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**BARRIERS TO  
ACCESSING HIV  
AND SEXUAL  
HEALTH CARE  
FOR PEOPLE  
FROM A CALD  
BACKGROUND**

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**afao**

**Discussion Paper**

June 2022



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# INTRODUCTION

## PURPOSE OF THE PAPER

This paper has been developed by the Australian Federation of AIDS Organisations (AFAO), in partnership with six culturally and linguistically diverse (CALD) and blood-borne virus (BBS) specialist organisations\* and the Federation of Ethnic Communities Councils of Australia (FECCA), with input from AFAO member organisations and national organisations representing priority populations. This paper identifies specific issues and barriers to universal health care for people from a CALD background in relation to HIV and sexual health. The paper summarises key research from within Australia, as well as international research with people from CALD backgrounds in high-income countries, as well as including reference to the experiences of services providers. The final section proposes recommendations that can help build on our strengths and partnerships in our response to HIV in Australia.

## PEOPLE FROM A CALD BACKGROUND

This paper uses the term 'cultural and linguistic diversity' (CALD) as this is the terminology commonly used by the government and non-government sector. The term is often used to encompass anyone from a non-Anglo-Celtic origin. The Australian Bureau of Statistics define CALD mainly by country of birth, language spoken at home, and English proficiency.<sup>1</sup> Aboriginal and Torres Strait Islander people are not included within the definition in recognition of being First Nations peoples with significantly different experiences. Prior to the adoption of the term CALD in the mid-1990s, the term Non-English Speaking Background was in common use but Commonwealth and state/territory governments dropped support for use of this term after it was seen as being oversimplified indicator of disadvantage and developed negative connotations.<sup>1</sup> For some commentators and academics, the term CALD has come to be seen as problematic as it can mask diversity and it can be unclear about who is included and excluded.<sup>2,3</sup> The Federation of Ethnic Communities' Councils of Australia (FECCA) uses the term 'cultural, ethnic and linguistic diversity' to ensure consideration of race/ethnicity and its impact on health and other inequalities.<sup>4</sup> One argument against use of the term 'CALD' is that the term is not used by people from a CALD background to self-describe themselves nor understood by them. However, currently there is no singular term used by different communities which captures their divergent experiences.

## ENDING HIV TRANSMISSION FOR ALL

Australia has a world-leading response to HIV. It has achieved this through a strong partnership between governments, affected communities, researchers and health care providers. As a result, it has a low national HIV incidence particularly when compared to many other high-income countries.<sup>5</sup> The *Eighth National HIV Strategy* has an ambitious goal to achieve the virtual elimination of HIV transmission within Australia.† Advancements in biomedical prevention technologies, such as Pre-Exposure Prophylaxis (PrEP), undetectable viral load (UVL), and Post-Exposure Prophylaxis (PEP) have placed this goal within reach.

Throughout the Australian HIV response, prioritisation has been accorded to the population groups most at risk. This approach recognises that some population groups have been disproportionately affected by HIV. Gay, bisexual and other men who have sex with men (GBMSM) continue to be the most affected group. But over recent years the profile of HIV in Australia has been changing, necessitating an increasing focus on people from a CALD background. Achieving an end to HIV transmission requires the inclusion of people from a CALD background in prevention, testing and treatment services, if health equity is to be achieved.

\* Victorian African Health Action Network (VAHAN), Centre for Culture, Ethnicity and Health (CEH) Multicultural HIV and Hepatitis Service (MHAHS), Relationships Australia South Australia (RASA), Ethnic Communities Council of Queensland (ECCQ), Community of Practice for Action on HIV and Mobility (CoPAHM)/Sexual Health and Blood-borne Virus Applied Research and Evaluation Network (SiREN), Curtin University.

† AFAO's *Agenda 2025* identifies virtual elimination as a 90% reduction in preventable HIV diagnoses (compared to 2010 baseline).

## OVERVIEW OF HIV IN AUSTRALIA TODAY

Australia is estimated to have an HIV prevalence of **0.14%**, which is very low compared to other high-income countries.<sup>7</sup> Over recent years, HIV epidemiology in Australia has been changing and notifications have been declining. In 2018, there was a **23%** reduction in HIV notifications compared to 2014.<sup>7</sup> This is being driven mostly by a reduction in HIV transmission attributed to male-to-male sex, as HIV notifications among these men declined **29%** between 2014 and 2018.<sup>6</sup> Newly acquired infections (last 12 months) declined even more rapidly among these men, at **50%** between 2014-2018.

Male-to-male sex continues to be the major HIV risk exposure in Australia accounting for **59%** of HIV notifications in 2019, with heterosexual notifications at **23%**, male-to-male sex and injecting drug use **7%** of notifications and injecting drug use **3%** of notifications.<sup>15</sup> Male-to-male sex continues to account for the largest proportion of new HIV notifications, though this proportion has been declining.<sup>15</sup> By way of example, in 2015 male-to-male sex accounted for **68%** of HIV notifications. From 2008 to 2018, the number of HIV notifications attributed to heterosexual sex has remained relatively stable in most states and territories, though with some fluctuations.<sup>5</sup>

It is estimated 28,180 people live with HIV in Australia.<sup>7</sup> Ninety per cent of these people are estimated to be diagnosed, leaving **10%** (2,690) living with undiagnosed HIV. Among those with undiagnosed HIV, the estimated proportion was higher in people with reported risk exposures of injecting drug use and heterosexual sex, and lower among men with male-to-male sex as their HIV risk exposure. The estimated proportion with undiagnosed HIV was also higher among people born in Southeast Asia and among Aboriginal and Torres Strait Islander people.<sup>7</sup> Factors contributing to undiagnosed HIV, such as HIV stigma, low health literacy and lower perceptions of risk, are addressed in later sections.

