



# HIV in the NSW Aboriginal and Torres Strait Islander population







#### A word from the artist, Ngaire Pakai

“My artwork celebrates Indigenous LGBT+ health through layers of intricate Indigenous designs and bold colour palette. The design in the foreground displays large and small meeting circles that represent the many communities formed to support our brothers and sisters whether that be family circles, friend or professional health circles. Whilst the background design follows a similar concept of meeting circles and meeting places, it differs by being outlined in organic groupings to resemble delicate bacteria. This artwork reflects the pride of our LGBT+ Indigenous peoples and the importance of their health.”

## ABOUT ACON

ACON is NSW’s leading health organisation specialising in community health, inclusion and HIV responses for people of diverse sexualities and genders. Established in 1985, ACON works to create opportunities for people in our communities to live their healthiest lives.

In 1997, the ACON Aboriginal Project was formally established to provide culturally appropriate HIV and sexual health services. This includes peer education and health promotion activities delivered in partnership with other organisations on days of cultural significance to Aboriginal people and/or LGBT communities and health retreats for Aboriginal & Torres Strait Islander people living with HIV.

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We pay respects to the traditional Owners of all the lands on which we work, and acknowledge their Elders, past, present and emerging.

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# INTRODUCTION

The HIV landscape has radically changed since the early days of the epidemic. With access to modern antiretroviral treatments, people living with HIV (PLHIV) are now able to live long, healthy lives and, with undetectable viral loads, can have condomless sex without transmitting the virus.

A combination of evidence-based behavioural, social and biomedical approaches, including increased testing rates and the roll-out of the HIV prevention pill 'PrEP' (Pre-Exposure Prophylaxis), have significantly reduced HIV transmissions.

Nevertheless, obstacles to reach the virtual elimination of HIV transmissions remain. The benefits of these advances have not been shared equally among the Australian population, and HIV-related stigma and discrimination continue to affect prevention efforts and the quality of life of PLHIV.

Aboriginal and Torres Strait Islander people are a priority population for HIV responses in NSW<sup>1</sup> and nationally<sup>2,3</sup>. The gap in HIV notification rates between Aboriginal and Torres Strait Islander peoples and the Australian-born non-Indigenous population in Australia has widened since 2013.<sup>4</sup>

This paper seeks to identify what needs to change so that we can end HIV transmissions in the NSW Aboriginal and Torres Strait Islander population.

The paper is grounded in ACON's belief that health policy and services are best led by and for the communities they ultimately affect. This calls for three clarifications on the terms used in this paper:

**Health** is not just the absence of disease. ACON works under the philosophy that Aboriginal health "means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total well-being of their Community."<sup>5</sup>

**Health promotion**, as defined in the Ottawa Charter for Health Promotion, is the process

of enabling people to increase control over, and to improve, their health.<sup>6</sup> It is not just the responsibility of the health sector, and goes beyond healthy lifestyles to well-being. Effective health promotion requires building healthy public policy, creating supportive environments, strengthening community actions, developing personal skills and reorienting health services beyond the sole provision of clinical and curative services.<sup>5</sup>

**Self-determination** is a rich concept that has evolved and can have different meanings in different contexts.<sup>7</sup> In this paper, the term self-determination is used with a health-focused lens. We have retained the definition of Odette Mazel (2016) who focuses on what Aboriginal and Torres Strait Islander peoples' right to self-determination looks like in practice, i.e. "grassroots initiatives that are defined by and for their local communities to improve health outcomes"<sup>8</sup>. Aboriginal Community-Controlled Health Services are an integral component of health responses.

ACON acknowledges the diversity of Aboriginal and Torres Strait Islander people's genders and sexualities, and the unique cultural ways in which they may be expressed. This includes sistergirls and brotherboys.<sup>9</sup>

Due to a lack of data on HIV transmissions in Aboriginal and Torres Strait Islander trans and gender diverse people, and cis women, this paper focuses more significantly on cis gay and bisexual men who account for the large majority of new HIV notifications.

Section one of this paper provides an overview of health and policy frameworks and outcomes for Aboriginal and Torres Strait Islander people in NSW. Section two highlights the epidemiological specificities of HIV in this population. Section three assesses progress in testing, prevention and care. Recommendations to improve HIV responses are provided in section four.

# 1.

## CONTEXT

*Aboriginal and Torres Strait Islander people experience poorer health outcomes compared with the non-Indigenous population (1.1).*

*Inconsistent and unpredictable funding decisions pose recurring challenges to addressing this health gap and delivering effective HIV responses for Aboriginal and Torres Strait Islander people (1.2).*

### 1.1 The health of Aboriginal and Torres Strait Islander people in NSW

Aboriginal and Torres Strait Islander people have lived in the area now known as NSW for at least 45,000 years. Before 1788, there were over 500 different Aboriginal nations on the continent, with a variety of belief systems, cultures and over 70 languages. Today, an estimated 265,700 Aboriginal and Torres Strait Islander people live in NSW, accounting for 3.5% of the state's population.<sup>10</sup>

#### Demographic profile

Compared with people from a non-Indigenous background, the Aboriginal and Torres Strait Islander population is markedly younger, with a median age of 22.6 compared with 38.2 in the non-Aboriginal population.

46% Aboriginal and Torres Strait Islander people live in major cities<sup>10</sup>. The five Local Government Areas with the largest Aboriginal and Torres Strait Islander population are the Central Coast, Blacktown, Western Plains Regional, Lake Macquarie and Penrith.

#### Health inequity

Health outcomes are poorer for Aboriginal and Torres Strait Islander people compared with non-Indigenous Australians.<sup>11</sup> There is a life expectancy gap of 10.6 years between Aboriginal and non-Aboriginal males and 9.5 years for females.<sup>12</sup> Aboriginal and Torres Strait Islander people are more likely to be hospitalised and to have a disability or a long-term health condition that restricts their everyday activities.<sup>13, 14</sup>

The reasons behind this health gap are complex. Colonisation and the state violence inflicted on Aboriginal and Torres Strait Islander people, including the removal of children and its associated intergenerational impacts<sup>15, 16</sup>, have resulted in entrenched disadvantage, which is reflected in a range of health determinants.

