abingdon. [125]
- Catalan, J, Harding, R, Sibley, E, et al. 2011, HIV infection and mental health: suicidal behaviour – systematic review. *Psychol. Health Med.* 16(5): 588–611. DOI:10.1080/13548506.2011.582125. [57]
- Catalan, J, Meadows, J, and Douzenis, A, 2000, The changing pattern of mental health problems in HIV infection: the view from London, UK. *AIDS Care.* 12(3): 333–41. DOI:10.1080/09540120050042990. [126]
- Health Quality Improvement Partnership (HQIP). *Guidance and resources on clinical audit.* [127]
- NSW Department of Health, 2008, *Strengthening health care for people with chronic illness.* NSW Chronic Care Program: Phase Two 2003–2006. NSW Department of Health, Sydney. Available from: [http://www.health.nsw.gov.au/pubs/2005/pdf/chronicare2\\_exec.pdf](http://www.health.nsw.gov.au/pubs/2005/pdf/chronicare2_exec.pdf). [128]
- Olatunji, BO, Mimiaga, MJ, O'Cleirigh, C, et al. 2006, Review of treatment studies of depression in HIV. *Topics in HIV medicine: a publication of the International AIDS Society, USA.* 14(3): 112–24. [129]
- Smart, T, 2009, *Mental health and HIV: a critical review.* HIV & AIDS treatment in practice. NAM Publications: London. [16]
- Wagner, EH, 1998, Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract.* 1(1): 2–4. [64]
- World Health Organization (WHO), 2008, *HIV/AIDS and mental health (EB124/6).* WHO, Geneva. Available from: [http://apps.who.int/gb/archive/pdf\\_files/EB124/B124\\_6-en.pdf](http://apps.who.int/gb/archive/pdf_files/EB124/B124_6-en.pdf). [5]

## Appendix A – The stepped care model

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People with HIV (PWHIV) can often assess their own emotional support needs and meet those needs by themselves; for example, by choosing support from family, friends, peer networks or support groups. They may also develop personal self-management strategies on their own and self-refer to services they know how to access.

However, PWHIV may require some form of psychological support to help them with their needs. Sometimes PWHIV may lack a support network, may be reluctant to disclose their status due to stigma and discrimination concerns, or have concerns about burdening loved ones. In addition, the needs of some PWHIV are complex and require intense professional and specialist support. The stepped care model (Table 1) outlines comprehensive care for psychological support that makes the most of resources at all levels of expertise. The aim of stepped care is to:

- improve health outcomes and experiences of PWHIV
- improve quality of life of PWHIV
- prevent the development or exacerbation of more severe psychological and psychiatric comorbidities
- use limited resources cost effectively
- help in the planning and provision of psychological support services based on need
- promote positive wellbeing.

The model describes four essential levels of psychological support provision for PWHIV based on levels of complexity of need. Mapped against these are increasing practitioner training, specialisation in psychological and psychiatric problems, and competency, presented in relation to the types of assessment and interventions required of providers. It may not always be possible to make clear distinctions between the boundaries of expertise of various practitioners, and some overlap is likely to occur. This is a reactive model that should be used alongside proactive prevention and outreach models to maximise PWHIV's engagement and wellbeing.

Care pathways based on the stepped care model can be linked to practitioner competencies (see Standard 6) in order to:

- provide holistic care
- avoid duplication of roles, inequalities in provision of psychological support between localities, or a lack of recognition of psychological and psychiatric problems
- ensure that practitioners operate within their levels of competence.

Standards 2 and 7 outline how the model can be used to provide comprehensive and coordinated psychological support pathways.


