

A review of the availability, accessibility and uptake of HIV education and support service provision to sub-Saharan African migrants in metropolitan Melbourne, Australia

by  
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## **Declaration**

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## **Abstract**

The elevated prevalence of HIV among the sub-Saharan African (SSAn) born community of Australia stands as an anomaly to the low prevalence status of the wider Australian population. This study aimed to review and evaluate the provision of HIV education and support services within Melbourne, Australia with regard to availability, accessibility and uptake by the SSAn community. HIV service providers from within a defined geographical area were identified and representatives from ten organisations interviewed.

HIV service providers identified within Melbourne work with a range of community sectors including multicultural groups. Engagement with the SSAn community is limited and presents challenges for all providers. Members of this community link most readily with services that are community-centric, integrated into wider health services, respectful of the individual and cognisant of cultural norms. However, the effectiveness of such services is limited by under-resourcing and a lack of collaboration between service providers.

Barriers to community engagement and service delivery were found to be significant being both structural and cultural. Structural impediments relate to the focus and location of services, legal and financial barriers and the limited availability of multilingual workers and materials. Entrenched socio-cultural norms, such as stigmatisation of HIV/AIDS and homosexuality, and gender inequality, present the greatest challenge to wider engagement. Recommendations for addressing these barriers are presented with a view to reducing the vulnerability to HIV of the SSAn community within Melbourne and Australia.

## **Opsomming**

Die hoër voorkoms van MIV onder die gemeenskap wat in Sub-Sahara Afrika gebore is en tans in Australië woon is in skerp teenstelling met die lae voorkoms van MIV in die bevolking van Australië. Die doel van hierdie studie is om MIV-ondersteuningsdienste in Melbourne, Australië te evalueer in terme van beskikbaarheid, bereikbaarheid en opname deur die immigrante van Sub-Sahara, Afrika. MIV-diensverskaffers binne 'n bepaalde geografiese area is geïdentifiseer en daar is onderhoude gevoer met verteenwoordigers van tien diensverskaffers.

Die diensverskaffers wat in Melbourne geïdentifiseer is werk binne 'n wye reeks gemeenskappe, insluitende multi-kulturele groepe. Kontak met die gemeenskap wat oorspronklik uit Sub-Sahara Afrika kom is beperk en verskeie uitdagings word ondervind ten einde kontak te maak met hierdie groep. Lede van die Sub-Sahara gemeenskap sal normaalweg meer geredelik gebruik maak van dienste wat gemeenskap-georiënteerd is en wat geïntegreer is by meer algemene gesondheidsorg waarbinne daar respek getoon word vir individuele- en kulturele norme. Die doeltreffendheid van laasgenoemde word ongelukkig beperk deur 'n gebrek aan die nodige hulpbronne asook deur die afwesigheid van behoorlike samewerking tussen diensverskaffers.

Die studie het bevind dat daar beduidende struikelblokke van beide strukturele en kulturele aard voorkom. Strukturele struikelblokke is veral gesetel in geografiese en finansiële beperkings, maar dit kan ook gedeeltelik toegeskryf word aan die skaarste aan meertalige diensverskaffers en materiaaltekorte. Diep-gesetelde sosio-kulturele norms, soos die stigma gekoppel and MIV/Vigs, homoseksualiteit en geslagsongelykheid, bied die grootste uitdagings aan groter betrokkenheid.

Voorstelle word in die studie gemaak ten einde bogenoemde probleme meer doeltreffend aan te spreek en daardeur die MIV-kwesbaarheid van die Sub-Sahara gemeenskap van Melbourne, Australië, te beperk.

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## **Chapter 1. Introduction**

The HIV epidemic in Australia is very different, both in nature and scale, from that which exists in sub-Saharan Africa (SSA). Specifically, the estimated national prevalence in Australia in 2011 was 0.11% compared with 17.30% in South Africa (Kirby Institute, 2012) and 4.9% across the SSA region as a whole (UNAIDS, 2012). Similarly, the annual incidence of HIV is correspondingly low with approximately 1,000 new infections being diagnosed on an annual basis, an age-standardised incidence rate of 4.5 per 100,000 population (Kirby Institute, 2012) (Australian Bureau of Statistics, 2013). This compared with approximately 205.0 per 100,000 population across SSA (UNAIDS, 2012) (World Bank, 2013). Further, the modes of HIV transmission that predominate in Australia differ markedly from those in SSA. Between 2007 and 2011, 63% of newly diagnosed infections in Australia were attributed to sexual activity between men (Kirby Institute, 2012), which contrasts with SSA where transmission is predominantly through heterosexual interactions (UNAIDS, 2012). However, while these differences are stark, the situations do not exist independently. Indeed, the latest annual surveillance report on the Australian epidemic reveals some distinct national characteristics that are linked directly to the epidemic in SSA (Kirby Institute, 2012).