The Australian Institute of Health and Welfare estimate that socioeconomic factors account for a larger proportion of the health gap (34% of the gap) than selected behavioural/biomedical risk factors (19%).<sup>17</sup> Household income is the largest individual contributor to the overall gap (14%), followed by employment status (12%). The remaining 47% of the gap is due to other unexplained factors, which may include poorer access to health services.

The health gap has significant consequences for HIV responses. Health services face a wide range of priorities, including a higher prevalence of multi-morbidities<sup>18</sup>, chronic diseases, other infectious diseases, childhood and maternal health outcomes, and blood-borne viruses (BBVs) and sexually-transmissible infections (STIs) which potentiate HIV transmission.

Holistic approaches are required to improve health outcomes for Aboriginal and Torres Strait Islander peoples.

### Aboriginal community responses

Aboriginal and Torres Strait Islander people have been at the forefront of responses to address the failures of the health system to deliver positive outcomes for their health. In 1971, the first Aboriginal Medical Service (AMS) was established to address the lack of accessible health services for the largely medically-uninsured Aboriginal population of Redfern.

The community-controlled approach adopted by the Redfern Aboriginal Medical Service, and later by other Aboriginal Community-Controlled Health Services (ACCHS), addresses needs in a more holistic way.<sup>19</sup> The AMS model takes into account the social, emotional, physical and spiritual well-being of individuals.

Aboriginal health is generally understood as a concept that encompasses multiple aspects of individual and community life. Aboriginal health 'means not just the physical well-being of an

individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total well-being of their Community'.<sup>20</sup>

## 1.2 Policy context

The policy context for HIV responses includes national and NSW health policies, HIV-specific strategies, and Aboriginal and Torres Strait Islander-specific strategies, including those aimed at influencing the social determinants of health.

### Health policy

National and state approaches to Aboriginal and Torres Strait Islander health have shifted under successive governments.

Today's system reflects a legacy of inconsistent policies and investments that have alternated between supporting self-determination in health through dedicated funding for Aboriginal Community-Controlled Health Services, and cuts to Aboriginal funding in favour of mainstream non-Indigenous health services.

In 2018, a ten-year review<sup>21</sup> of the Australian Government's commitment to *Close the Gap*<sup>22</sup> pointed to the dramatic effect of political instability and funding cuts:

'Over the decade since 2008, Aboriginal and Torres Strait Islander affairs have experienced discontinuity and uncertainty. Regular changes to the administration and quantum of funding, shifting policy approaches and arrangements within, between and from government, cuts to services, and a revolving door of Prime Ministers, Indigenous Affairs Ministers and senior bureaucrats have all but halted the steady progress hoped for by First Peoples [...]. The Strategy was effectively

abandoned with the extensive cuts (over \$530 million) made to the Indigenous Affairs portfolio in the 2014 Federal Budget.<sup>23</sup>

In response to calls for action from Aboriginal and Torres Strait Islander people across Australia, the Government announced the *Closing the Gap Partnership Agreement* in March 2019, which ‘is about making sure that Aboriginal and Torres Strait Islander peoples can share in the decision-making about policies and programs that impact on them’.<sup>24</sup>

### HIV policy

Aboriginal and Torres Strait Islander people are a priority population under the national<sup>25</sup> and the NSW HIV responses<sup>26</sup>, both of which aim to end HIV transmissions.

The *5th National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy (2018-2022)* seeks to ensure that ‘there is full and ongoing participation by Aboriginal and Torres Strait Islander people and organisations in all levels of decision-making affecting their health needs’.<sup>27</sup>

NSW has also developed a specific *Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Framework (2016-2021)*<sup>28</sup>, which outlines the priorities for BBV and STI prevention, testing, and treatment and management for Aboriginal people in priority settings including Aboriginal Community-Controlled Health Services and other primary health care settings, Local Health Districts (LHDs), and Non-Government Organisations (NGOs).

Despite an alignment of national and NSW HIV strategies, funding has not been commensurate with policy objectives. Funding decisions have not always been made in partnership with Aboriginal and Torres Strait Islander communities and have

resulted in reduced capacity for sexual health promotion.

In mid-2016, it was confirmed that a \$2.3 million funding package\* for Aboriginal sexual health programs would cease in 2017 without alternative arrangements in place, resulting in severely diminished Aboriginal sexual health staff capacity.

### Policies affecting health determinants

Beyond HIV and health policies, a range of other policy areas and funding decisions impact the determinants of Aboriginal and Torres Strait Islander people’s health and the effectiveness of HIV responses.<sup>29</sup> This includes socio-economic and criminal justice policies that disproportionately affect this population.

Aboriginal and Torres Strait Islander people have a long history of fighting for their political rights. In recent years, there have been renewed calls for Aboriginal and Torres Strait Islander leaders to have a stronger voice in their affairs. This includes the 2017 Uluru Statement from the Heart<sup>30</sup>, which was released at a constitutional convention of 250 Aboriginal and Torres Strait Islander delegates following a series of 13 regional dialogues across Australia.

The Uluru Statement called for the establishment of a ‘First Nations Voice’ enshrined in the Australian Constitution and the establishment of a ‘Makarrata Commission’ to supervise agreement-making and truth-telling between governments and Aboriginal and Torres Strait Islander peoples.

\* The funding package was linked to a National Partnership Agreement between the Commonwealth and NSW.