## HIV AND POPULATION MOBILITY

The *Eighth National HIV Strategy* identifies CALD people from high HIV prevalence countries and people who travel to high-prevalence countries and their partners as a priority population group. Particular sub-groups at risk include:<sup>11</sup>



**People who inject drugs from high HIV prevalence countries**



**People living with HIV from high HIV prevalence countries**



**Australian GBMSM acquiring HIV overseas**



**Australian heterosexual people acquiring HIV overseas**



**International students and backpackers**



**Sex workers from CALD backgrounds**

Prior to the COVID-19 pandemic, there was significant population mobility. In ten years prior to 2020, 1.9 million people in Australia were recent migrants or temporary residents, approximately half on permanent visas or having become Australian citizens.<sup>8</sup> In 2019, there were 500,000 international student enrolments, with a high rate of annual turnover.<sup>9</sup> Population mobility has been identified as a key driver of the HIV epidemic.<sup>10</sup> Mobility can be a risk factor for HIV acquisition, as it can result in individual behaviour change, reduced access to health services and social support.<sup>11</sup> People may be at risk pre-departure, during transit and at destination.<sup>11</sup> Mobility presents challenges to HIV prevention efforts across multiple international and domestic jurisdictions. Mobile populations can include people across a range of cultures, countries of birth, ethnicities, genders, sexualities and legal statuses.<sup>12</sup>

Over time migration to Australia has changed to include permanent migration, semi-migration, and people who are temporarily mobile or constantly mobile, with each experiencing their own unique challenges.<sup>13</sup> Understanding reasons for migration, such as whether for employment, study, escaping war and conflict, or family reunion, can help inform program design. Research has highlighted the need for programs and services to focus on migrants who experience high HIV diagnosis rates, such as Asian-born GBMSM and heterosexual men and women born in Southeast Asia and sub-Saharan Africa.<sup>53</sup>

## CULTURAL, LINGUISTIC AND RELIGIOUS DIVERSITY IN AUSTRALIA

The Australian Census 2016 provides an overview of the cultural, linguistic and religious diversity of the Australian population.<sup>14</sup> Twenty-eight per cent of the Australian population were overseas born (first generation Australians) and 21% had one or both parents born overseas (second generation Australians). In total, approximately half (49%) of Australians were born overseas or had one or both parents born overseas. Among Australians who were born overseas, United Kingdom (17.7%) and New Zealand (8.4%) were still the most common countries of birth. The next most common countries of birth were China (8.3%), India (7.4%), Philippines (3.8%) and Vietnam (3.6%). Among the overseas born population, 83% live in a capital city compared with 61% of people born in Australia. Sydney has the largest overseas-born population.

One-fifth (21%) of Australians speak a language other than English at home. Of those, 82% reported speaking English very well or well and 17% reported speaking English not well or not at all. More than 300 different languages are spoken. After English, the most spoken languages were Mandarin, Arabic, Cantonese and Vietnamese. Australia is also a religiously diverse nation. Fifty-two per cent of Australians report being Christian. Islam was the second largest religion (2.6%), closely followed by Buddhism (2.4%). While the majority of Australians identify with a religion, a significant and increasing minority of Australians report 'no religion', with 30% reporting no religion in 2016 up from the 22% in 2011.

## HIV IN AUSTRALIA SNAPSHOT



Australia is estimated to have an HIV prevalence of 0.14%



HIV epidemiology in Australia has been changing and notifications have been declining



Male-to-male sex accounts for 59% of HIV notifications



Heterosexual sex accounts for 23% of HIV notifications



It is estimated that 28,180 people live with HIV in Australia



It is estimated that 2,690 Australians live with undiagnosed HIV



Male-to-male sex and injecting drug use account for 7% of HIV notifications



Injecting drug use accounts for 3% of HIV notifications



1.9 million people in Australia were recent migrants or temporary residents in the ten years prior to 2020



Research has highlighted the need for programs and services to focus on migrants who experience high HIV diagnosis rates

## CALD, CULTURAL, LINGUISTIC AND RELIGIOUS DIVERSITY IN AUSTRALIA SNAPSHOT



In total, approximately half (49%) of Australians were born overseas or had one or both parents born overseas



One-fifth (21%) of Australians speak a language other than English at home

# 1. CHANGING HIV TRENDS IN AUSTRALIA

## HIV DIAGNOSES AMONG AUSTRALIAN-BORN AND OVERSEAS-BORN PEOPLE

In 2019, **47%** of all HIV diagnoses were in people born outside Australia.<sup>15</sup> Of HIV notifications between 2014 and 2017 with male-to-male sex as the exposure risk, **70%** of Australian-born men were likely to have acquired HIV in Australia whereas it was 48 per cent among men not born in Australia.<sup>5</sup>

Among Australian-born people who acquired HIV through heterosexual sex, **40%** were likely to have acquired HIV in Australia whereas it was **17%** among people born overseas. One significant limitation of this data is that they may not represent the actual proportion, as the place of acquisition was not available for between **17%** to **28%** of HIV notifications.

HIV notifications among Australian-born GBMSM declined by **33%** between 2016 and 2018, but among overseas-born GBMSM there was only a **13%** decline.<sup>6</sup> This small reduction in HIV notification among overseas born GBMSM is due to a sustained rise in late infections. Among the new HIV diagnoses in overseas born GBMSM, there was an increase in the proportion born in Asia from 2009 to 2018 (**32%** to **54%**, respectively), and in Latin America and the Caribbean (**8%** to **14%**, respectively). Among those born in high-income English-speaking countries there was a decline in the proportion of new HIV diagnoses from 2009 to 2018 (**28%** to **13%**, respectively).<sup>6</sup>

Currently, there is no accurate way to assess cultural diversity among Australian-born GBMSM diagnosed with HIV. Understanding what proportion are in Anglo-Australian and people from CALD backgrounds, or how these trends may have changed over time, may highlight gaps and enable appropriate responses.<sup>6</sup>