**Table 1: Recommended model of stepped care provision of psychological support**

LEVEL	ASSESSMENT	INTERVENTIONS
<b>1</b> <b>Information and support</b>	<p>Recognising the psychological needs of people with HIV</p> <p>Initial screening of risk of harm to self and others</p> <p>Recognising and responding to overt psychological distress</p>	<p>Effective provision of relevant information in accessible formats</p> <p>Supported self-help</p> <p>Referral to appropriate providers</p> <p>Response to overt distress</p> <p>Supportive communication and general psychological support</p> <p>Referral to self-management strategies (e.g. books and computerised resources, and courses for the newly diagnosed)</p> <p>Referral to peer support and peer support organisations</p>
<b>2</b> <b>Enhanced support</b>	<p>Screening for psychological distress</p> <p>Screening for cognitive difficulties</p> <p>Assessment of risk of harm to self and others</p>	<p>Discussions aimed at acceptance and adaptation to living with HIV</p> <p>Referral to more appropriate services and peer support</p> <p>Education around the nature of psychological and psychiatric problems and how to cope with them</p> <p>Brief interventions aimed at behavioural change (e.g. sexual risk behaviour and substance use concerns)</p>
<b>3</b> <b>Counselling and psychological therapies (including HIV-specialist services)</b>	<p>Assessment and formulation of psychological problems</p> <p>Identification of psychiatric problems</p> <p>Screening for cognitive impairment</p> <p>Assessment of risk of harm to self and others</p>	<p>Counselling and psychological interventions based on explicit theoretical frameworks for specific psychological difficulties such as:</p> <ul style="list-style-type: none"> <li>• adjustment issues</li> <li>• moderate or severe anxiety</li> <li>• substance use concerns</li> <li>• moderate or severe depression</li> <li>• psychosexual or relationship problems</li> <li>• trauma</li> </ul> <p>Interventions for cognitive impairment</p> <p>Psychological interventions based on explicit theoretical frameworks to develop and enhance positive psychological processes such as adaptive coping strategies that increase resilience</p>
<b>4</b> <b>Specialist psychological and mental health intervention (HIV or other specialist)</b>	<p>Psychiatric diagnosis</p> <p>Assessment and formulation of complex psychological problems</p> <p>Assessment for cognitive impairment</p> <p>Assessment of risk of harm to self and others</p> <p>Neuropsychological assessment</p>	<p>Specialist psychological and psychiatric interventions for severe and complex psychological problems, and comorbidities such as:</p> <ul style="list-style-type: none"> <li>• trauma</li> <li>• psychosis</li> <li>• severe anxiety and depression</li> <li>• mania</li> <li>• personality disorder</li> <li>• cognitive impairment</li> <li>• complex childhood and family issues</li> </ul> <p>Cognitive supports and interventions</p>

# Appendix A

## A1 Level 1

Level 1 psychological support is provided by all practitioners directly responsible for the care of PWHIV in government, nongovernment and community settings. Level 1 psychological support focuses on general supportive emotional care, supported self-help, referral and the identification of more serious problems for onward referral. All PWHIV should have access to this level of care.

### A1.1 Assessment at level 1

All practitioners at this level should:

- recognise signs of psychological distress and risks
- perform initial screening of the impact of HIV on living circumstances and relationships
- know when they have reached the boundary of their competence and refer the PWHIV on when this boundary is reached
- have an understanding of referral pathways and referral criteria for more specialist services (see Standard 7)
- provide referrals or information relating to confidentiality, disclosure of HIV status and other relevant information such as immigration, criminalisation and access to treatments (practitioners should be careful to avoid encouraging or counselling clients towards or against a course of legal or medical action)
- understand and respond to cultural issues pertaining to HIV, health beliefs, sexuality and stigma.

### A1.2 Interventions at level 1

Interventions at this level include:

- general psychological support based on skilled communication
- provision of information on the wider range of resources and services available
- establishing and maintaining supportive therapeutic relationships
- treating PWHIV with compassion, dignity and respect
- recognising HIV as a stigmatising condition and respecting confidentiality
- talking about sexual matters in relation to HIV
- clearly but empathically breaking bad news
- enhancing self-efficacy
- providing peer support.

## A2 Level 2

Level 2 psychological support is provided by practitioners who have additional expertise in providing psychological support through training and experience. This will include brief interventions that are standardised in manuals (e.g. motivational interviewing and post-test discussion).

### A2.1 Assessment at level 2

Practitioners operating at this level should provide formal screening for psychological distress and cognitive difficulties at key points in the life of PWHIV, and assess risk of harm to self and others, for example:

- at time of HIV diagnosis
- at initial onset of physical symptoms
- when there are negative changes in blood counts or other changes in physical health status
- when starting or switching HIV medication
- at times of non-adherence
- at the development of medication side effects
- at times of treatment failure
- after change of HIV care provider
- after a period of non-attendance and loss of contact with HIV care provider
- at the development of psychosocial problems such as housing and financial difficulties, immigration, relationship issues or loss



- when experiencing family problems including those arising from children's HIV status
- when experiencing stigma, violence or abuse
- at times of coinfection, such as with hepatitis B or C or tuberculosis (TB)
- at times when substance use becomes a concern.