## 2. THE HIV GAP

*Compared with the non-indigenous population, rates of HIV and STI notifications are higher among the Aboriginal and Torres Strait Islander population (2.1), highlighting the lack of resources in the Aboriginal sexual health sector, and the shortcomings of mainstream services (2.2).*

### 2.1 Specificities of the HIV epidemic in the Aboriginal and Torres Strait Islander population

In NSW, HIV responses have included targeted efforts to increase HIV testing through more convenient methods and promote a combination of prevention strategies (i.e. condoms, biomedical prevention, effective negotiated safety agreements, risk reduction and harm minimisation) among key target populations.

While HIV responses have been effective at reducing overall HIV transmissions in NSW, they have not fully addressed the specificities of the HIV epidemic in the Aboriginal and Torres Strait Islander population.

#### Higher rates of HIV notifications

In NSW, ten Aboriginal men and one Aboriginal woman were newly diagnosed with HIV in 2018, accounting for 4% of the 278 new HIV notifications recorded in the state. These 11 notifications represent an increase compared with an average of eight notifications each year among this population during the 2013-2017 period.<sup>31</sup> Between January and September 2019, however, three Aboriginal people and one Torres Strait Islander person were diagnosed with HIV in NSW, a decrease compared with previous years.<sup>81</sup>

Across Australia, 31 (3%) of the 963 HIV notifications in 2017 were amongst the Aboriginal and Torres Strait Islander population.<sup>32</sup> There has been a 33% increase in HIV notifications for Aboriginal and Torres Strait Islander people between 2012 and 2016, and a 22% decrease in HIV notifications for Australian-born non-Indigenous people during the same period.<sup>33</sup>

Across Australia, the rate of HIV notification is 1.6 times higher among the Aboriginal and Torres Strait Islander population (4.6 notifications per 100 000 people compared to 2.8 per 100 000 in the Australian-born non-Indigenous population).<sup>34</sup>



The HIV notification rates in the Aboriginal and Torres Strait Islander population have particularly increased in regional and remote areas between 2008 and 2017, while notification rates have fluctuated with a downward trend in major cities.

### Different types of HIV risk exposure

The epidemiological factors of HIV acquisition differ between Aboriginal and Torres Strait Islander people and the non-Indigenous population.

Across Australia, including in NSW (see table below) the majority of new HIV notifications in the Aboriginal and Torres Strait Islander population occur among sex who have sex with men (MSM), although a larger proportion of HIV notifications is attributed to heterosexual sex and injecting drug use than in the Australian-born non-Indigenous population.<sup>35</sup>

Women accounted for 17.5% (52) of the 297 cases of newly diagnosed HIV in the Aboriginal and Torres Strait Islander population in 2008-2017.<sup>35</sup>

A greater proportion of new HIV acquisitions occur via injecting drug use in the Aboriginal population, compared with the non-Indigenous population.

A study on patterns of injecting drug use and BBV-related risk practices found that, compared with

non-Aboriginal people who inject drugs, Aboriginal participants were more likely to inject daily (72.7 vs. 55.0 %), more likely to share ancillary equipment (64.9 vs. 44.8 %) and less likely to know about BBV transmission (72.0 vs. 87.7 %) and treatment (47.2 vs. 67.6 %).<sup>36</sup> Aboriginal participants were also more likely to have been in prison (37.6 vs. 16.5 %), where access to sterile injecting and ancillary equipment is limited and no needle and syringe programs are able to operate.

Data from the Needle and Syringe Program show that the overall HIV prevalence among Aboriginal and Torres Strait Islander people who use this program has increased between 2008-2009 and 2016-2017. Prevalence increased from 1.0% to 4.2% for men and from 0.8% to 1.9% for women.<sup>35</sup>

### Higher rates of other sexually transmissible infections

HIV responses in the Aboriginal and Torres Strait Islander population should take into consideration high rates of blood-borne viruses and sexually transmissible infections which potentiate HIV transmission. STIs have consistently been shown to facilitate HIV transmission and acquisition.<sup>37, 38, 39</sup>

Australia-wide, rates of notification for chlamydia, gonorrhoea, infectious syphilis, hepatitis C and

**Table: Australian-born NSW residents newly diagnosed with HIV during 2010-2018**

Risk Exposure	Aboriginal or Torres Strait Islander person		Not Aboriginal or Torres Strait Islander		Unknown or not stated
MSM	38	50%	1152	77%	14
MSM and PWID	13	17%	101	7%	2
Heterosexual sex only	15	20%	183	12%	0
PWID	7	9%	41	3%	0
Vertical transmission	0	0%	1	0%	0
Other or unknown	3	4%	18	1%	0
<b>Total</b>	<b>76</b>	<b>100%</b>	<b>1496</b>	<b>100%</b>	<b>16</b>

Source: NSW Ministry of Health. Please note that the NSW Ministry of Health indicates that caution in interpreting the data is warranted due to small numbers.



hepatitis B in 2017 were two to seven times as high in Aboriginal and Torres Strait Islander people as in the non-Indigenous population.<sup>40</sup>

There is an ongoing outbreak of infectious syphilis affecting young Aboriginal and Torres Strait Islander people in northern Australia, which could spread across the country.<sup>42</sup>

Differences in other STI notification rates are concerning in NSW. In 2016, the notification rates for chlamydia and gonorrhoea were 1.9 and 1.3 times higher, respectively, among Aboriginal people than among non-Indigenous people.<sup>43</sup>

Additional STI prevention efforts are required. A survey of 2,320 young Indigenous Australians found that earlier age at sexual debut was associated with higher rates of drug and alcohol use, risky sexual behaviours and sexually transmissible infections.<sup>44</sup> These findings highlight the need to ensure that targeted age-appropriate and culturally-appropriate sexual health education that encompasses healthy relationships and STI prevention is delivered to Indigenous young people.

Increasing rates of condom use, rates of testing (the proportion of people who get tested) and the frequency of testing (how often people test) in the Aboriginal and Torres Strait Islander population is essential to ensure that STIs are detected, treated and stopped. Partner notifications systems, including the possibility to send anonymous text messages to partners who may have been exposed to one's STI through sexual contact, contribute to stopping the spread of STIs.