## LATE HIV DIAGNOSIS

Late diagnosis refers to a diagnosis of HIV where the illness has progressed. This can have significant impact on immediate and long-term health outcomes. The proportion of late HIV diagnoses in Australia has been relatively stable from 2008 to 2017, but as newly acquired infections decline late diagnoses are likely to make up a greater proportion of notifications.<sup>5</sup> In 2017, **48%** of people reporting heterosexual sex as their exposure risk were diagnosed late compared with **31%** reporting male-to-male sex. From 2013 to 2017, the proportion of late diagnoses was higher among people born in Central America, sub-Saharan Africa, and Southeast Asia.<sup>5</sup> The challenge of late HIV diagnoses among migrants is not unique to Australia. A systematic review of research concluded that migrants (particularly those from HIV endemic countries) to high-income countries are at high risk of HIV and have a higher frequency of delayed HIV diagnosis.<sup>16</sup>

Among Australian-born GBMSM, late HIV notifications from 2009 to 2018 declined by **28%**, however, late notifications in overseas-born GBMSM increased by **47%**.<sup>6</sup> In 2018, for the first time there were more late diagnoses among overseas-born GBMSM (**55%**) than Australian-born (**43%**). Among overseas-born GBMSM with late diagnoses, HIV was more likely acquired prior to their arrival in Australia.

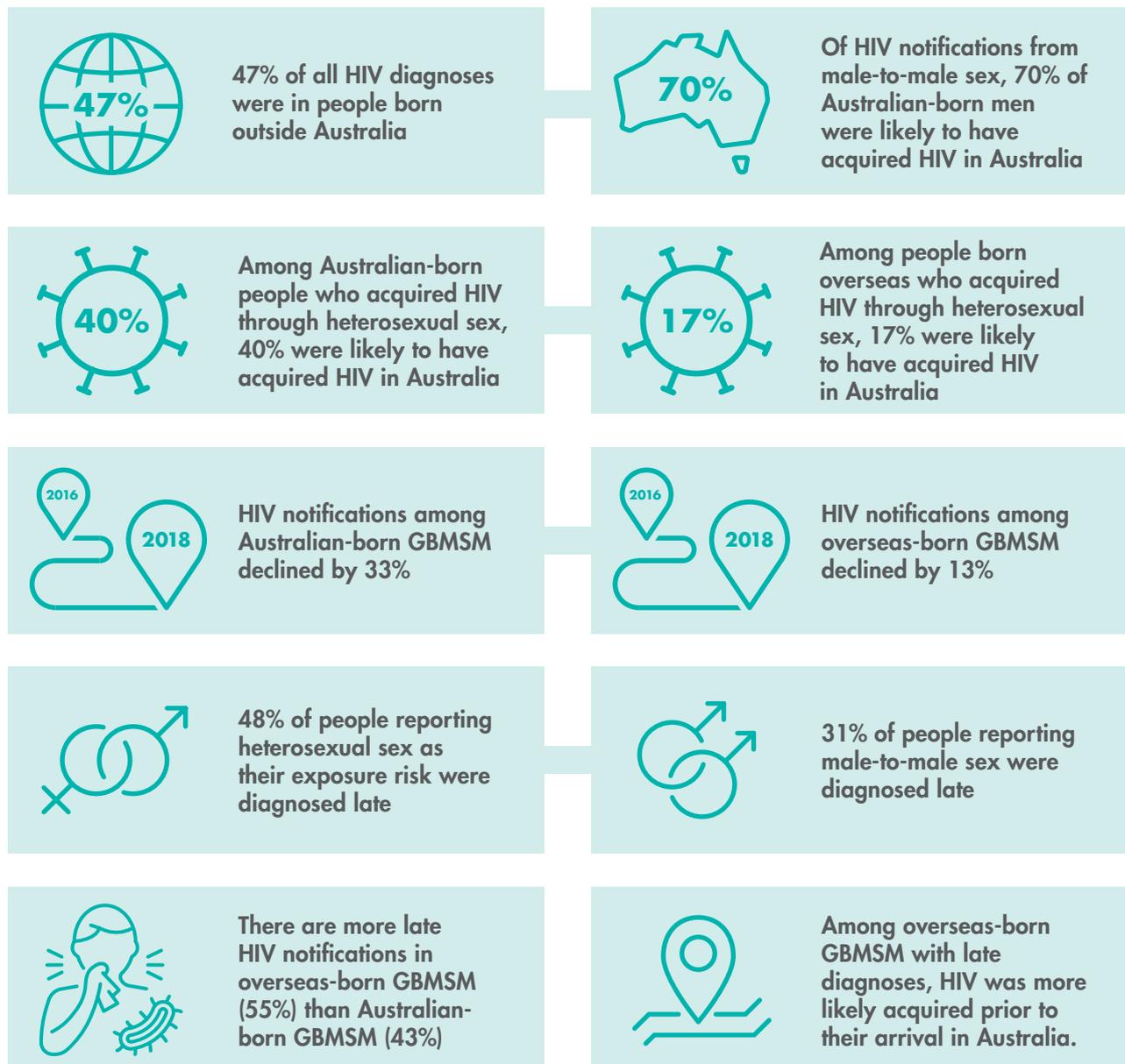
## HIV DIAGNOSIS AND CARE CASCADE

The 'HIV diagnosis and care cascade' aims to have **90%** of people living with HIV diagnosed, **90%** of those diagnosed on treatment and **90%** of those on treatment with viral suppression. In 2018 it was estimated that **90%** of people living with HIV in Australia had been diagnosed, **89%** of those diagnosed were receiving treatment and **95%** of those on treatment had suppressed viral load.<sup>5</sup> An analysis of the HIV care cascade among migrants in Australia found they had lower HIV diagnosis, treatment and viral suppression (85-85-93) compared

to non-migrants (94-90-96).<sup>17</sup> The study reported a particularly low proportion of people living with HIV born in Southeast Asia who were diagnosed and that migrants from countries who were not eligible for reciprocal health care arrangements in Australia had lower HIV diagnoses and care cascades compared to those who were eligible.

