

# **National Preventive Health Strategy**

**AFAO Submission** 

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# **Australian Federation of AIDS Organisations**

The Australian Federation of AIDS Organisations (AFAO) is the national federation for the HIV community response in Australia. AFAO works to end HIV transmission and reduce its impact on communities in Australia, Asia and the Pacific. AFAO's members are the AIDS Councils in each state and territory; the National Association of People with HIV Australia (NAPWHA); the Australian Injecting & Illicit Drug Users League (AIVL); the Anwernekenhe National HIV Alliance (ANA); and Scarlet Alliance, Australian Sex Workers Association. AFAO's affiliate member organisations – spanning community, research, public health and clinical workforce – share AFAO's values and support the work we do.



# **Background**

AFAO welcomes the opportunity to provide feedback on the Consultation Paper for the development of a National Preventive Health Strategy (the Strategy). Our comments highlight concerns we have with the focus of the National Preventive Health Strategy and the lack of recognition of the poor health outcomes experienced by many LGBTIQ+ people and, in particular, the central role of LGBTIQ+ community controlled organisations as safe and inclusive settings for these communities to access healthcare services.

AFAO is Australia's national peak community-controlled HIV organisation. Our <u>member</u> organisations include state and territory based AIDS Councils who provide primary healthcare to priority populations in their jurisdiction. The services provided by these members supported their communities to access services across the HIV screening, prevention and treatment and care continuum. The focus of these organisations was to involve the communities affected by HIV in the development and implementation of policy, services and programs and support and care.

As the HIV epidemic evolved our members have adapted to respond to their communities' needs. These changes have been driven by member organisations' deep connections to, and understanding of, contemporary issues facing their communities. These organisations have evolved to provide services that range from General Practice and nurse led care to peer-to-peer point of care testing, counselling and community support services for the LGBTI+ community. In addition to HIV and sexual health services, these organisations now provide safe spaces for continuity of care in the areas of alcohol and other drugs and mental health, as well as services for people with multi-morbidities, in aged care and for trans and gender diverse communities. All state-based members either have, or are in the process of, developing General Practice clinics to address the scale of health issues facing our communities.

Our state-based community-controlled member organisations differ from mainstream providers of healthcare to LGBTIQ+ people in that they are embedded in their community and have accountability back to their community through formal governance structures.

## **Executive Summary**

AFAO is concerned that the Consultation Paper (the Paper) sends confusing messages about the Strategy's purpose. The Paper notes the Strategy's aim to ensure "Australia builds an enduring prevention system [that] will not be disease specific in its approach", while on the other hand highlighting a range of health conditions in need of a preventive health strategy. Non-communicable diseases such as heart disease, dementia, cancer and tobacco related conditions are framed as the disease areas that will inform Australia's Preventive Health Strategy.

While the paper mentions HIV and LGBTI communities it has not been informed by, and does not highlight, the unique role of AFAO's community controlled state based members in working with LGBTIQ+ and HIV communities to strengthen their capacity to make positive decisions about their health and wellbeing.

If the Strategy's focus is on specific issues requiring a preventive health response it is our recommendation the Strategy incorporate the unique infrastructure that has evolved to address HIV in Australia and the communities most affected by HIV in Australia. If the intent is an overarching Strategy we recommend the document focus on the institutional and structural barriers in Australia that inhibit the achievement of preventive health objectives. These include:

- evaluation of successful preventive health programs to understand what works, why and the investment needed to scale up these programs across affected communities
- the fragmentation of roles and responsibilities for service delivery created by Australia's system of federalism and, in particular, the state/territory and federal divide
- the relationship between government and the not-for-profit sector as service providers



- the role of community controlled organisations as providers of integrated and comprehensive primary healthcare that includes care and support to people to assist them to continue living in the community (as opposed to accessing the hospital system) and health promotion to increase the capacity of communities to make informed decisions about their health.

#### Issues

## 1. Data on the health of LGBTIQ+ people and communities

LGBTI people experience a range of health inequities that place us at higher risk of poorer health outcomes. These outcomes occur from experiences of being judged, mis-characterised and abused. There is robust Australian research to substantiate this point.