## 2.2 Why aren't HIV notifications in the Aboriginal and Torres Strait Islander population going down?

Several factors are likely to explain why HIV responses have failed to reduce HIV notifications amongst Aboriginal and Torres Strait Islander

peoples while new HIV notifications in the Australian-born non-Indigenous population are at historically low levels.

### Capacity

Firstly, there is a lack of culturally-appropriate HIV-related services. The funding changes that occurred in 2016 have resulted in a reduced capacity for sexual health services for Aboriginal and Torres Strait Islander peoples. Successive reforms have also led to confusion within communities and difficulty navigating complex health systems which do not always offer culturally appropriate care.

### Shortcomings of mainstream health approaches

Mainstream health services (i.e. services that are not controlled by and do not focus specifically on Aboriginal and Torres Strait Islander people) are often inconsistent in creating culturally-inclusive sexual health programs.

Aboriginal and Torres Strait Islander people's experiences of racist, discriminatory or culturally insensitive behaviour have significant impacts on their health. Stigma and discrimination contribute to distrust in health services, which in turn contributes to poor HIV and other health outcomes among Aboriginal peoples.<sup>46</sup>

Aboriginal and Torres Strait Islander people also report experiencing racism and discrimination in community spaces. This includes sexual racism within the gay community, which can occur both online, particularly on dating apps<sup>47</sup>, and offline.

Additional layers of stigma, discrimination and shame are experienced by Aboriginal and Torres Strait Islander peoples based on sexuality and gender identity, which impacts their health and trust in health services.

Other barriers include a lack of information, barriers for people with a disability and/or those who need to travel long distances to get to health services, and socio-economic impediments.





## TOM'S EXPERIENCE

'As a Black man who was new to the gay scene, I was searching for myself and did not have any real understanding of risks.

When I started using online dating apps, my attempts to form relationships were met with diverse and complex responses. At the time I was unsure of myself and of the risks of leading a gay lifestyle. I was unprepared for the blatant racist responses, disguised preferences and prerequisites, when scrolling through the apps.

Back then, I kept my gay life somewhat on the down-low, which had led to a lower sense of self-worth and a longing for affirmations of love and acceptance of self in all the wrong places. That vulnerability had led to an increase in the frequency of risky sex.

I had also grown up in a family that only saw a doctor if something was very wrong and the only doctor we saw was the one at the local Aboriginal medical centre where everyone knew everyone. So, I had no conception of regular sexual health check-ups or anonymity when using health services.

I had heard about the PrEP trials and thought it would be a good idea to enquire considering my increased sexual activity. So I attended my first rapid test, which came back negative, and to be honest I was surprised. When I phoned to get on the trial at a later stage, I was told that I couldn't, that it was too late, and they were looking for people who were at risk. I felt shame and did not follow up on the second call that they wanted me to do.

After two months of becoming sexually active on the gay scene, I was diagnosed with HIV. I was somewhat relieved but realised I had to deal with the stigma of family and community.

I have found comfort in the ever-growing queer black community that has been supported by ACON through the camps, Mardi Gras activities, support groups, and research initiatives. I am a part of a community that sustains me, all of me, and allows me to be the best version of myself.

My life and career are dedicated to my people and building resilience. I am an active leader in the Aboriginal community that has seen the queering of black spaces, the establishment of community support groups and social activities that promote and support members find acceptance.'

*For confidentiality purposes, we have changed the name of the person who agreed to anonymously share their story for this paper.*



### 3. IMPROVING ACCESS TO HIV TESTING, PREVENTION, TREATMENT AND CARE

*While new testing, prevention, and treatment methods are available, access barriers must be overcome to end HIV transmissions and improve the health and quality of life of Aboriginal and Torres Strait Islander people in NSW.*

*The lower uptake of biomedical HIV interventions suggests more targeted, nuanced and culturally-appropriate health strategies are warranted to reach these communities.*

*Additional efforts are also required to ensure Aboriginal and Torres Strait Islander people who inject drugs, and those who have heterosexual sex, are not left behind.*

#### 3.1 Testing

Effective HIV treatments mean that people with HIV can live long and fulfilling lives and, with undetectable viral loads, do not transmit the virus.

Across Australia, there are an estimated 2,899 people living with HIV who are unaware of their HIV status (11% of all people living with HIV).<sup>48</sup> This proportion is estimated to be higher in Aboriginal and Torres Strait Islander people (14%) than in the Australian-born non-Indigenous population (10%).

Not knowing about one's HIV status or being diagnosed at a late stage has individual and population-level implications.

At the individual level, the sooner a person living with HIV is aware of their status, the sooner they can receive anti-retroviral treatment, stop the progression of HIV in their body and achieve an undetectable viral load.

At the population level, early diagnoses are key to stopping the virus from getting passed on. HIV does not get transmitted during sex between people living with HIV who have an undetectable viral load and HIV-negative people.

Improving access to conventional (blood-draw) and rapid testing in a range of settings is essential to increase HIV status awareness among this priority population. Access to testing should be available in primary care, emergency departments, drug services and prisons. Testing for HIV should also be routinely conducted after a positive STI diagnosis.

A national survey of Aboriginal and Torres Strait Islander people aged 16–29 in relation to STIs and BBVs highlights the crucial role of Aboriginal medical services. 30% of respondents reported they had been tested for HIV, with Aboriginal medical services being the most common place where STI testing occurred.<sup>49</sup>



New ways to test for HIV from home – Dried Blood Spot (DBS) and self-testing – may be a good option where testing services are unavailable, to overcome transport barriers or to accommodate personal preferences, however, their reach has been limited so far.

DBS testing kits can be ordered online, through a pilot program<sup>50</sup>, and allow a person to collect a finger prick sample of blood at home, post it to a laboratory and get results in about one week. With self-testing kits, which are available for purchase online, a person pricks their finger to get a blood drop into a device that returns a result in 15 minutes.