While absolute numbers are relatively small, the incidence of new HIV infections in Australia occurs disproportionately in the population of sub-Saharan African (SSAn) origin. In 2010, the age standardised rate of new HIV diagnoses among Australian born residents was 4.0 per 100,000 population compared with 37.1 per 100,000 population among those born in SSA (Kirby Institute, 2012). In addition, the demographics of HIV in SSAn migrants mirror more closely those of the epidemic in SSA rather than those of the general Australian population (Lemoh, Baho, Grierson, Hellard, Street, & Biggs, 2010). This is reflected most clearly in the gender distribution of infection and mode of transmission to which infection is attributed. A relatively high number of infections in migrants of SSAn origin occur in females (51.6% - 2007-2011) while, in the general population, the preponderance of infections occur in men (86.3% - 2007-2011) (Kirby Institute, 2012). The latter figure is not unexpected as the primary mode of transmission in Australia, as previously stated, is through men who have sex with men (MSM). However, in the SSAn

migrant population, 79.7% of new infections are attributed to heterosexual contact (2007-2011) (Kirby Institute, 2012).

While it may be expected that recent immigrants from a high prevalence area display the health profile characteristics of that region, the situation relating to Australia is complicated by the immigration policies of the country. Controversially, it is a legal requirement that all migrants seeking permanent residency in Australia, and some entering the country temporarily, be tested for HIV prior to acceptance into the country. Those individuals testing positive (with the exception of those granted refugee status), may be excluded from entry. While this health requirement can be waived on economic, social and/or compassionate grounds, a waiver is dependent on the visa type being sought and the circumstances of the individual (HIV/AIDS Legal Centre, 2012) (Australian Federation of AIDS Organisations, 2013). Data to understand the proportions of diagnoses occurring in migrants that arrive in Australia with a HIV-negative status and subsequently acquire the virus, and those who enter the country with a positive status and are diagnosed during subsequent migration screening or when they engage healthcare services is limited (Lemoh, Baho, Grierson, Hellard, Street, & Biggs, 2010).

However, it is clear that a sub-population of migrants exists within a very low prevalence country that may be both more vulnerable to HIV infection while resident in Australia than the wider population, and more likely to be HIV-positive on entry to the country. This higher prevalence in the SSAn-born population potentially threatens the low prevalence status of Australia generally and raises questions over the HIV/AIDS support services directed towards this community.

## **Chapter 2. Literature Review**

### **2.1 HIV and Migration in Sub-Saharan Africa**

Throughout the history of the HIV/AIDS epidemic, migration and population mobility have been significant contributory factors in the rapid spread of the virus and rise in number of infections (Decosas, Kane, Anarfi, Sodji, & Wagner, 1995) (Whiteside, 2008). Most catastrophically, this has occurred in SSA, the region in which 69% of the individuals living with HIV reside (UNAIDS, 2012).

Economic development and the subsequent movement of peoples from Central Africa, the region where the zoonotic transfer of HIV from primates into humans first occurred, began the process that has resulted in a global epidemic. The WHO estimate that generalised epidemics already existed in eleven countries in Central and Eastern Africa by the time the virus was identified in the early 1980's (Buve, 2006). The trans-continental spread of the virus has been associated particularly with certain population sub-groups.

Truck drivers and other mobile workers (such as itinerant traders) remain a focus of HIV prevention efforts as their sexual behaviours along major transport corridors (i.e. engagement in transactional sex) have been identified as a key mode of transmission, particularly in the propagation of the virus over large distances (Bwayo, et al., 1994). Indeed, it has been suggested that truck drivers acted as the primary vector for the virus moving, initially to East Africa, and subsequently to other African regions (Ramjee & Gouws, 2002). Consequently, populations intersecting with these groups, such as residents in border towns and communities close to major roads, have also been associated with higher rates of HIV (Brockhoff & Biddlecom, 1999) (International Organization for Migration, 2005).