Of the same sex attracted and gender questioning young people who participated in a Latrobe University study<sup>1</sup>:

- 61% reported verbal abuse because of homophobia
- 18% reported physical abuse because of homophobia
- 80% reported physical abuse in schools.

Another Australian study<sup>2</sup> highlights the experiences and challenges of trans and gender diverse (TGD) people from around Australia when accessing healthcare for gender affirmation surgery and cancer care. Participants who indicated an experience of one of the types of harassment or assault were asked if they had experienced harassment or assault in the previous 12 months.

- 86.6% had experienced silent harassment
- 74.1% had experienced verbal harassment
- 49.2% had experienced physical intimidation
- 34.3% had experienced physical violence
- 57.8% had experienced sexual harassment
- 32.3% had experienced sexual assault

298 participants indicated that in the previous 12 months they had not received healthcare when they felt they needed it. Of these 298, 44.3% felt they would be disrespected or mistreated and 8% were refused services.<sup>3</sup> When asked about what caused TGD people to avoid going to the doctor 68.9% were unable to find a doctor they were comfortable with and 58.8% feared mistreatment.<sup>4</sup> When asked about their experiences with healthcare "[a]lmost a quarter [had] been refused gender affirming care and one in five [had] been refused general healthcare. Over a third were asked invasive or inappropriate questions by healthcare providers and almost one sixth have had a healthcare provider use harsh or abusive language. One in twenty have had a healthcare provider be physically rough when treating them and within a healthcare setting, 14.2% were verbally harassed, 5.7% experienced unwanted sexual contact and 2.3% were physically attacked".<sup>5</sup>

<sup>&</sup>lt;sup>1</sup> Hillier, L., Jones, T., Monagle, M., Overton, N., Gahan, L., Blackman, J. & Mitchell, A. (2010). Writing Themselves In 3 (WTi3), Monograph Series No. 78. The Australian Research Centre in Sex. Health and Society. La Trobe University

<sup>&</sup>lt;sup>2</sup> Kerr, L., Fisher, C.M. & Jones, T. (2019). TRANScending Discrimination in Health & Cancer Care: A Study of Trans & Gender Diverse Australians. ARCSHS Monograph Series No. 117, Bundoora: Australian Research Centre in Sex, Health & Society, La Trobe University

<sup>&</sup>lt;sup>3</sup> Ibid pp 41-42

<sup>&</sup>lt;sup>4</sup> Ibid p 47

<sup>&</sup>lt;sup>5</sup> Ibid pp 49-50



A different study<sup>6</sup> focussing on the lived experiences of indigenous and non-indigenous transgender Australians. It concluded that "[w]hile there is some indication that issues facing nonindigenous [sic] transgender Australians are relevant to Aboriginal and Torres Strait Islander [sic] transgender Australians, what is distinctly experienced by indigenous [sic] transgender Australians is racism within wider Australian communities (including queer communities) and transphobia within traditional indigenous [sic] communities."<sup>7</sup>

Another report<sup>8</sup> investigating the mental health and wellbeing of gender diverse and trans young people in Australia found that over 90% of young people who had experienced physical abuse had thought about suicide.<sup>9</sup> '[Y]oung people who had experienced physical and/or verbal abuse had a higher risk of suicidal thoughts, suicide attempts and forms of self-harm; for example, [92%] of the young people who had experienced physical abuse had thought about suicide due to the discrimination and harassment that they had experienced.'<sup>10</sup>

A national report<sup>11</sup> on the mental health and wellbeing on LGBT Australians found:

- 53% of trans male respondents experienced heterosexist harassment or abuse in the 12 months' period leading into their participation in the study
- 55.3% of trans female respondents experienced heterosexist harassment or abuse in the 12 months' period leading into their participation in the study
- 49.2% of trans female respondents experienced heterosexist harassment or abuse in the 12 months' period leading into their participation in the study
- 35% of male respondents experienced heterosexist harassment or abuse in the 12 months' period leading into their participation in the study<sup>12</sup>
- 33.8% of female respondents experienced heterosexist harassment or abuse in the 12 months' period leading into their participation in the study