These methods have practical limitations (e.g. DBS requires leaving the testing card out to dry for about 24 hours before packaging it up and sending it back). There are also issues around literacy and cost (self-testing kits are sold online for approximately \$30), and other barriers for those who do not have an internet connection or have privacy concerns (e.g. kits received by mail may unintentionally be opened by other members of a household).

Other testing options, including conventional blood-draw and rapid testing, remain available in different parts of NSW.

## 3.2 Prevention

The HIV prevention landscape has significantly changed in recent years. In addition to health promotion and the distribution of condoms and sterile injecting equipment, biomedical prevention strategies are highly effective at reducing HIV transmissions. Combined, these strategies have been attributed to reducing rates of HIV in gay and bisexual men in NSW, especially in inner city areas.

Much remains to be done, however, to make

sure Aboriginal and Torres Strait Islander people are able to access the whole range of existing prevention methods.

### Health promotion

Targeted campaigns are an important component of HIV prevention. Sustained, community-driven and targeted efforts to reduce HIV transmissions among gay and bisexual men are at the centre of the *Ending HIV* campaign. There have been challenges, however, to sustain health promotion activities for HIV in NSW for Aboriginal and Torres Strait Islander people.

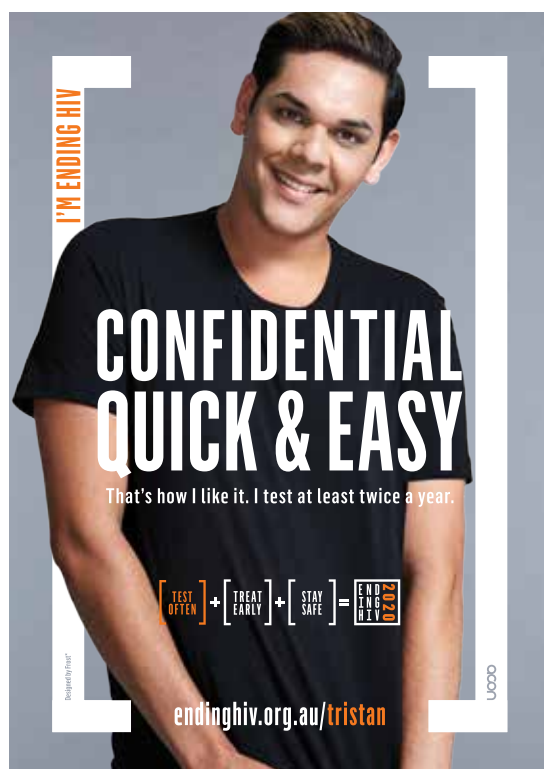
ACON's *Ending HIV* campaign ensures that Aboriginal and Torres Strait Islander gay and bisexual men are represented in campaign materials, however, there is a need for specific campaigns targeting this population.

Health promotion efforts need to be sustained, ongoing, targeted, and holistic. This can be done by learning from past HIV health promotion campaigns produced by Aboriginal and Torres Strait Islander community members working in partnership with community and government health organisations.<sup>51</sup>

### Condom use

Condoms remain a highly effective method to prevent HIV and other sexually transmissible infections. Maintaining the distribution of free condoms through ACCHSs, and other services that Aboriginal and Torres Strait Islander people use in NSW, should remain a priority. Across Australia, just over a third (37%) of participants to the Goanna study on STIs and BBVs among young Aboriginal and Torres Strait Islander people reported using a condom always in the last year.<sup>52</sup>

According to the Australian Needle and Syringe Program Survey, a higher proportion of Aboriginal and Torres Strait Islander female participants report inconsistent condom use with casual partners compared with non-Indigenous female participants.<sup>53</sup>



### Sterile injecting equipment

Considering that a greater proportion of new HIV notifications in the Aboriginal and Torres Strait Islander population occurs via injecting drugs compared with the non-Indigenous population, improving access to sterile injecting equipment is vital.

Access to sterile injecting equipment is currently available through two highly effective programs:

- **The Needle and Syringe Program (NSP)** – In NSW, 14,130,769 units of equipment were distributed through 31 primary outlets (i.e. dedicated to the provision of services to people who inject drugs), 288 secondary outlets (i.e. within existing health or community services with staff that are not solely dedicated to the provision of services to PWID), 540 pharmacy NSPs (i.e. community retail pharmacies that dispense needles and syringes to PWID) and 233 syringe dispensing machines in 2017/18. An estimated 21% of Needle and Syringe Program users in NSW identify as Aboriginal or Torres Strait Islander.<sup>54</sup>
- **The Kings Cross Medically Supervised Injecting Centre (MSIC)**<sup>55</sup> – Supervised injecting facilities have been shown to be highly effective at reducing the harms associated with drug use. They are associated with reductions in needle and syringe sharing, reduced public injecting and numbers of publicly discarded syringes, and greater uptakes of drug addiction treatment programs.<sup>56</sup>

Access to sterile injecting equipment could be improved by expanding their availability in a range of settings, including in ACCHSs, various community settings via vending machines, and in prisons.



Considering that Indigenous Australians are the most incarcerated people on Earth<sup>57</sup> due to a legacy of ‘dispossession, discrimination and trauma’ and laws that ‘have had a disproportionate impact on them’<sup>58</sup>, improving access to effective drug harm reduction programs in NSW prisons should be prioritised. The prison setting should be used to deliver risk reduction messages<sup>59</sup> and provide access to sterile injecting equipment.

### Biomedical prevention strategies

Biomedical strategies consist of different medication regimens to prevent the transmission of HIV. They include treatment as prevention (TasP), post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP).