Practitioners should be able to screen for psychological distress and cognitive difficulties, and to use counselling techniques to elicit worries and feelings that a PWHIV may have in an empathic, nonjudgemental way. If significant psychological distress is identified, practitioners should also be equipped to contain this and to refer on to specialist psychological support. They should also be able to assess the competence of PWHIV to consent to referral and treatment (see Standard 6 on competencies required).

### **A2.2 Interventions at level 2**

Level 2 psychological support interventions can include discussions around adjustment to having HIV, newly diagnosed programs, problem solving, motivational interviewing around HIV prevention and referral. Level 2 psychological support practitioners should have competencies (see Standard 6) to provide structured psychological interventions, such as:

- post-test discussion
- chronic disease management
- adherence support
- sexual risk reduction
- antenatal and postnatal support
- peer support groups
- support around living with HIV
- education around coping with and understanding mental health problems
- assistance with substance use concerns.

These practitioners should work within agreed referral and communication pathways, and to specific referral criteria. They should also practise within their levels of competence and know when to refer onwards.

## **A3 Level 3**

Level 3 psychological support is provided by qualified, professionally registered practitioners in counselling and psychological therapies who receive appropriate supervision.

### **A3.1 Assessment at level 3**

Assessment at this level should be carried out by practitioners with qualifications and professional registration in psychological therapies and interventions, or professionally registered and supervised practitioners from other disciplines who have completed accredited training to achieve the required competency in psychological therapies and interventions (see Standard 6 on competencies required). Practitioners should identify psychological problems, assess risk of harm to self and others, confirm competence of PWHIV to consent to referral and treatment, and differentiate between moderate and severe levels of psychological need that may require referral to psychological or mental health specialists. Screening for cognitive impairment will be carried out by appropriately trained and accredited practitioners at this level.

### **A3.2 Interventions at level 3**

Level 3 psychological support interventions are based on explicit theoretical frameworks with proven effectiveness for specific psychological issues that may be more complex. Such issues include anxiety, depression, substance use, psychosexual or relationship problems, cognitive impairment or sexual trauma. The support can also include psychological interventions focused on developing and enhancing adaptive coping strategies that increase positive psychological outcomes such as resilience. Medication management of conditions such as anxiety and depression at this level may be undertaken. Interventions for cognitive impairment may also be carried out by appropriate practitioners.

# Appendix A

## A4 Level 4

Level 4 psychological support is provided by psychological and mental health specialists who have clear pathways developed from HIV services. To enable PWHIV to receive general (non-HIV-related) psychological and psychiatric provision when needed, referral from liaison psychiatry or HIV-specialist counsellors and psychological therapists is preferred. However, where these roles are absent, more direct pathways to level 4 will need to be developed from services at levels 1 and 2.