Among HIV positive Australian-born and overseas-born GBMSM, the situation in 2018 was identical. A similar proportion of people with HIV were on treatments (95% for Australian-born and 94% for overseas-born) and among men on treatments there were no differences in viral suppression by region of birth.<sup>6</sup>

## AUSTRALIAN HIV DIAGNOSES SNAPSHOT



## 2. HIV PREVENTION, TESTING AND TREATMENT

### HIV AWARENESS AND KNOWLEDGE

Research conducted with several CALD communities (Thai, Cambodian, Ethiopian, Sudanese) in Australia found that knowledge and HIV awareness was very high, though this was not surprising given the high levels of education among survey respondents (85% had attended high school, technical college or University).<sup>18</sup> A significant association between levels of education and HIV knowledge has been reported in studies with migrants in high-income countries.<sup>19</sup>

The Kirby Institute research with six CALD communities (Thailand, Cambodia, Zimbabwe, Ethiopia, Sudan, South Africa) found that 84% correctly identified that HIV can be transmitted by sexual intercourse, but that almost four-fifths were not able to correctly identify all five modes of HIV transmission.<sup>20</sup> The researchers concluded that respondents had both lower levels of knowledge and condom use when compared to general population surveys. Gray and colleagues' research with people from Southeast Asia and sub-Saharan Africa living in Western Australia found a similar proportion (85%) correctly identified that HIV can be transmitted by sexual intercourse but by contrast 37% of respondents incorrectly believed HIV could be acquired by mosquitos.<sup>21</sup> They reported that increased length of time in Australia did not appear to increase HIV knowledge. Overall, they concluded that respondents' HIV knowledge was on par with knowledge among Australian high school students.

A consultation to develop an understanding of the health needs of culturally diverse GBMSM in Melbourne identified that it should not be assumed that all migrants to Australia did not receive sex education in their country of origin.<sup>22</sup> Research with migrants living in Perth found the experiences of sex education in countries of origin were varied with most sub-Saharan African participants not having been exposed to sexual health education, and for those that had received information the content was diluted and delivered mostly from a religious perspective.<sup>23</sup> This contrasted to Asian participants who were taught about sexual health in high schools, including some focus on HIV and sexually transmissible infections (STIs). Even when sex education occurs it may be minimal, as was reported by international students from Asian countries in Melbourne<sup>24</sup> or it may focus on body parts and physical development as, for example, research with young people in Vietnam reported.<sup>25</sup>

### PERCEPTIONS OF PERSONAL HIV RISK

In summarising findings of their research with people from CALD backgrounds in Sydney, Asante and Körner found that while their mostly heterosexual participants may have knowledge about HIV risk and prevention and access to health services, they rarely applied this knowledge to themselves as they perceived their HIV risk as low.<sup>26</sup> The Kirby Institute survey with people from a CALD background in NSW found low levels of HIV testing, just over half of respondents reported having ever being tested, with the main reason for not testing related to a perception of not being at risk.<sup>20</sup> Research with migrants in Canada found similar results that people's perception about their HIV risk may be inconsistent with their actual risk.<sup>27</sup>

There are multiple factors that may influence how people from a CALD background perceive their own HIV risk. HIV transmission in Australia has mostly occurred through male-to-male sex and therefore much of the response has focussed on HIV prevention among this group. An unintended consequence is that has reinforced a perception that heterosexual people are not at risk in Australia.<sup>28</sup> Furthermore, the mandatory requirement for HIV testing when migrating permanently to Australia, the assumption that any applicant who tests positive will be rejected, low HIV prevalence in Australia, and low visibility of HIV in mainstream media may reinforce this perception that they are at low risk of HIV in Australia.<sup>29</sup> The experience of GBMSM may be different, as community surveys with Asian men in Sydney and Melbourne found that those who engaged in high levels of sexual activity were more likely to frequently seek out HIV/STI testing.<sup>30</sup>

## HIV PREVENTION AND TESTING

Behavioural research has monitored shifts in unprotected condomless anal intercourse (CLAIC) and protected CLAIC (either via PrEP or an HIV positive person on treatment with UVI). While there has been a small decline in the proportion of Australian-born GBMSM reporting unprotected CLAIC from 2014-2018, there was no change for overseas-born GBMSM during the same period.<sup>6</sup> Importantly given there were concerns about uptake of PrEP among Asian GBMSM in some initial PrEP trials<sup>31</sup>, the proportion of overseas-born men reporting protected CLAIC increased from 6% in 2014 to 27% in 2018. This was identical to the 28% Australian-born men using protected CLAIC in 2018.

Between 2010 and 2018, one data set showed that the proportion of men having had an HIV test in the previous twelve months has been consistently higher among overseas-born GBMSM compared to Australian-born GBMSM.<sup>6</sup> According to another data set, there was no difference. Among heterosexual people from a CALD background, a Kirby Institute study in 2016 found that just over half (54%) had ever had an HIV test.<sup>20</sup> This is higher than around 40% of men and women in the general community who had never been tested for HIV.<sup>32</sup>

## HIV SHAME, STIGMA AND DISCRIMINATION

The Kirby Institute found positive attitudes towards people with HIV more prevalent than negative attitudes among people from a CALD background.<sup>20</sup> For example, 57% of respondents when thinking about people with HIV felt 'It was not their fault, anybody can be infected'. Similarly, Gray found that most participants had accepting views of people living with HIV, with 88% of people willing to care for a family member if they had HIV.<sup>21</sup> Yet despite these findings, shame, stigma and fear of discrimination have also been recurring themes in HIV research with people from CALD backgrounds.

Some Australian migrants believe people living with HIV were at fault due to 'bad behaviour', particularly given HIV transmission risk for those with multiple sex partners, homosexual people and people who use drugs.<sup>33,35</sup> A systematic review of the barriers to HIV testing among migrants in high-income countries found that stigma was a significant issue.<sup>34</sup> The review identified that HIV stigma related to association of HIV with social exclusion and rejection and death. Migrant perceptions of HIV shame and stigma have often been shaped by their experiences in their country of origin.<sup>35,23</sup> Migrants who knew people living with HIV in their country of origin saw how they were stigmatised in their community, being considered to have breached strong and persistent cultural norms and values around morality, sexuality and gender roles.