In NSW, biomedical prevention options are used by a significant number of gay and bisexual men. In 2018, over half of men reporting condomless anal sex with casual partners in the Sydney Gay Community Periodic Survey were either HIV-positive with an undetectable viral load or HIV-negative men using PrEP.<sup>60</sup>

As highlighted in the ASHM PrEP guidelines, when used with optimal medication adherence, *daily* PrEP is a highly effective HIV prevention strategy for men who have sex with men, heterosexual men and women, transgender people, and people who inject drugs who are at-risk of HIV acquisition.

It is important to note, however, that *on-demand* PrEP, also known as ‘2 + 1 + 1’ dosing is not recommended for cis-gender women. Evidence suggests this regimen does not provide adequate tissue levels of PrEP to provide high levels of HIV protection for cis-gender women.

The PrEP guidelines also highlight that, due to the paucity of data on trans and gender diverse people in PrEP studies, PrEP is recommended for this population based on their sexual history.

It is essential for clinicians to take a sexual history using appropriate language to assess risk and to avoid making assumptions about trans people and their sexual practices.

The uptake of biomedical prevention strategies by Aboriginal and Torres Strait Islander people has been limited:

- **PrEP** – only 2.1% of the 9,415 people enrolled in EPIC-NSW, the State’s large trial for PrEP, identified as Aboriginal and/or Torres Strait Islander.<sup>61</sup> There are indications that, since the end of the trial, the uptake of PrEP among Aboriginal and Torres Strait Islander people has been limited. Between 1 April 2018 and 30 June 2019, 106 NSW residents were prescribed PrEP under the *Closing The Gap* Scheme.<sup>81</sup>

Qualitative research has highlighted that while AIDS councils and sexual health clinics had been instrumental in promoting PrEP to at-risk gay and bisexual men, many Aboriginal and Torres Strait Islander gay and bisexual men may not have been exposed to their health promotion, and therefore have not accessed PrEP effectively.<sup>62</sup>

- **PEP** – there is limited publicly-available data on the use of PEP in the NSW Aboriginal and Torres Strait Islander population.
- **TasP** – there is limited publicly-available data on the use of PEP in the NSW Aboriginal and Torres Strait Islander population. Across Australia, the percentage of Aboriginal or Torres Strait Islander PLHIV who know their HIV status is lower compared with non-indigenous Australians<sup>63</sup>, which means that they are not receiving treatment.

This limited uptake of biomedical prevention methods has led to calls for more involvement of Aboriginal and Torres Strait Islander people in these approaches.<sup>64</sup> Although the biological effectiveness of these interventions has been shown, they need to be embedded in culturally-safe settings.

Some caution that the potential of biomedical interventions ‘to address HIV among indigenous populations will only be realised if policy makers explicitly recognise the role of colonialism in

producing disparities in HIV incidence, give Indigenous people self-determination over their health care, and embed cultural safety and humility throughout health-care systems.<sup>65</sup>

One study highlighted both individual barriers – including non-identification with mainstream gay communities, stigma, and different worldviews – and provider barriers, including over-burdened and under-resourced Aboriginal Community-Controlled Health Services and a lack of funding for HIV and sexual health promotion in Aboriginal and Torres Strait Islander people.<sup>66</sup>

The low level of representation in clinical trials and overall significant gaps in reducing HIV notifications in comparison to Australian-born non-Indigenous people demonstrate that operating under the assumption that mainstream health promotion strategies for HIV prevention will reach Aboriginal and Torres Strait Islander people is likely ineffective and inadequate.

### 3.3 Treatment and Care

Preliminary analysis of national data suggests that more work is required to achieve parity with the non-Indigenous population in relation to HIV diagnosis, treatment and care.

Across Australia, there were an estimated 582 Aboriginal and Torres Strait Islander people living with HIV in 2017.<sup>67</sup>

HIV treatment targets are tracked against global UNAIDS goals. For the following targets<sup>68, 69</sup>, results achieved in 2016 were:

1. In relation to the target of ‘90% of people living with HIV will know their status’ – Australia achieved 89% overall, and 80% for Aboriginal and Torres Strait Islander people in particular.

2. In relation to the target of ‘90% of people living with HIV will receive sustained anti-retroviral treatment (ART)’ – Australia achieved 86% overall, and 90% for Aboriginal and Torres Strait Islander people.
3. In relation to the target of ‘90% of those who have received sustained ART will have achieved an undetectable viral load (UVL)’ – Australia achieved 94% overall, and 76% for Aboriginal and Torres Strait Islander people.

Substantial gaps are witnessed in goals 1 and 3, indicating that a ‘higher proportion of Aboriginal and Torres Strait Islander people living with HIV remain undiagnosed and do not achieve a UVL even when on ART’.<sup>70</sup>


In NSW, of the 11 Aboriginal and Torres Strait Islander people diagnosed with HIV in 2017, 5 were on ART within two weeks, 8 were on ART within four weeks and all 11 were on ART by the time the HIV surveillance report was published (March 2018).

The NSW HIV Strategy aims to increase the proportion of people with diagnosed HIV on ART to 95% and to ensure that 90% of people newly-diagnosed with HIV are on ART within 6 weeks of diagnosis in 2016.

A study on the clinical care of Indigenous Australians living with HIV found that clinical outcomes were no worse among Indigenous study participants compared with their non-Indigenous counterparts but noted that the ‘significantly lower rate of testing for immunological, virological and other health parameters among Indigenous participants is of concern’.<sup>71</sup>

Given the elevated risk of cardiovascular disease in the Aboriginal and Torres Strait Islander community, the study recommended focusing on modifiable risk factors to maximise life expectancy in Aboriginal and Torres Strait Islander people living with HIV.



A smiling man with dark hair and a beard, wearing a black t-shirt and blue jeans, stands against a vibrant, abstract background. The background is a collage of colorful, circular, and organic patterns in shades of green, blue, purple, yellow, and red. A semi-transparent dark grey circle is overlaid on the left side of the image, containing a quote in white text.