**Figure 1: Filter model of provision of psychological support for people with HIV**

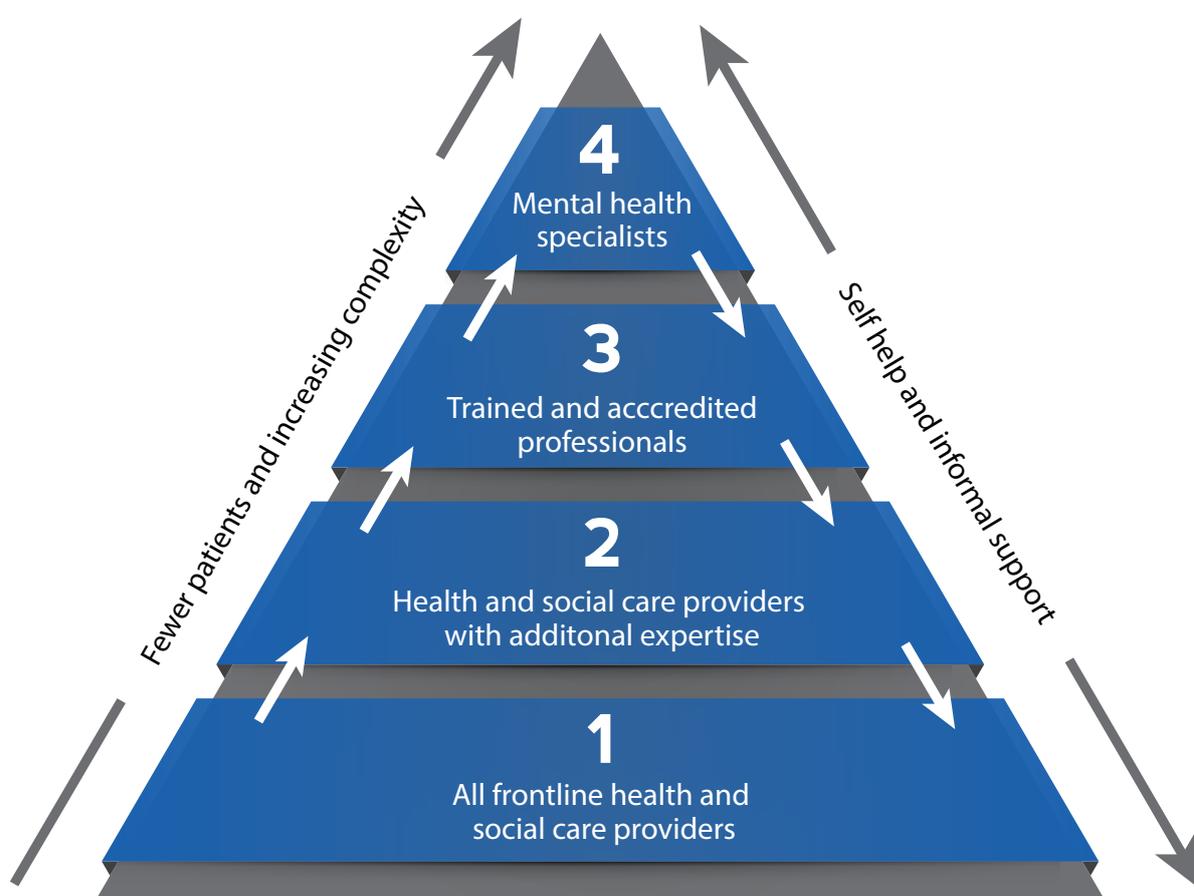


Figure 1 demonstrates the filter model of psychological support and the variety and expertise of practitioners associated with each level of psychological support (this model is related to the stepped care model). Level 1 indicates that all frontline care providers for PWHIV provide for low-level psychological needs. As the degree or complexity of need increases, psychological support is provided by practitioners of increasing expertise and specialisation. The highest level of psychological support, level 4, is provided by practitioners with specialist psychological or psychiatric expertise. Supported self-help and informal support is encouraged at all levels of psychological support. The diagram, with a wide base decreasing to the apex, indicates the decreasing numbers of practitioners required at each increasing level of support, in line with the decreasing number of PWHIV requiring psychological support at each level. Throughout their journey with HIV, PWHIV may move both up and down the model as their needs change. Clarity can be achieved by using the model as a template for developing pathways in order to facilitate referral and discharge between the levels.



#### A4.1 Assessment at level 4

Assessment at this level should be carried out by mental health specialists. These professionals should provide assessment of severe psychological problems in the context of physical ill health, or psychiatric problems such as severe depression, personality disorders, psychosis or mania. To ensure a holistic assessment of needs, even where the psychological or psychiatric problems predominate, practitioners should have competency in assessment of coexisting psychiatric and physical health conditions. Assessments could involve psychiatric diagnosis and risk assessment, and lead to the identification of complex psychological problems from a variety of psychological theoretical frameworks. Cognitive assessment will be carried out by appropriately trained and accredited practitioners at this level, and may include neuropsychological testing for HIV-associated cognitive impairment.

#### A4.2 Interventions at level 4

Level 4 psychological support requires specialist evidence-based psychological and psychiatric interventions to manage severe or complex HIV-related psychological problems or severe mental health problems, such as psychosis, mania, personality disorder and severe depression. Severe mental health problems are usually managed in multidisciplinary mental health teams. Psychiatric treatment could also relate to complex prescribing issues including attention to drug interactions or contraindications to specific medication regimens in people with other health problems. This level of intervention may necessitate provision of emergency psychiatric services in addition to outpatient, inpatient and community services. Interventions for cognitive impairment at this level would be delivered by a multidisciplinary cognitive rehabilitation team.