The ability and necessity of individuals to leave communities in search of employment has also served as a significant contributory factor. Epidemiologists have shown how mass migration of predominantly male workers from southern African states to mines, farms and other industries in South Africa established conditions that facilitated rapid spread of sexually transmitted infections (STIs) (Whiteside, 2008). Specifically, these transient communities of largely young males

attracted a high density of commercial sex workers creating overlapping and concurrent sexual networks, an environment associated with the rapid transmission of HIV and other STIs (Mah & Halperin, 2010). Subsequently, in a pattern of recurrent circular migration, infected individuals from this migrant worker community spread the virus further when returning to their home communities (Beyrer, 2007) (Haour-Knipe, 2009) (Deane, Parkhurst, & Johnston, 2010). Contrary to the popular perception of some, African men and women do not have a higher number of sexual partners than other demographic groups. Rather, studies indicate that the higher rate of sexual concurrency that exists in SSA (such as that associated with migrant workers) is a key factor that distinguishes the epidemic here from that present in other regions and, at least in part, explains SSA's elevated prevalence (Beyrer, 2007) (Morris, Epstein, & Wawer, 2010).

Further, it has been suggested that the large numbers of migrant and transient workers in SSA also serve as a driver of HIV transmission within the rural communities from which they originate, and not simply due to onward transmission by returning infected workers. An analysis of discordant heterosexual couples in rural KwaZulu-Natal shows the female partner to be HIV-positive in approaching one-third (29%) of couples studied (Lurie, et al., 2003). On the basis that migrant workers are almost exclusively male, the proposed explanation for this finding is that some women who are left alone when male partners work away from home, seek other relationships for either financial or emotional support (Crush, Raimundo, Simelane, Cay, & Dorey, 2010).

As such, studies have shown that both migrant men and their partners have an increased risk of HIV in communities that donate significant numbers of migrant workers (Lurie, et al., 2003) (Corno & de Walque, 2012). This should be contrasted with mining areas employing mostly local workers (e.g. in Zimbabwe), where miners and their partners are not at increased risk of HIV infection compared to their non-mining counterparts (Corno & de Walque, 2012).

The era of HIV in SSA has also coincided with many African states enduring man-made or natural disasters such as armed conflict or famine. These circumstances result in large scale population mobility as families seek food sources or safe havens,

often with women and children travelling unaccompanied. Once again the conditions associated with increased risk of HIV transmission are created as incidences of sexual violence increase dramatically, poverty is ingrained and girls and women often resort to transactional sex as their only means of survival (Ateka, 2001).

Subsequently, post-conflict circumstances may further fuel economic migration as individuals seek employment opportunities no longer available locally (International Organization for Migration, 2009).

## **2.2 HIV and Migration in Other Developing Regions**

While the association between migration and HIV is discussed mostly in relation to the emergence of a generalised epidemic in SSA, it is not limited to this region. Population mobility remains a significant issue for many developing countries and regions that have, to date, experienced only limited epidemics restricted to high-risk groups (e.g. MSM or injecting drug users (IDUs)). As such, there are fears that the countries in these areas risk the emergence of a more widespread, even generalised, epidemic due to continued large scale migration (International Organization for Migration, 2009). For example, both China and India have successfully lifted significant proportions of their population out of poverty and created a burgeoning middle-class sector (Asian Development Bank, 2010). As a consequence, there is large-scale rural to urban migration, as those in the lower socio-economic classes seek employment to improve their circumstances. As an example, the Indian census of 2001 recorded 30% of the Indian population (307 million people) as migrants (International Organization of Migration, 2009). Therefore, while China and India currently experience centralised epidemics within certain sub-groups, there is the potential for the situation in SSA to be replicated, with migrants acting as the 'bridge population' for transmission of the virus into the wider community (Anderson, Qingsi, Hua, & Jianfeng, 2010) (Samuels & Wagle, 2011). Indeed, there are worrying indications that such circumstances are already developing.