## HIV PREVENTION, TESTING AND TREATMENT SNAPSHOT



A small decline in the proportion of Australian-born GBMSM reporting unprotected CLAIC from 2014-2018



27% of overseas-born GBMSM reported protected CLAIC



Among heterosexual people from a CALD background, a Kirby Institute study in 2016 found that just over half (54%) had ever had an HIV test



40% of men and women in the general community have never been tested for HIV

# 3. STRUCTURAL BARRIERS TO ACCESSING HEALTH CARE

## CONFIDENTIALITY AND TRUST IN HEALTH SERVICES

Confidentiality is of the utmost importance for people living with HIV from CALD backgrounds.<sup>35</sup> While confidentiality is a key component of Australia's HIV Testing Policy,<sup>36</sup> research with migrants in high-income countries has found that they are concerned that an HIV diagnosis could result in their being reported to the government or immigration authorities which could threaten their residency status.<sup>54</sup> Research with sub-Saharan African migrants in Australia align with these findings as they found confidentiality was the most frequently nominated barrier to seeking sexual health care.<sup>23</sup> Participants were concerned about the security of information, trusting the system and the repercussion of an HIV positive diagnosis. Negative experiences with healthcare providers can limit uptake of health services. Concerns about privacy and confidentiality may be influenced by negative experiences in their country of origin where health care workers breached the confidentiality of HIV positive patients.<sup>23</sup>

## IMPLICATIONS OF AN HIV POSITIVE DIAGNOSIS ON RESIDENCY STATUS

All permanent visa applicants to Australia must undergo a health check to see if they meet the health criteria for permanent residency. In general, most HIV positive applicants will be deemed to be a significant cost to the Australian community and will likely fail the health criteria due to the costs.<sup>37</sup> Applicants can then apply for a health waiver. Understandably, new migrants to Australia see an HIV positive diagnosis as a barrier to permanent residency.<sup>38</sup> In fact migrant populations living in high-income countries have often ranked legal status concerns about how an HIV positive diagnosis may impact residency applications among their highest concerns.<sup>39</sup> Migrants who are already living in Australia and considering applying for permanent residency may not seek regular HIV testing due to concerns about how an HIV positive diagnosis may impact on their migration status.<sup>38</sup> Prolonged uncertainty about permanent resident status can have negative impacts on health as learning a new language, finding accommodation and employment and building new social relationships is more difficult in such situations.<sup>38</sup>

## CULTURAL COMPETENCY OF HIV AND SEXUAL HEALTH PROVIDERS

The National Health and Medical Research Council (NHMRC) defines cultural competency as "a set of congruent behaviours, attitudes, and policies that come together in a system, agency or among professionals and enable that system, agency or those professions to work effectively in cross-cultural situations."<sup>40</sup> The focus is on improving health and wellbeing by integrating culture into the delivery of health services. Research has identified that a barrier for people from a CALD background accessing HIV and sexual health services has been due to a lack of investment in culturally competent services including:<sup>54,16</sup>

- a perception of poor services from providers
- communication and language barriers
- lack of appropriate interpreter service or bicultural workers
- perceptions of 'negative attitudes' from health care providers based on their ethnicity
- perception among providers that 'everyone from Africa is living with HIV' resulting in perceived discrimination
- participants believing they were tested for HIV without giving consent
- preference for health care providers from their own community (though others may prefer a person outside their community).

While capacity may have progressed since a needs analysis was conducted with the Australian HIV sector in 2007, respondents at the time often questioned their own cultural competency perceiving that they lacked the knowledge, skills and self-efficacy to work people from CALD backgrounds.<sup>41</sup> This was addressed through a cultural competency training program, though its reach was limited. Over the past 20 years or so, cultural competency training has been widely used by health services across high-income countries. Peer-reviewed evidence of the effectiveness of strategies to improve the cultural competency of health services is generally scant. One systematic review concluded that there was limited research showing improved patient outcomes, but they noted a paucity of high-quality research.<sup>42</sup> Another systematic review of cultural competency specifically in health care settings reported positive outcomes for improved practitioner knowledge and improved attitudes and beliefs. However, there was very limited evidence of positive intervention impacts.<sup>43</sup> It has been hypothesised that cultural competency training as a standalone strategy is probably insufficient to improve patient outcomes and that concurrent systemic and organisational change is also required.<sup>44</sup> The NHRMC focus on whole-of-organisation competence can at times be lost as organisations instead focus on individual staff completing a training module.

## **SOCIO-ECONOMIC FACTORS SUCH AS COSTS AND TIME**

Immigrants to Australia may often face a number of barriers finding employment, and can end up in low quality jobs or jobs that do not match their qualification.<sup>45</sup> A systematic review of barriers to HIV testing in migrants in high-income countries reported that barriers included high levels of unemployment and poverty in migrant and ethnic communities, low social status and inequalities.<sup>46</sup> It found that even when free health care is available it fails to account for incidental costs such as transport, childcare and pharmaceuticals. Services working with refugee and humanitarian entrants report that those who have yet to find employment will face financial constraints and this will influence their decision to seek health services such as public transport costs or if they are referred to services not covered by Medicare (e.g. allied health providers) or to private specialists who charge a fee above the Medicare rebate.<sup>47</sup> Research on barriers to accessing health services with people from Southeast Asia and sub-Saharan African in WA found that for most participants cost was an issue but this is not surprising given that half did not have access to Medicare.<sup>21</sup> Interestingly, the Kirby Institute survey asked respondents to identify which factors (if any) made it less likely for them to have an HIV test and they found that structural barriers such as cost and finding time were only reported by a small proportion of respondents (92% of survey respondents had a Medicare card).<sup>20</sup> Far more common factors were a dislike of blood tests, fear about their HIV test results and not wanting to have a discussion with their doctor and having a regular partner.