### A5 Further supporting documents and guidance

- The model of stepped care described here was based on the 2011 British Standards for psychological support for adults living with HIV [1], which was inspired by models in the following documents:
- Gutmann, M and Fullem, A, 2009, Mental health and HIV/AIDS: technical brief. USAID, AIDSTAR-One project, Arlington, VA. Available from: <http://www.encompassworld.com/resources/mental-health-and-hiv-aids>. [60]
- Handford, CD, Tynan, AM, Rackal, JM, et al. 2006, Setting and organization of care for persons living with HIV/AIDS. Cochrane Database Syst. Rev. (3): DOI:10.1002/14651858.CD004348.pub2. [130]
- National Institute for Clinical Excellence (NICE), 2004, Improving supportive and palliative care for adults with cancer: cancer service guideline (CSG4). NICE, London. Available from: <https://www.nice.org.uk/guidance/csg4>. [131]
- Victorian State Government, 2009, Hospital Admission Risk Program (HARP) Chronic disease program. 2001–2002 (update) Victorian State Government, Department of Human Services, Victoria. Available from: <http://www.health.vic.gov.au/harp-cdm/>. [132]

## Appendix B – Auditable outcomes and indicators

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### B1 Measuring outcomes of psychological support

Access to high-quality psychological support, as set out in these standards, will contribute to improvements in both mental health and physical health outcomes in people with HIV (PWHIV), as well as reductions in onward transmission of HIV and the rate of new infections. It is important to measure these outcomes, because this will provide a high-level assessment of whether the standards for psychological support (and other standards and guidelines relevant to the care of PWHIV) are being implemented in an effective way.

The Australian Government Department of Health provides performance indicator frameworks that include indicators relevant to mental health and physical health [133]. Progress against these performance indicators should be assessed among PWHIV, taking into account any particularities associated with HIV that may affect what to measure and how best to measure.

At local and national level, ongoing surveillance and specific audits can measure health outcomes for PWHIV, and adherence to standards and guidelines designed to improve these outcomes.

### B2 Outcomes to which psychological support for PWHIV contributes

Psychological support both improves individual health outcomes and reduces the risk of onward transmission of HIV through its positive impact on:

- adherence to antiretroviral therapy (ART)
- retention in HIV treatment and care
- management of risk behaviour.

Psychological support for PWHIV also reduces:

- number of hospital admissions
- length of inpatient stays
- time in medical consultations
- number of medical investigations.

Thus, audits to measure progress against these factors will provide an indication of the impact of the standards and their implementation, as part of the full range of health-care, social-care and preventive interventions.

Such audits are important in measuring both health outcomes and cost efficiencies. Also, they are relevant in relation to the productivity and prevention elements of quality improvement frameworks.

### B3 Overarching outcomes of psychological support

Measuring mental health outcomes is a way of assessing more directly the impact of psychological support. Outcome measures developed to assess the mental health and wellbeing of the general population or of people living with other long-term conditions may be useful, though not all will be suitable for use in PWHIV.

It is suggested that the following overarching outcomes be assessed in PWHIV as a measure of the effectiveness of psychological support in line with these standards. The development and testing of specific indicators and tools to measure these outcomes is recommended, if they are not already in place. The overarching outcomes to be assessed are:



- levels of psychological morbidity, quality of life and wellbeing (measured regularly using HIV-appropriate and culturally sensitive measures including holistic factors such as quality-of-life measures, including surveys of service users)
- satisfaction of PWHIV with:
  - the response of services to their psychological support needs
  - the coordination of psychological support
  - the impact of psychological support on their quality of life and wellbeing (measured through qualitative and quantitative methods for one-off 'snapshots', or undertaken regularly for trends over time).

## B4 Auditable indicators for each standard

In addition to the overarching outcomes suggested above, the use of specific indicators is recommended to measure how well each individual standard is being met. As such, the suggested indicators below (taken from the respective standards) are a mixture of process and outcome measures. Defined simply, 'process' indicators measure what service providers do, whereas 'outcome' indicators measure the results for service users.

Other indicators may be identified at the local level, depending on strategic priorities and the logistics of data collection. The development of a local 'scorecard' may be helpful to monitor progress against a set of indicators over time.

The indicators below suggest what can be measured to assess the quality of care and progress over time. They do not propose benchmarks or targets to be achieved, because these will need to be determined according to local circumstances and progress to date.