In Mumbai, HIV prevalence in sex workers has reached 50%, indications are that 5-10% of truck drivers are infected and studies in mobile workers are beginning to indicate a link between migration and HIV transmission (International Organization for Migration, 2009). The impact of such a situation is far reaching. A study conducted in a number of villages in the Doti region of Nepal revealed 10% of

migrant workers to be HIV positive, all of whom had travelled to Mumbai in search of employment (Vaidya & Wu, 2011).

Elsewhere, a study in Russia has indicated that domestic population mobility was a factor positively associated with regional HIV prevalence (Moran & Jordaan, 2007), while the Sri Lankan Bureau of Health has collected data that suggests approaching half of all HIV infections in that country occur in migrant workers (International Organization for Migration, 2009).

Such indications are troubling, however absence of reliable data from the areas outside of SSA remains an critical issue. Better information is required to consolidate understanding of this phenomenon and enable the implementation of effective interventions in these regions (International Organization of Migration, 2009).

### **2.3 HIV, Migration and the Developed World**

A further element to consider in relation to global population mobility and the HIV epidemic is the migration of peoples from high to low prevalence countries, which typically equates to populations transitioning from developing to developed countries.

This phenomenon has been a characteristic of the epidemic since the virus was first identified in the United States, when a key sub-population associated with HIV infection was shown to be the migrant Haitian community (Carael, 2006). Indeed, the first link to the African origins of the virus came in 1983 when three AIDS patients from Central Africa were identified in a Belgian hospital in Brussels (Buve, 2006).

However, the increased accessibility to, and affordability of, international travel in recent decades has led to a greatly accelerated movement of peoples between countries for both economic and security reasons. The 4<sup>th</sup> World Migration Report published by the International Organization for Migration (IOM) (2008) estimated that in 2005 there were 200 million international economic migrants, with Europe and North America hosting 70 million and 45 million migrants respectively. Such large-scale migration leads to challenges within developed countries in regard to integrating an increasingly multicultural population. This is particularly true in relation to health needs, and the engagement of migrant populations with HIV/AIDS

education, prevention and treatment services remains a difficult issue (Healy & McKee, 2004).

The European Union first formally and collectively addressed the international impact of HIV within its region with the 2004 Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia. Subsequently, specific attention was drawn to migration, health and HIV in the Lisbon conference of 2007 and the EU has continued regular efforts to address this issue (European Centre for Disease Prevention and Control (ECDC), 2009). Further international collaboration has followed including a joint satellite session at the International AIDS Conference of 2012 bringing together the ECDC, the IOM, the Public Health Agency of Canada and the United States Centers for Disease Control and Prevention for a session entitled 'Responses to HIV and migration in western industrialized countries: current challenges, promising practices, future directions' (European Centre for Disease Prevention and Control, 2013). These efforts have identified a number of barriers and challenges to addressing HIV in migrant populations from areas of high prevalence that appear to be somewhat common across 'recipient' countries. The single greatest challenge is that individuals from migrant communities do not readily access healthcare services and particularly those related to HIV/AIDS (Staehelein, Egloff, Rickenbach, Kopp, Furrer, & Swiss HIV Cohort Study, 2004) (African and Black Diaspora Global Network on HIV and AIDS, 2010). The barriers to individuals engaging services are several but can broadly be divided into those that are structural and cultural in nature (Soskolne & Shtarkshall, 2002).

Structural factors include uncertainty about legal status to remain in the country (particularly in the event of a positive HIV test), lack of health insurance or issues around affordability of healthcare, lack of health information in relevant languages and lack of healthcare professionals trained in culturally-appropriate service provision (European Centre for Disease Prevention and Control, 2009).

Cultural beliefs are equally relevant with the fear of stigma associated with disclosing a HIV-positive status being a pre-eminent factor. In addition, lack of knowledge regarding HIV and/or HIV services, and limited previous experience of using

healthcare services also contribute (European Centre for Disease Prevention and Control, 2013) (Soskolne & Shtarkshall, 2002).

In some countries, there may be issues for migrants in relation to the characteristics of the wider society within which they live. Racism or discrimination towards immigrants engenders feelings of isolation and further inhibits wider community engagement (including with health services) (African and Black Diaspora Global Network on HIV and AIDS, 2010). Finally, the socio-economic standing of the migrant community is frequently low when first arriving in a country, which in turn can contribute to further social exclusion (Soskolne & Shtarkshall, 2002).