“Ensuring  
adequate funding  
for sexual health  
services is key”





## 4. IMPROVING HIV RESPONSES

To end HIV transmissions and improve the health and wellbeing of Aboriginal and Torres Strait Islander people living with HIV, a range of practices, policies and legislation at both the Australian Government and the NSW Government levels need to change.

Aboriginal and Torres Strait Islander people should be at the centre of the decisions that affect their health (4.1) and barriers to accessing testing, prevention and treatment should be addressed (4.2).

### Community-led responses

Initiatives to draw attention to HIV in Aboriginal and Torres Strait Islander communities and calls for change have been issued through multiple forums, including the Aboriginal & Torres Strait Islander HIV Awareness Week (ATSIHAW)<sup>72</sup> and the 2014 Eora Action Plan<sup>73</sup>.

*The International Indigenous Strategic Plan on HIV and AIDS for Indigenous Peoples and Communities* has also underpinned a collective action to lower the disproportionate impact of HIV and AIDS experienced by Indigenous peoples around the world. At the core of these initiatives is the principle of self-determination.

*The National Aboriginal and Torres Strait Islander Blood-Borne Viruses and Sexually Transmissible Infections Strategy* acknowledges that a clear demand and ‘desire to be involved in the service planning, design and implementation of policies to support their health and wellbeing’ has been continually expressed by Aboriginal and Torres Strait Islander people.<sup>4</sup>

Ensuring adequate funding for sexual health services is required to actualise the principle of Aboriginal and Torres Strait Islander community control and engagement<sup>75</sup>. In 2016, it was confirmed that a \$2.3 million funding package for Aboriginal and Torres Strait Islander sexual health programs in NSW would cease<sup>76</sup>, resulting in severely diminished Aboriginal sexual health staff capacity in Aboriginal Community-Controlled Health Organisations.

Self-determination should also be prioritised to improve primary health care, which is understood as a ‘holistic approach which incorporates body, mind, spirit, land, environment, custom and socio-economic status’<sup>77</sup>. There is a need for a greater recognition that the social and cultural determinants of health drive much of the differentials in HIV.



HIV transmissions and the health and wellbeing of people living with HIV are affected by factors such as income inequality, education, employment, housing and social support, and a range of other social determinants of health.<sup>78</sup> Aboriginal and Torres Strait Islander people should have a voice in laws, policies and regulation that affect the determinants of their health.

#### Access to HIV-related services

Higher rates of undiagnosed HIV, a lower uptake of biomedical prevention strategies and a greater proportion of HIV transmissions occurring via injecting drug use and heterosexual sex among Aboriginal and Torres Strait Islander populations are indications that HIV responses have insufficiently addressed the specificities of the epidemic in this population.

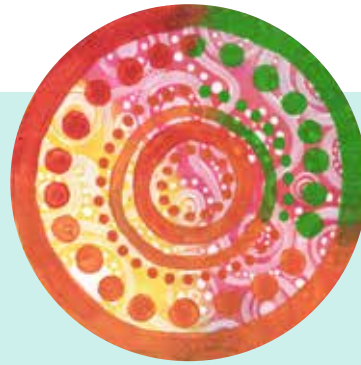
It is important to expand the range of sexual health services options available for Aboriginal and Torres Strait Islander people. This includes increasing the capacity of Aboriginal Community-Controlled Health Services, and removing barriers to accessing prevention methods in a range of settings.

People who are in prison should have access to the same prevention methods as other members of the community. Despite the effectiveness of NSW's community-based Needle and Syringe Program (NSP), people who are in prison are still denied access to it.

The limited uptake of PrEP among Aboriginal and Torres Strait Islander people should also be addressed. Tailored campaigns are required to increase access to PrEP for cis and trans men and women at risk of HIV, in line with the ASHM PrEP guidelines. The provision of free PrEP through Aboriginal Community-Controlled Health Organisations should also be considered.

Considering the greater proportion of HIV notifications occurring through heterosexual sex and higher rates of STI notifications among Aboriginal and Torres Strait Islander people, renewed efforts to promote condom use and regular testing are required.





## RECOMMENDATIONS

### **Put Aboriginal and Torres Strait Islander people at the centre of HIV responses**

1. Ensure the greater and meaningful involvement of Aboriginal and Torres Strait Islander people living with HIV in the preparation and delivery of the next NSW HIV Strategy and STI framework.
2. Create a NSW governance group to drive and monitor Aboriginal and Torres Strait Islander HIV responses. This would include ACCHSs, the AH&MRC, sexual health services like ACON, Positive Life NSW and PosHets, the NSW Government and research institutions.
3. Ensure that Aboriginal and Torres Strait Islander people shape the policies and laws that affect health determinants, including by establishing mechanisms for a voice in Parliament.<sup>79</sup>

### **Re-invest in Aboriginal and Torres Strait Islander sexual health services**

4. Ensure adequate funding is provided to increase the number of Aboriginal and Torres Strait Islander sexual health professionals across NSW.
5. Support the development of Aboriginal Community-Controlled Health Services staff capabilities and knowledge of HIV prevention methods, including through the funding of training/mentoring programs and engagement with LGBTQ+, HIV and drug support organisations.
6. Improve educational pathways with a sexual health promotion focus and provide opportunities for Aboriginal health workers to develop new skills, including a sexual health specialisation.
7. Support the ongoing national

Aboriginal and Torres Strait Islander HIV Awareness Week, the Anwernekenhe National HIV/AIDS Alliance and the bi-annual Anwernekenhe Conference.

### **Improve access to HIV and STI prevention and testing methods in a range of settings**

8. Increase funding for community-led targeted campaigns to reduce the prevalence of STIs and HIV in Aboriginal and Torres Strait Islander communities.
9. Ensure that HIV and STI testing methods are widely available across NSW in a range of Aboriginal Community-Controlled Health Services and culturally-competent settings. This includes expanding culturally-appropriate testing programs that reduce stigma and fear within the community, such as rapid testing mobile clinics.
10. Develop a plan to increase the uptake of biomedical prevention strategies for Aboriginal and Torres Strait Islander people at risk of HIV. This may include targeted campaigns among Aboriginal Community-Controlled Health Services clinicians and sustained community campaigns with dedicated resources for Aboriginal health workers to distribute.
11. Expand the distribution of sterile injecting equipment, including through the trial of an access program in a NSW prison using evidence-based models that have been effective in non-custodial settings.
12. Consult with Aboriginal and Torres Strait Islander people who use drugs to examine what specific harm reduction initiatives would benefit their communities.