## **ENGLISH LANGUAGE PROFICIENCY AND HEALTH LITERACY SKILLS**

Among people for whom English is a second language, one-quarter have been evaluated as having adequate or better health literacy compared with 44% of people who speak English as a first language.<sup>48</sup> This research focussed on ability to understand health information though different results may have occurred if a broader definition of health literacy was used such as ability to navigate new and complex health systems. Among particular migrant population groups, such as humanitarian entrants, health literacy may be a more significant issue given English-proficiency does not play a part in their immigration selection.<sup>47</sup> People living with HIV have said that limited English language proficiency has been a barrier to getting information and making contact with HIV services.<sup>35</sup> Making decisions about HIV care and treatment in a foreign language with obscure medical terminology can be an overwhelming experience.<sup>49</sup> In addition, health resources may be written in a way that requires a high level of English language competency to read and understand the resource.<sup>50</sup> Providing health resources in other languages is beneficial, but there is a significant cost that prevents this occurring or limits the languages used (though this should be weighed against the benefit of ensuring the information reaches priority populations). Even when HIV resources have been translated into community languages the translation can be problematic as original meanings were often lost or changed in translation or failed to ensure the messaging reflected community values and cultures.<sup>51</sup> During the development of this paper, service providers commented that, messages needed to be redeveloped in collaboration with people from CALD backgrounds to ensure they are effective. In addition, service providers emphasised the value of ensuring resources that were not translated into other languages were written in plain English.

## **The Australian Commission on Safety and Quality in Health Care defines health literacy in two parts:**

### **Individual health literacy**

is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.

### **Health literacy environment**

is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way that people access, understand, appraise and apply health-related information and services.

<https://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/health-literacy>

## **PEOPLE LIVING WITH HIV WHO ARE MEDICARE INELIGIBLE**

A person who is Medicare Ineligible is someone who does not hold a Medicare Card, is not an Asylum Seeker or is not a visitor from a country that has a Reciprocal Health Care Agreement with Australia. This can include international students, overseas visitors, and temporary entrants or temporary visa holders. People living with HIV who are Medicare Ineligible experience problems accessing health care and treatment after been diagnosed, including affording the medication they required.<sup>52</sup> Recently, the Australian Government announced that every person living with HIV in Australia would have free access to antiretroviral treatment, regardless of Medicare eligibility. This news was welcomed by HIV organisations as closing an important gap in the care of people living with HIV and the drive towards ending HIV transmission.<sup>†</sup> When this improved access is achieved, a challenge will be reducing the time delay between diagnosis and treatment commencement, as people from CALD backgrounds are significantly less likely to have commenced treatment within six month of HIV diagnosis than people born in Australia.<sup>53</sup>

## **ACCESS TO HEALTH CARE SERVICES IN AUSTRALIA, INCLUDING HIV TESTING AND PREP**

Migrants may have inadequate information about the health system in the country they are living in and experience problems navigating access, including knowing how to make medical appointments or knowing the necessary documents required.<sup>54</sup> Gray's research with people from Southeast Asia and sub-Saharan Africa noted that it is not clear whether difficulties in making appointments is due to lack of knowledge of services, cultural differences or issues common to the general population.<sup>21</sup> Studies have also reported lack of knowledge of sexual health services and their location.<sup>54</sup> A systematic review of barriers to accessing HIV testing concluded that the issue is not about availability but accessibility.<sup>8,34</sup> Reeder highlighted that often GBMSM students rely on word-of-mouth to find out about services and that this can leave socially unconnected students more vulnerable.<sup>24</sup>

People in Australia on temporary visas who are ineligible for Medicare are unable to access subsidised HIV PrEP through the Pharmaceutical Benefits Scheme (PBS) to protect themselves from HIV acquisition. People who are ineligible for Medicare can only access PrEP by paying the full costs out of pocket (which are substantial) or import PrEP medication from overseas (which is administratively burdensome).<sup>55</sup> Stakeholders reported hesitancy among international students accessing PrEP on their private health insurance due to their fears this information will be disclosed to their families. A lack of access to subsidised PrEP results in fewer at-risk people on PrEP resulting in lower population coverage and higher risk of HIV transmission.

† <https://www.afao.org.au/media-release/world-aids-day-marked-by-fresh-commitment-to-end-hiv-transmission/>

§ Accessibility has been defined as a person's ability "to reach, to obtain or use health care services and to actually have the need for services fulfilled". (Source: Levesque J-F, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *Int J Equity Health* 2013;12;18.

## PRIMARY HEALTH CARE'S ROLE IN HIV RISK ASSESSMENT AND TESTING

Primary health care providers play an important role in the delivery of HIV prevention, testing and treatment services in Australia. As noted earlier, many people from a CALD background may perceive that HIV is a risk within the community, but do not personally view themselves at risk. GPs play an important role in this regard as many migrants expect that their doctor will discuss HIV and offer testing if they are at risk, otherwise it is seen as a non-issue.<sup>21</sup> Alvarez and colleagues review of research support this finding that health care provider endorsement was a significant predictor of HIV testing.<sup>16</sup> Yet summarising findings from their two research studies with CALD participants, researchers from the University of NSW found it striking that a majority of respondents who had tested for HIV at least once tested either because they were sick in hospital, or for immigration or employment purposes or through contact tracing.<sup>56</sup> They noted that voluntary HIV testing was rare. Stakeholders commented that a challenge is that GPs with a CALD background, particularly in suburban and regional settings, may have similar perceptions of HIV risk as the communities they serve. Research has found a range of strategies can impact on HIV testing among migrant communities, such as home-based testing and outreach testing, but that provider-initiated testing at the point-of-care produces the best results.<sup>57</sup>

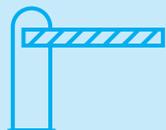
## STRUCTURAL BARRIERS TO ACCESSING HEALTH CARE SNAPSHOT



Confidentiality is of the utmost importance for people living with HIV from CALD backgrounds



New migrants to Australia see an HIV positive diagnosis as a barrier to permanent residency



A lack of culturally competent services is a barrier for people from a CALD background accessing HIV and sexual health services



Barriers to HIV testing for migrants in high-income countries include high levels of unemployment and poverty in migrant and ethnic communities