The cumulative effect of these barriers to connecting with healthcare services is that late diagnosis of HIV is a recurring characteristic of the HIV epidemic within migrant communities in developed countries (Asante, Korner, & Kippax, 2009) (Alvarez-del Arco, et al., 2012). The consequence of late diagnosis is problematic for both the individual, their family and community, and the host country, as health outcomes are poorer and the economic burden to health services is significantly increased. As an example, a UK study investigating late diagnosis of HIV in heterosexual individuals between 2000-2004 indicated the proportion of individuals presenting late was highest in the black African population (43%). Further, it was estimated that early diagnosis could have prevented 249 early deaths in this cohort, a potential reduction in short-term mortality of 56% (Chadborn, Delpech, Sabin, Sinka, & Evans, 2006).

#### **2.4 Immigration to Australia and HIV**

Given the contribution globally of population mobility and migration to the emergence of the global HIV epidemic, and subsequently the impact of the movement of peoples from high to low prevalence countries, it is particularly interesting to explore the status of HIV in Australia, a low prevalence country overwhelmingly populated by a migrant community. In 2006, the indigenous community accounted for just 2.5% of the national population, with the remaining population comprising migrants or the descendants of those arriving since the first European settlement in 1788 (Australian Bureau of Statistics, 2007). There continues to be substantial migration to Australia with approximately 425,000 overseas arrivals in 2010-11 (Australian Bureau of Statistics, 2012).

Migrants from high prevalence HIV regions constitute an increasing proportion of the immigrant population with approximately 136,000 people from SSA arriving in the decade from 1997-2007. Within this total, the annual number of SSAns has risen steadily from 2000-01 onwards. In 2010, SSAn-born residents accounted for 1.3% the estimated resident population of Australia, with South Africa, Zimbabwe and Sudan being the highest contributing countries (Australian Bureau of Statistics, 2011).

The significance of immigration to Australia on this scale in relation to the local HIV situation is not immediately evident. Looking at summary data, any negative impact of migration on HIV prevalence in Australia is not apparent, with national prevalence remaining low (0.11%) and concentrated within the MSM population (Kirby Institute, 2012). While there has been an unwelcome increase in incidence since 2007, this has been linked to the increase in risky behaviours among the MSM community and not associated with a net influx of migrants (Kirby Institute, 2012). This is, perhaps, not unexpected when the health requirement element of Australia's immigration policy is taken into consideration. Specifically, migrants applying for permanent, or in some cases temporary, residency within Australia are required to take a HIV test and can be refused entry on economic grounds if found to be positive (HIV/AIDS Legal Centre, 2012). However, a closer evaluation shows that, despite this requirement, there are marked differences in HIV incidence across populations when divided by region of birth. In 2011, all populations born overseas had a higher incidence of HIV (as measured by age standardised rate per 100,000 population) compared with that reported for Australian born individuals (Kirby Institute, 2012). While the incidence in those born in Australia was 4.5 per 100,000 population, this increased to 8.6 per 100,000 population in those born overseas. The differences in incidence for those born in most regions were modest, however the incidence rate in those born in SSA was dramatically higher at 27.3 per 100,000 population. Further inspection reveals that this is not a single year anomaly with the mean annual incidence between 2007-2011 in those migrating from SSA being 31.9 per 100,000 population (Kirby Institute, 2012). While these rates equate to relatively small numbers of people (due to the low proportion of total migrants arriving from SSA), the difference compared to other demographic populations is clear.

This elevated incidence in this group is due to a combination of individuals who have become infected prior to entry into Australia and those that acquire the infection after their arrival. Data is scarce to inform the relative contributions, however a study of a small cohort of HIV-positive patients in Victoria (n=20) by Lemoh et al. (2010) found 35% of participants reported exposure to have occurred in Australia, while 40% reported exposure in their country of birth. The remaining participants did not indicate where exposure occurred or believed it to have happened in a third country. Timing of exposure was not recorded and so for those reporting exposure outside of Australia, it is not clear whether this occurred before or after the individual was resident in the country. Further study is required to understand this demographic aspect of the HIV-positive SSAn community better. It is clear, however, that in comparison to the Australian born population or those residents born in other regions of the world, the SSAn migrant community in Australia appears to be uniquely vulnerable to HIV.