In regards LGBTI use of crisis support services, 334 out of 472 participants in a Victorian study indicated they had elected not to access these services because of concerns of discrimination.<sup>13</sup>

The SWASH study<sup>14</sup> of lesbian, bisexual, queer (LBQ) and other non-heterosexual identifying women engaged with Sydney's lesbian, gay, bisexual, transgender and queer (LGBTQ) communities found that:

- 22% of participants were tobacco smokers, which is substantially higher than the general community
- 49% of participants consumed more than the NHMRC guidelines recommend for reducing the lifetime risk of alcohol-related disease or injury. 19% of drinkers drank 5 or more drinks (binge drinking) weekly or more often in the past 6 months
- Women who had never had sex with a man were three times more likely to be overdue for cervical cancer screening

<sup>&</sup>lt;sup>6</sup> Kerry, S. (2014). Sistergirls/Brotherboys: The Status of Indigenous Transgender Australians. International Journal of Transgenderism, 15(3-4), 173–186. https://doi.org/10.1080/15532739.2014.995262

<sup>&</sup>lt;sup>7</sup> Ibid p 185

<sup>&</sup>lt;sup>8</sup> Smith, E., Jones, T., Ward, R., Dixon, J., Mitchell, A., & Hillier, L. (2014). From Blues to Rainbows: Mental health and wellbeing of gender diverse and transgender young people in Australia. Melbourne: The Australian Research Centre in Sex, Health and Society. Retrieved from: <a href="https://www.latrobe.edu.au/">https://www.latrobe.edu.au/</a> data/assets/pdf file/0007/598804/from-blues-to-rainbows-report-sep2014.pdf

<sup>&</sup>lt;sup>9</sup> Ibid p 59

<sup>10</sup> Ibid p 62

<sup>&</sup>lt;sup>11</sup> Leonard, W., Lyons, A., & Bariola, E. (2015). A closer look at Private Lives 2: Addressing the mental health and well-being of lesbian, gay, bisexual and transgender (LGBT) Australians. Monograph Series No. 103. The Australian Research Centre in Sex, Health & Society, La Trobe University: Melbourne. Retrieved from: https://www.latrobe.edu.au/\_\_data/assets/pdf\_file/0009/631755/ACloserLookatPrivateLives2.pdf

<sup>12</sup> Ibid p 28

<sup>&</sup>lt;sup>13</sup> Waling, A., Lim, G., Dhalla, S., Lyons, A., & Bourne, A. (2019). Understanding LGBTI+ Lives in Crisis. Bundoora, VIC & Canberra, ACT: Australian Research Centre in Sex, Health and Society, La Trobe University & Lifeline Australia. Monograph 112. Retrieved from:

https://www.latrobe.edu.au/ data/assets/pdf file/0008/991061/Understanding-LGBTI-Lives-in-Crisis.pdf p 25

<sup>&</sup>lt;sup>14</sup> https://www.acon.org.au/wp-content/uploads/2020/01/Sydney-SWASH-Report-2018-FINAL.pdf



The impact of COVID-19 on LGBTIQ+ communities has magnified the risk of poor health outcomes for LGBTIQ+ people. AFAO has separately compiled data on COVID-19's effect on our communities. This information is attached to this submission as appendix A.

#### 2. **HIV**

The eighth *National HIV Strategy 2018 – 2022* highlights quality health services as a guiding principle. In particular, the "Coordination and integration of health services across a number of settings is essential in order to respond to new technologies, best practice, and to best support people with or at risk of HIV to make informed choices about their treatment and prevention." <sup>15</sup> In the face of this guiding principle some people with HIV continue to face challenges in navigating the health system to ensure they have access to the best healthcare available. In a longitudinal study <sup>16</sup> of people with HIV "more than half of participants (56%) reported experiencing stigma within the last 12 months in relation to their HIV status, including 9% reporting that they 'often' or 'always' experienced stigma." "One-third of participants (33%) reported any negative treatment by health workers, including 5% who indicated that this was 'often' or 'always' the case." <sup>17</sup>