One quarter of people with English as a second language have been evaluated as having adequate health literacy



Limited English language proficiency has been a barrier to accessing HIV information and services for people living with HIV



Every person living with HIV in Australia will have free access to antiretroviral treatment, regardless of Medicare eligibility



GBMSM students rely on word-of-mouth to find out about services and this can leave socially unconnected students more vulnerable

# 4. SOCIAL AND CULTURAL ISSUES

## COMMUNITY AND INDIVIDUAL NORMS AND BELIEFS

Social, cultural and religious beliefs can restrict discussion of sexuality and impact upon sexual health seeking behaviour.<sup>23,58</sup> Sexual health has a taboo connotation in many migrants' countries of origin.<sup>23</sup> Gender norms has been found to be an obstacle to accessing sexual health services, particularly if migrant identities are shaped by the norms of their country of origin.<sup>59</sup> Women from a CALD background have said that when accessing sexual and reproductive health that providers do not have knowledge about their cultural norms, traditions and religious beliefs.<sup>60</sup> If people feel afraid of being judged and feel embarrassed to discuss sexual health this can act as a barrier to seeking sexual health services.<sup>54</sup> Southeast Asian participants in one research study described their culture as conservative, making sexual health a topic rarely discussed.<sup>23</sup> Even though constructions and understandings of sexual health may change, others may experience difficulty integrating new cultural values after migration.<sup>61</sup> However, it should be noted that not all migrants' constructions are different from those held in Australia. Dune observed that it may not be ethnic culture which drove understanding of sexual health but instead their religious beliefs.<sup>61</sup>

Research with heterosexual men and women from CALD backgrounds living with HIV in Australia has identified that the stigma of HIV was experienced differently by women, due to perceptions about HIV impacting women who did not behave according to the gender norms of their culture. This has led to fears of how they may be labelled and how this would reflect on their family.<sup>65</sup> The research has highlighted that disclosing HIV status can be influenced by gender, sexual orientation and cultural background.<sup>65,61</sup>

Another issue impacting on health-seeking behaviour is the cultural norm in many non-Western countries whereby the individual's needs and wishes are overridden by family and community ties and interest.

## ATTITUDES AND ACCEPTANCE OF HOMOSEXUALITY

Homosexuality is still illegal in 69 countries throughout the world, including some in the Asia and Pacific region.<sup>62</sup> The Global Commission on HIV and Law reported that such laws have significant impact as they discourage at risk populations from getting tested and treated. Recently, there have been cultural shifts in attitudes towards homosexuality and sexuality in Asia that has impacted upon the knowledge and experience of GBMSM who migrate to Australia. Even with such progress, GBMSM must negotiate family and cultural expectations. *Writing Themselves in 3* highlighted that there is a tension for young people between their religious and CALD-specific beliefs and their same sex attraction.<sup>63</sup> Reeders commented that GBMSM may go through an experience of crisis in relation to their ethnic identity and sexual identity, negotiating homophobia and heterosexist beliefs in their community, as well experiencing social exclusion and discrimination from the gay community.<sup>22</sup> A disconnection from social support may result in sexual risk taking, as well as impacting upon mental health.

## STIGMA, DISCRIMINATION AND RACISM

Stigma, discrimination and racism can reduce access to health services and impact an individual's health and wellbeing. This may include systemic discrimination where institutions are biased in their dealing with minorities. Interestingly, the systematic review of cultural competency training referenced earlier noted that few of the studies they included within the review addressed racism and bias.<sup>43</sup>

'Layered' stigma associated with multiple stigmatised identities require specific attention.<sup>64</sup> This has been identified as a particular issue for people from culturally and linguistically diverse backgrounds (especially men who have recently arrived from countries where HIV and homosexuality stigma is higher than in Australia), and also stigma for people who are multiply labelled because of their HIV status and other practices and identities which attract stigma (such as sexual orientation, injecting drug use, sex work or co-occurring health conditions).

When accessing health services, research with women from CALD backgrounds found that they often experienced racism and/or discrimination.<sup>60</sup> This occurs when health care workers held stereotypical assumptions about them and they were treated in negative ways because of their ethnic background. Women from CALD backgrounds living with HIV may find disclosing their HIV status problematic because of the stigma attached to HIV, and concerns about discrimination.<sup>65</sup> This can act as a major constraint on seeking out social and support services.<sup>52</sup>

Experiences of stigma and discrimination extend beyond just accessing health services, and can impact employment, accommodation, education and social exclusion. Participants in one Australian sexual health study reported that systemic discrimination was particularly present when seeking employment and accommodation.<sup>23</sup> These experiences have been found to deter help seeking behaviour.<sup>23</sup>

## REGIONAL RESPONSES TO HIV

Globally, there has been recognition of the increases in HIV risk associated with mobility.<sup>12</sup> People from high HIV prevalence countries and people who travel to high prevalence countries and their partners are a priority population group in the *Eighth National HIV Strategy*. Targeted interventions are required to support and educate highly mobile populations who may be at increased risk, both before, during and after travel or migration.<sup>13</sup> Researchers have called for greater leadership to effectively implement and evaluate responses to address overseas acquired HIV within migrant and mobile populations (particularly as there is often little evidence that single strategy interventions have been effective<sup>66</sup>), as well as to better understand the drivers of migrations.<sup>66</sup> The HIV and mobility in Australia Road Map for Action<sup>13</sup> called for a variety of strategies including: a) better research, surveillance and evaluation, b) public health policies reflecting a human rights approach, c) a nationally coordinated, sustained response with commitment to ongoing investment and evidence-informed prevention strategies, and d) cross-jurisdictional responses.<sup>66</sup> Australia can play an important role in supporting HIV responses in countries in its region to ensure effective HIV testing, prevention and treatment and abolishing laws and policies that stigmatise and act as barriers.<sup>12</sup> This has mutual benefits for all countries in the region.