## **2.5 Addressing HIV in the Sub-Saharan Migrant Community in Australia**

### **2.5.1 Federal and Local Government Response**

Historically and in international terms, Australia's response to HIV has been considered innovative and proactive, being based on strong leadership and a partnership approach involving state and federal governments, community organisations, clinicians and affected communities and individuals (Australian Federation of AIDS Organisations, 2002). However, a recent report by a coalition of national and state groups claims that efforts have slowed and opportunities to maintain a high-level response missed, including furthering engagement with high-risk populations, such as culturally and linguistically diverse (CALD) groups (AFAO, NAPWA, NATSIHA, ASWA, AIVL, 2012).

If these deficiencies exist, the greater issue appears to be implementation of effective interventions, rather than recognition of vulnerability within these populations. Indeed, a review of government policy reveals that, since 2002, successive national HIV/AIDS strategy documents issued by Australian Governments have nominated people from CALD backgrounds as a focus for HIV education, prevention and treatment programs (Australian Government Department of Health and Ageing, 2010). More specifically, the current document, the Sixth National HIV Strategy (2010-2013), identifies people from (or who travel to) high prevalence countries as

one of seven priority populations towards which the strategy is directed. The strategy outlines priority areas of action including that “HIV prevention must be focused on communities and populations most at risk and most affected by HIV” and that “more research on this priority population (i.e. people from high prevalence areas) is required, to inform tailored health promotion interventions”.

This National HIV Strategy links to the Second National Sexually Transmissible Infections Strategy (2010-2013) that sets out comprehensive guiding principles to underpin Australia’s response to HIV and other STIs including *inter alia* (Department of Health and Ageing, 2010):

- Active participation of affected communities
- Community ownership
- Application of law and public policy to encourage healthy behaviours
- Elimination of stigma and discrimination
- Partnership of governments, affected communities, researchers and health professionals
- A skilled and supported workforce.

Similarly, in Victoria (the state in which the current study was conducted), the state government strategy between 2002 - 2009<sup>1</sup> (Victorian Department of Human Services, 2006) identified the same high risk population proposing to implement strategies to:

- Develop health promotion programs to target people originating from countries with high prevalence of HIV and people who travel regularly to these countries
- Increase the capacity of culturally and linguistically diverse communities most affected by HIV/AIDS to contribute to policy and program development and implementation”

The statement of such intentions within overarching strategy documents is necessary to underpin efforts in these areas. However, it is the translation of such policies into

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<sup>1</sup> From 2010, the Victorian government adopted the national strategy previously described (Australian Government Department of Health and Ageing, 2010).

effective interventions that presents the most considerable challenge. Indeed, the Victorian government acknowledges this in the 2005-2009 addendum to its HIV strategy, noting that certain barriers exist inhibiting migrant communities engaging with HIV support and treatment services, and specifically citing language, cultural and cost issues as disproportionately affecting CALD groups (Victorian Department of Human Services, 2006). However, studies indicate that the barriers to migrant communities within Australia are more extensive still and fully reflect those identified within other developed countries.

### **2.5.2 Barriers to Addressing HIV in SSAn Migrant Community**

The Australian SSAn community face many challenges to effective engagement with healthcare services. Language barriers and the lack of culturally appropriate service provision are both major impediments in this regard (Australian Human Rights Commission, 2010). Elements of service provision that can assist CALD communities include multi-lingual information sources, provision of translators and interpreters, use of workers from local communities, mechanisms to ensure confidentiality and community involvement in designing education programmes (Australian Federation of AIDS Organisations, 2013). In 2006, the National Health and Medical Research Council (NHMRC) issued a guide to establish 'cultural competency in health' (National Health and Medical Research Council, 2006). This policy looks at cultural competency at an individual, organisational and systematic level emphasising the importance of partnerships in healthcare provision, both between service providers and with the communities they serve. The suggestion is that this can only be achieved effectively by underpinning cultural competence through 'systemic and organisational commitment and capacity' and the relevance to addressing HIV in CALD communities is clear. Similarly, the Victorian state government has issued a 'Cultural Diversity Guide' directed towards planning and delivering culturally appropriate programs (Department of Human Services, 2004). This guide recognises the distinct needs of individual communities, encourages partnerships between services, use of multilingual services and workers and seeks community participation. However, within HIV agencies, recent evaluations indicate that further work is required to improve the knowledge and skills to work with migrant groups (McMahon, Moreton, & Luisi, 2010). This is, perhaps, not unsurprising, as it can be reasonably expected that services and the skills of the service providers will

be directed most adequately to the needs of the majority of the HIV community, which in Australia is predominantly MSM of Caucasian origin (Kirby Institute, 2012).