Unsubstantiated and harmful comments about people with HIV persist to this day in both the mainstream media and social media. Recent research has shown that the media is a common source of stigma, with 70% of participants in a national survey of people with HIV in 2016 reporting that they had experienced stigma or discrimination from the media within the previous twelve months (including nearly 40% who indicated this 'often' or 'always' occurred). <sup>18</sup> Extensive evidence indicates that stigma (both experienced and anticipated) acts as a barrier to seeking HIV-related healthcare. <sup>19</sup> <sup>20</sup> <sup>21</sup>

#### **Conclusion**

The Paper references the social determinants of health, and highlights the important role of 'community' in enabling "individuals to meet their potential". However, it does not explore the health disparities experienced by LGBTIQ+ people and the impact of HIV stigma on people with HIV and priority HIV populations. The combination of these health inequities and stigma magnifies fears of judgement from healthcare providers in healthcare settings.

AFAO is concerned the Paper does not acknowledge the scale of poor health among LGBTIQ+ communities and the evolution of community controlled LGBTIQ+/HIV organisations into platforms providing safe and inclusive settings where integrated and comprehensive healthcare services are provided for their communities. These services include community controlled mental health services, alcohol and other drug services, cancer screening, including cervical cancer screening for trans men, and sexual health services. The lack of recognition of these services creates inconsistencies in the delivery of services across Australia. AFAO would welcome the opportunity to arrange for our member organisations to meet with the Strategy's steering committee to ensure the unique perspectives of these organisations are considered in the next phase of the development of the Strategy.

<sup>15</sup> https://www1.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-1/\$File/HIV-Eight-Nat-Strategy-2018-22.pdf p 9

 <sup>16</sup> Centre for Social Research in Health (CSRH) (2019). Stigma Indicators Monitoring Project: People living with HIV. CSRH, UNSW: Sydney. Retrieved from: <a href="https://www.arts.unsw.edu.au/sites/default/files/documents/Stigma%20Indicators%20Summary%20HIV%20%2B%20MSM%202019.pdf">https://www.arts.unsw.edu.au/sites/default/files/documents/Stigma%20Indicators%20Summary%20HIV%20%2B%20MSM%202019.pdf</a>
17 Ibid p 1

<sup>&</sup>lt;sup>18</sup> Unpublished results from the Stigma Indicators Monitoring Project, Centre for Social Research in Health, UNSW Sydney, <a href="https://www.arts.unsw.edu.au/centre-social-research-health/our-projects/stigma-indicators-monitoring-project">https://www.arts.unsw.edu.au/centre-social-research-health/our-projects/stigma-indicators-monitoring-project</a>

<sup>&</sup>lt;sup>19</sup> C Logie & T Gadalla. Meta-analysis of health and demographic correlates of stigma towards people living with HIV. *AIDS Care* 2009;21(6):742-753 <sup>20</sup> S Gari, et al. Access to HIV/AIDS care: A systematic review of socio-cultural determinants in low and high income countries. *BMC Health Services Research* 2013:13(1):198

<sup>&</sup>lt;sup>21</sup> I Katz et al. Impact of HIV-related stigma on treatment adherence: Systematic review and meta-synthesis. J Int AIDS Society 2013;16(3):18640 S2.



Appendix A: Data on the impact of COVID-19 on LGBTIQ+ communities

### Data on the impact of COVID-19 on LGBTIQ+ communities

Like others, LGBTIQ people have been profoundly affected by COVID-19. LGBTIQ people:

- make up the majority of those living with HIV
- are at higher risk of mental health conditions including anxiety and depression
- are more likely to attempt suicide, have thoughts of suicide and/or engage in self-harm
- are at higher risk of developing certain cancers, and
- report higher rates of alcohol consumption and illicit drug use
- are more likely to experience discrimination from healthcare workers and support staff during medical consultations and service engagement
- less likely to report episodes of family or intimate partner violence.

#### Factors contributing to this include:

- higher rates of disadvantage relative to the social determinants of health (risk of disruption to education or employment, homelessness and exposure to violence and trauma)
- additional barriers to timely access to safe and appropriate clinical care, including primary care and specialist care
- growing but still limited access to LGBTIQ-sensitive or delivered health and service delivery.

