

STRUCTURAL BARRIERS TO ACCESSING HEALTH CARE BRIEFING PAPER

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This briefing paper draws from a discussion paper 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. The full discussion 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 of the discussion paper proposes recommendations that can help build on our strengths and partnerships in our response to HIV in Australia.

The full discussion paper with references for all papers can be viewed here: <https://tinyurl.com/ye26awxu>.

CONFIDENTIALITY AND TRUST IN HEALTH SERVICES

Confidentiality is of the utmost importance for people living with HIV from CALD backgrounds.³⁵ While confidentiality is a key component of Australia's HIV Testing Policy,³⁶ 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.⁵⁴ 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.²³ 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.²³

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.³⁷ Applicants can then apply for a health waiver. Understandably, new migrants to Australia see an HIV positive diagnosis as a barrier to permanent residency.³⁸ 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.³⁹ 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.³⁸ 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.³⁸

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."⁴⁰ 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

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sexual health services has been due to a lack of investment in culturally competent services including:^{54,16}

- 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.⁴¹ 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.⁴² 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.⁴³ 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.⁴⁴ 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.⁴⁵ 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.⁴⁶ 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.⁴⁷ 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.²¹ 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).²⁰ 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.⁴⁸ 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.⁴⁷ People living with HIV have said that limited English language proficiency has been a barrier to getting information and making contact with HIV services.³⁵ Making decisions about HIV care and treatment in a foreign language with obscure medical terminology can be an overwhelming experience.⁴⁹ 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.⁵⁰ 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.⁵¹ 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.

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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.⁵² 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.[†] 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.⁵³

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.⁵⁴ 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.²¹ Studies have also reported lack of knowledge of sexual health services and their location.⁵⁴ A systematic review of barriers to accessing HIV testing concluded that the issue is not about availability but accessibility.^{8,34} 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.²⁴

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).⁵⁵ 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.

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.²¹ Alvarez and colleagues review of research support this finding that health care provider endorsement was a significant predictor of HIV testing.¹⁶ 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.⁵⁶ 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.⁵⁷