## SOCIAL AND CULTURAL ISSUES SNAPSHOT

 <p><b>Gender norms</b> has been found to be an obstacle to accessing sexual health services</p>	 <p><b>Women from CALD backgrounds</b> often experience racism and/or discrimination when accessing health services</p>
 <p><b>Homosexuality</b> is still illegal in 69 countries throughout the world</p>	 <p><b>Women from CALD backgrounds</b> living with HIV may find disclosing their HIV status problematic due to stigma and discrimination</p>
 <p><b>Stigma, discrimination and racism</b> can reduce access to health services and impact health and wellbeing</p>	 <p><b>Globally,</b> there has been recognition of the increases in HIV risk associated with mobility</p>

# 5. INSIGHTS INTO WORKING WITH CALD COMMUNITIES

This is a summary of insights from stakeholders on the approaches to working with people from CALD backgrounds that have proven effective.

## **Building partnerships and trust with communities**

Engaging CALD communities and partnering with existing CALD community infrastructure was critical. While this may vary for different communities it may include religious organisations, social and sport groups, health professional associations, non-government organisations, and community leaders and activists. Developing relationships and building trust takes time, particularly with newly arrived immigrant populations, but it was considered important to ensure that appropriate solutions to HIV priorities are implemented that work for the community and to help build trust and confidence in the Australian health system. One-off funding or short timeframes for projects were considered significant barriers to building partnerships and trust.

## **Adopting a strengths-based approach by supporting communities**

Focussing on a 'strengths-based' approach values the knowledge, skills and competencies of individuals and communities to improve their health. Supporting individuals, groups, and leaders can help communities to improve health outcomes. Having a cultural understanding, from customs, norms, traditions, history, role of family and religious beliefs, of the communities you are working with can inform how to best provide and deliver HIV programs and services. As HIV may not be the highest priority, it is important to listen, consult and partner with communities to identify how to best work together.

## **Supporting diversity, representation and input from people from a CALD background**

Staff, peers, volunteers and people living with HIV who are bilingual and bicultural bring along their own cultural understanding of their communities providing a bridge between communities and HIV services. In addition to cultural and linguistic diversity, recognising that people have different migration experience depending on how and why they migrated. While there is not one approach, it is important to ensure people from CALD backgrounds are leading, collaborating, co-designing and/or inputting into programs, services and research that impact their communities and that there is a commitment to building the capacity of people from CALD backgrounds to participate in projects and research.

### **Adaptable, flexible and sustainable programs and services**

A 'one size fits all' approach may not work given the differences between communities. There is a need for flexibility in the models used when implementing programs and services. A related theme was the need to develop interventions at the intersection between health and culture, so that communities are engaged in a manner that is effective and culturally appropriate. For example, one health intervention focussed on food and cooking in different cultures and another on ensuring education occurred at significant community cultural events. There has also been increasing use of innovative online HIV prevention programs. One-off or time limited interventions were often considered less effective at achieving change with mobile populations (for example, a high rate of turnover among international students requires sustainable interventions).

### **Providing health information in plain English and community languages**

Providing information in languages other than English should extend beyond just translation of existing resources, taking account of different cultures and how to effectively engage the audience. This is particularly the case with health advertisements that do not always translate effectively (campaign slogans and key messages are often plays on words). Rigorous pre-testing of translated and plain English resources is essential to ensure accurate understanding.

# 6. CONCLUSION AND RECOMMENDATIONS

The development of the *Ninth National HIV Strategy* presents an opportunity to further invest in programs and services to help overcome the barriers for people from a CALD background in accessing HIV and sexual health services and therefore help contribute to achieving our ambitious national goal of ending HIV transmission in Australia.

## HIV PREVENTION, TESTING AND TREATMENT

1. Invest in local solutions as the priority populations at risk will vary in each jurisdiction, build on the strengths of communities and implement HIV programs in partnership with people from CALD backgrounds.
2. Promote and increase access to HIV testing among overseas-born GBMSM, particularly from Asia and Latin America, soon after arriving in Australia.
3. Advocate for a policy mechanism that enables individuals who want to take PrEP, but who are not eligible for Medicare due to their visa status, to access subsidised PrEP as a public health measure to prevent HIV.
4. Explore and evaluate different options for HIV testing, such as dried blood spot testing and rapid HIV testing, and make them available in different settings to increase HIV testing uptake among people from CALD backgrounds.
5. Develop national and state/territory processes to ensure people from a CALD background input into the development, implementation and monitoring of responses to working with their communities.

## STRUCTURAL BARRIERS TO ACCESSING HEALTH CARE

6. Review immigration health screening policies to ensure they do not deter people in Australia from HIV testing.
7. Support HIV organisations to implement systemic and organisational change, including providing professional development, to enable the provision and co-design of culturally appropriate services and programs for people from a CALD background.
8. Support GPs to identify people from a CALD background who may be at increased risk and maximise opportunistic testing and provide education on cross-cultural communication on HIV testing.
9. Funding to support organisations to develop HIV social marketing campaigns and resources that are culturally engaging and appropriate, tested with the audience, written in plain English and available in community languages for priority populations.

## SOCIAL AND CULTURAL ISSUES

10. Use the Australian Human Rights Commission's Anti-Racism Framework to inform the next *National HIV Strategy* and its implementation.
11. Invest in research studies to demonstrate what interventions are effective at reducing stigma and discrimination for people from a CALD background living with and at risk of HIV when accessing health services.
12. Engage people from CALD backgrounds in all levels of policy, program, service, and research design.
13. Promote Australian government leadership on HIV in the Asia Pacific region to support effective local HIV policies, legislation and programs, particularly with mobile populations.

## RESEARCH AND EVALUATION

14. Invest in evaluation to identify which HIV programs are effective at increasing HIV prevention, testing and treatment among people from CALD backgrounds.
15. Reach national agreement on CALD indicators that could be collected by HIV national surveillance (ethnicity and visa status were specifically identified), behavioural research and program evaluations.
16. Invest in regular behavioural research with migrants to better understand factors related to HIV and other STIs, in partnership with NGOs, state/territory health departments and CALD communities.

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