A report from **Rainbow Health Victoria** illustrated the increased risk of LGBTIQ communities to poorer health outcomes than the general population at the outset of the COVID-19 pandemic. These included:

- a lower rating of self-perceived health than the general population
- reduced likelihood of discussing sexual orientation or gender identity in a medical consultation for fear of being judged or stigmatised leading to sub-optimal engagement with care and services
- increased levels of anxiety and depression compared with heterosexual peers, with more greatly magnified levels of anxiety and depression for young people, bisexual people and trans and gender diverse people
- LGBTIQ people are more likely to experience family violence without reporting this violence to authorities
- increased tobacco consumption (in the context of C19) and alcohol and other drug use.

This report shows the population-wide baseline health of LGBTIQ communities was below the baseline health of the general community.

Unpublished data from **Newgate Research**, a national market research company undertaking weekly polling of the Australian population, including LGBTIQ Australians:

- Around half the population (both LGBTQI and heterosexual people) have in the last week avoided interaction with elderly or vulnerable people in the community.
- 60% of LGBTQI participants reported feeling more socially isolated than normal in the last week.
- 55% of LGBTQI participants reported less physical activity than normal in the last week (up from last month)
- 26% of LGBTQI participants reported experiencing more arguments or tension in the last week compared to normal.
- LGBTQI participants reported experiencing more mental health concerns in April than March. 38% reported more mental health concerns in the week before the survey than normal.
- In April, less of us are drinking more than normal compared to March, but more of us are still drinking more than normal.

- 78% of LGBTQI participants reported avoiding all non-essential contact in the last week with people outside their household.
- 73% of LGBTQI participants reported believing people should be doing more to uphold social distancing guidelines.

Unpublished data from the **Flux Study**, Kirby Institute, UNSW (not for public sharing without permission), captured during the month of April from 1,126 participants. The Flux Study is a national online cohort study to monitor changes in drugs and associated harms, beliefs and attitudes, and engagement with gay community networks over time:

- 59% of participants reported they stopped physically engaging with peers
- 50% of participants initiating virtual connection to socially engage
- over 85% of participants strongly agreed or agreed that everyone should quarantine and keep their distance
- 36% of participants felt depressed
- 86% of participants stopped having sex
- 53% were concerned about losing their job as a result of COVID-19

Data from **Transform** (not for public sharing without permission), a longitudinal gender health study, received responses from 800 transgender Australians (over the age of 16) to understand the impact of the COVID-19 pandemic on the trans (including gender diverse and non-binary) community. Data from the survey indicated:

- 54% of respondents had thought that they would be better off dead or of hurting themselves in the past two weeks
- 84% had felt down, depressed, or hopeless in the past two weeks
- 16% are currently living with someone who makes them feel unsafe or afraid
- 42% are experiencing financial strain related to paying their rent/mortgage
- 60% are experiencing financial strain related to buying food/groceries
- 31% have sought support from a mental health professional
- 21% have sought support from a LGBTIQA+ specific organisation
- 17% have sought support from a mainstream organisation

Data was collected by **Equality Australia** through a survey 2,600 LGBTIQ+ community members in Australia in late March and April. The survey results included:

- LGBTIQ+ unemployment rose from 7.5% pre COVID-19 to 12.7% post COVID-19. Trans and gender diverse unemployment rose from 15.2% to 20%
- Almost 1 in 3 LGBTIQ+ people have some lost income since COVID-19 restrictions, with almost 1 in 5 LGBTIQ+ people reporting having lost more than half or all of their income.
- Of the 13% of LGBTIQ+ people who reported living with a mental health issue, around 4 in 5 of them say they are more lonely now or feel low or flat because of COVID-19 restrictions.
- Around 1 in 20 LGBTIQ+ people have experienced violence, abuse, harassment or controlling behaviour in the last 12 months from someone they currently live with, or live with someone they fear may be violent, abusive or controlling towards them.
- Around half of LGBTIQ+ people who receive personal or domestic care were affected in getting the care they need by COVID-19 and its restrictions.
- Around half of LGBTIQ+ caregivers experienced an increase in their caring responsibilities because of COVID-19 and its restrictions.
- 1 in 20 LGBTIQ+ partners are physically separated by interstate or international border closures.



## **Consensus Page**