The cost of accessing healthcare is a significant consideration for migrant communities, many of whom are from lower socio-economic groups. Those on temporary visas may not be eligible for the healthcare subsidies that are available as part of Medicare and the Pharmaceutical Benefits Scheme, while others may simply not be aware of their eligibility for these schemes (Australian Federation of AIDS Organisations, 2011). Even with these subsidies, costs are not insignificant and can be prohibitive in terms of seeking out services. (Asante, Korner, & Kippax, 2009).

HIV-related stigma remains an issue for all people living with HIV/AIDS (PLWHA) across Australia. A recent survey of 697 HIV-positive people revealed that 77% of respondents remained concerned about disclosing their status, 40% have been hurt by how other people have reacted to learning their status and 35% have, at some time, felt ashamed about being HIV-positive (Slavin, 2012). However, this appears to be magnified within the SSAn migrant community (Lemoh, Biggs, & Hellard, 2008). Fear of disclosure and the negative consequences that may result from within their own and the wider community prevents individuals seeking HIV-related services (African and Black Diaspora Global Network on HIV and AIDS, 2010). A New South Wales study surveyed 114 HIV-positive individuals from CALD (n=61) and Australian (n=53) backgrounds with regard to their concerns regarding HIV before being diagnosed. The level of concern from the CALD participants was greater in all areas compared to those with Australian backgrounds with the three most common fears (each experienced by over 50% of participants) being shame, other people knowing their status and rejection from their family. Studies also indicate that racism is commonly encountered by migrants and particularly by Australian Africans (AFAO, NAPWA, NATSIHA, ASWA, AIVL, 2012) (Bitu, 2010). A University of Western Sydney study in 2008 indicated that over 40% of Australians thought that some cultural groups 'do not fit into Australian society' while 27% expressed 'concern' about Black Africans (University of Western Sydney, 2008). In addition, the SSAn community has been stereotyped specifically as vectors of HIV, fuelled largely by disproportionate media attention towards criminal charges brought against African men regarding transmission of HIV (Australian Federation of AIDS Organisations,

2013). This combination drives social isolation, itself a significant barrier to engagement with healthcare services (Lemoh, Biggs, & Hellard, 2008) (Australian Human Rights Commission, 2010).

A further difficulty is that knowledge of HIV within the SSAn community in Australia remains inconsistent, with a lack of understanding relating to methods of transmission, consequences of infection and HIV protection strategies widespread (Drummond, Mizan, & Wright, 2008). Knowledge can also be grounded in an African context without comprehension of the differences that apply in Australia (Australian Federation of AIDS Organisations, 2013). An additional concern in terms of HIV prevention is that studies indicate that improvements in collective knowledge relating to HIV do not always translate into modification of individual behaviours among SSA communities (McMahon, Moreton, & Luisi, 2010) (Alvarez-del Arco, et al., 2012). As a consequence, risk levels remain high, the recognition of health signals indicating HIV infection is limited and, as will be discussed, late presentation at services is common (Asante, Korner, & Kippax, 2009).

Finally, the Australian Government's immigration process stipulates health criteria for entry into the country and controversially requires all migrants to undergo a HIV test. As a basic principle, those testing positive will be denied entry, largely on the basis of economic cost to the country. However, for some visa classes there is an opportunity to apply for a waiver to the health requirements on the basis of economic, social and/or compassionate mitigations (HIV/AIDS Legal Centre, 2012). Each application is considered on its individual merits and, in the majority of cases (>95%), applicants are successful (Australian Federation of AIDS Organisations, 2013). In 2008-09, 59 health waivers were granted to HIV-positive applicants (Bitu, 2010). However, the health waiver is not available to all visa types, the process is time consuming and not easily understood (particularly by those with low English language or literacy skills) and the costs for legal and medical support for an application can be significant. As such, human rights groups and advocates for PLWHA campaign for the removal of this mandatory HIV test, as this health requirement element of Australia's immigration policy itself provides a strong deterrent to healthcare access. Migrants who develop symptoms or suspect they may have been exposed to HIV are reluctant to seek testing or treatment through fear their residency status may be jeopardised (Korner,