# GLOSSARY

## Aboriginal and Torres Strait Islander Nations

The continent today known as Australia consists of over 500 traditional Nations, which have diverse cultures, languages and beliefs. Aboriginal people are from nations across the mainland and Torres Strait Islander people are from island nations in the Torres Strait, north of the mainland.

While some key cultural elements are shared across nations, such as a strong relationship to land and a holistic concept of health, ACON acknowledges the diversity of Aboriginal people and Torres Strait Islander people and their cultures, histories and beliefs.

## Aboriginal Community Controlled Health Services (ACCHSs)

According to the ACCHSs peak body<sup>82</sup>, an ACCHS is a primary health care service initiated and operated by the local Aboriginal community to deliver holistic, comprehensive, and culturally appropriate health care to the community which controls it, through a locally elected Board of Management.

Aboriginal communities operate 143 ACCHSs in urban, regional and remote Australia. They range from large multi-functional services employing several medical practitioners and providing a wide range of services, to small services which rely on Aboriginal Health Workers and/or nurses to provide the bulk of primary care services, often with a preventive, health education focus.

## AH&MRC

The Aboriginal Health and Medical Research Council (AH&MRC) assists the Aboriginal Community Controlled Health Services (ACCHSs) across NSW to ensure they have access to an adequately resourced and skilled workforce to provide high-quality health care services for Aboriginal communities.

## Brotherboys and sistergirls

As a simplified and general definition, sistergirls

are Aboriginal women who were classified male at birth but live their lives as women. Brotherboys are Aboriginal men who were classified female at birth but live their lives as men. It must be noted, however, that sistergirl and brotherboy identities are unique and not necessarily the same as western conceptions of transgender identity. Across the many nations there are various perceptions of this identity, including but not limited to non-binary identities such as a 'two-spirit' identity or a 'third gender' identity.

## BBV

Blood-borne viruses.

## Bisexual

Someone who is attracted to both men and women.

## Cisgender

A person whose gender identity is the same as the sex they were assigned at birth.

## Combination prevention

A combination of evidence-based biomedical (PrEP, PEP, TasP, UVL), behavioural and social approaches to prevent HIV transmissions.

## Gay

Someone who identifies as a man and is attracted to other people who identify as men. Some older people still use the term as it was in the 1970s to encompass same-sex attracted people in general, or in an even broader sense to refer to the entire LGBTQ+ community.

## Gender

Refers to someone's personal sense of their gender identity. It may differ from the medically defined sex they were assigned at birth. (Currently the Western medical system only recognises two sexes – male and female.) Gender and sex are separate from, and unrelated to, sexuality or romantic attraction. A person, regardless of their gender, may be heterosexual, homosexual, bisexual, asexual or other sexual and romantic orientations.

### Health promotion

As defined in the Ottawa Charter for Health Promotion, the process of enabling people to increase control over, and to improve, their health.<sup>80</sup>

### Lesbian

Someone who identifies as a woman and is sexually and/or romantically attracted to other people who identify as women.

### LGBTQ+

Is an acronym for Lesbian, Gay, Bisexual, Transgender, and Queer, plus other identities outside of the cisgender, heterosexual majority population.

### MSM

Men who have sex with men.

### Non-binary

Some people consider gender to be a spectrum rather than a binary system. People who identify their gender as non-binary may consider themselves as encompassing both male and female or as neither male nor female. They may (or may not) present themselves in gender non-specific ways.

### PBS-listed drugs

Medication that is subsidised by the Australian Government under the Pharmaceutical Benefits Scheme.

### PEP

Is an acronym that stands for post-exposure prophylaxis. PEP is medication that can be taken up to 72 hours after a risk exposure to prevent HIV transmission.

### PrEP

PrEP is an acronym that stands for pre-exposure prophylaxis. It involves HIV-negative people taking antiretroviral drugs before any risk exposure such as condomless sex to prevent HIV infection. It typically involves taking one tablet a day but can also be used on-demand in certain circumstances. To be effective against HIV it must

be taken in accordance with medical advice as individual circumstances vary.

### PWID

People who inject drugs.

### Queer

Describes a range of sexual orientations and gender identities. Once an offensive term, 'queer' has been re-appropriated and now encapsulates political ideas of resistance. It is sometimes used to describe the full range of LGBTQ identities.

### Self-determination

This concept has evolved over time and can mean different things in different contexts. In this paper, self-determination is understood as 'grassroots initiatives that are defined by and for their local communities to improve health outcomes'.<sup>8</sup>

### Sexually-transmissible infections (STI)

Sexually-transmissible infections are infections which are passed from one person to another during sexual activity (e.g. through oral, vaginal or anal sex).

### Trans/Transgender

Refer to people whose assigned sex at birth does not match their gender identity. Transgender/trans and gender diverse people may identify as male, female, both genders, neither gender, non-binary, gender fluid or they may not subscribe to the idea of gender. Trans people have the same range of sexualities as cisgender people.

### Treatment as Prevention (TasP)

Treatment as prevention is the use of antiretroviral medication to prevent the transmission of HIV to sexual partners. Antiretroviral treatments can suppress the levels of HIV (viral load) in a person's bodily fluids to 'undetectable' levels.

### Undetectable Viral Load (UVL)

When someone who is HIV-positive has a UVL, it means that they have such a low level of HIV in their blood that it's impossible to detect it with testing, and they cannot pass on HIV to others.



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