### Standard 1: Promotion of mental and psychological wellbeing

#### S1.4.1 Indicator 1.1

Proportion of service users who report that:

- a) their service providers give them sufficient opportunity to discuss their psychological wellbeing
- b) their service providers understand the experience of living with HIV
- c) they have experienced stigma from health-care practitioners in the last year
- d) they have received information about HIV and their care that has included psychological wellbeing.  
(Measurable through surveys of service users.)

#### S1.4.2 Indicator 1.2

Evidence that accurate, evidence-based information is provided within services for PWHIV, including information in languages and formats that meet local needs, and information materials from accredited providers.  
(Measurable through observation and surveys of service users.)

### Standard 2: Comprehensive psychological support services

#### S2.4.1 Indicator 2.1

When psychological support needs have been identified, the proportion of PWHIV who have been referred on to appropriate psychological support.  
(Measurable through occasional fixed-period audit of service user records in HIV treatment centres and community support organisations.)

# Appendix B

## **S2.4.2 Indicator 2.2**

Proportion of PWHIV in whom a serious and immediate risk of harm to self or others has been identified through screening or clinical observation, who are referred to emergency mental health services on the same day.

(Measurable through audit of service user records.)

Standard 3: Meaningful involvement of people with HIV

## **S3.4.1 Indicator 3.1**

Evidence from providers of HIV-specialist psychological support that they have:

- a) developed a plan for engaging PWHIV
- b) implemented the plan
- c) taken action in response to PWHIV input.

## **S3.4.2 Indicator 3.2**

Inclusion of surveys in audits and evaluations of psychological support provision.

## **Standard 4: Support at the time of diagnosis**

### **S4.4.1 Indicator 4.1**

Proportion of people newly diagnosed with HIV who are offered appropriate psychological support. Of those who accept a referral, the proportion who receive it a) within 48 hours and b) within 2 weeks of diagnosis.

(Measurable, where possible, through audit of records of services providing testing or through service user feedback.)

### **S4.4.2 Indicator 4.2**

Evidence of a clear and agreed pathway for post-diagnostic psychological support from services providing HIV testing.

### **S4.4.3 Indicator 4.3**

Evidence of a clear and agreed pathway for the provision of support to people who have had a reactive result from an HIV home test, or a positive HIV result in a setting where counselling was not provided.

## **Standard 5: Identifying psychological support and treatment needs**

### **S5.4.1 Indicator 5.1**

Proportion of PWHIV receiving screening for a) psychological and b) cognitive difficulties at least once a year.

### **S5.4.2 Indicator 5.2**

Among PWHIV whose screen suggests significant psychological or cognitive difficulties, the proportion referred for further assessment by a suitably competent professional. The uptake of referrals and engagement in care could also be useful indicators. Surveys of PWHIV may be helpful in evaluating the effectiveness of referrals provided; however, surveyors are advised to be mindful of survey fatigue and should strive to minimise effort and maximise data.

## **Standard 6: Competence to provide psychological support**

### **S6.4.1 Indicator 6.1**

Proportion of practitioners delivering psychological support to PWHIV who have successfully completed competency-based training according to their scope of practice and fulfilled relevant CPD requirements.

(Measurable through audit across local providers of psychological support.)


**S6.4.2 Indicator 6.2**

Evidence of satisfactory assessment of competencies and appropriate professional registration of practitioners at levels 1 to 4 of the stepped care model.

(Measurable through audit across local providers of psychological support.)

**S6.4.3 Indicator 6.3**

Education and training budgets are included in service delivery agreements.

**Standard 7: Coordination of psychological support and treatment**
**S7.4.1 Indicator 7.1**

Evidence of inclusion of psychological support at levels 1, 2, 3 and 4 in agreed care pathways at each HIV treatment centre.

**S7.4.2 Indicator 7.2**

Supporting documents and policies that demonstrate coordination and integration across multiple agencies.

**Standard 8: Evidence-based practice**
**S8.4.1 Indicator 8.1**

Adherence by services providing psychological assessment, support and intervention for PWHIV to evidence-based guidelines of best practice, as set by organisations such as Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) and the Australian Psychological Society [124].

**S8.4.2 Indicator 8.2**

Evidence that services providing psychological support for PWHIV are using assessment and intervention methods that have been developed, standardised and evaluated for use with HIV or other chronic medical conditions.

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# Appendix C

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