2005) (Australian Federation of AIDS Organisations, 2011) (AFAO, NAPWA, NATSIHA, ASWA, AIVL, 2012). Further, a lack of understanding of the migration procedures leads to a misperception among some that all Africans entering Australia are HIV-negative and therefore, there is no risk of transmission (Australian Federation of AIDS Organisations, 2013). Finally, it is claimed that the health requirement, as it applies to people with HIV, is incompatible with Australia's own legislation against discrimination of the disabled (Disability Discrimination Act 1992) and does not meet international human rights standards and best public health practice (Australian Federation of AIDS Organisations, 2011). In January 2010, the United States removed HIV screening as part of its immigration procedure (Centers for Disease Prevention and Control, 2010), and most EU nations generally do not restrict the entry of individuals on the basis of HIV status (Alvarez-del Arco, Monge, & Caro-Murillo et al., 2013). Therefore, it would appear that Australia lags behind recognised international standards in respect of this aspect of migration policy and HIV, being aligned more closely with many less progressive nations within the Middle-East and Asia regions (CARAM Asia, 2013).

As recognised within other developed countries, the barriers to SSAn and other migrant communities accessing HIV services within Australia, and challenges faced by the providers themselves in engaging this community has led to a high frequency of late diagnosis. In 2006, national surveillance statistics indicated that 60% of HIV infections identified in those born in SSA, Asia and Europe (non-UK and Ireland) were diagnosed late compared to 40% of infections diagnosed in those born in Australia (NCHECR, 2006). A review of delayed HIV diagnosis in Victoria between 1994 and 2006 indicated birth in the Horn of Africa to be an independent risk factor for delayed diagnosis (Lemoh, et al., 2009). More recently, a Sydney study demonstrated that approaching two-thirds of participants from CALD communities presented late for diagnosis compared to around 50% of those with an Australian background (Asante, Korner, & Kippax, 2009). As previously discussed, timely diagnosis is essential for securing improved health outcomes, minimising the likelihood of onward transmission and reducing the cost and practical burdens on service providers (Lemoh, et al., 2009).

These difficulties in engaging migrants, and particularly the SSAn community, are reflected in the national statistics. Despite national and state policies over the last decade recognising the importance of addressing HIV in CALD populations, the incidence of HIV diagnoses in SSAn migrants between 2007-2010 continued to rise, increasing by around 33% over this period. There was a slight reduction between 2010 and 2011, however, it is yet to be confirmed if this marks a reversal of the previous trend and/or can be attributed to an effective implementation of the 2010 national strategy in this sub-population (Kirby Institute, 2012). Whatever the situation statistically, the literature suggests that a gap remains between stated aims of national and local policies directed toward CALD communities and effective implementation in regard to the SSAn migrant population.

While the situation is a complex one, it is clear that, for an effective response to the disproportionately high incidence within this vulnerable population, policy goals must be translated into local provision of HIV services that are fully accessible to the SSAn community. This includes programs delivering education, prevention, treatment, support and care services to PLWHA and their families. Key factors include location, cultural acceptability, protections around confidentiality, provision of language services and affordability. This study aims to investigate the nature of HIV education services in Melbourne, Victoria and their suitability and accessibility to the SSAn community.

## Chapter 3. Research Methodology

### 3.1 Research Problem

The elevated incidence of HIV within SSAn migrants stands as an anomaly within the wider Australian population, the rate of new HIV diagnoses over the last five years (age standardised rate per 100,000) being at least 2.5-3.0 times higher than that observed in the Australian born population or any other regional migrant group (Kirby Institute, 2012). Australian immigration policies are complex and have varied requirements in term of HIV testing. All individuals seeking permanent residency within Australia are required to be tested for HIV and HIV-positive individuals may be denied residency. However, those individuals granted refugee status and, depending on the visa being sought, HIV-positive migrants providing appropriate economic, social and/or compassionate justification will have this health requirement waived. Migrants entering the country on temporary visas may not be required to undergo a HIV test prior to entry. While data is limited, one study suggests that approximately equal proportions of SSAn individuals diagnosed are exposed to the virus in Australia and in their country of birth (Lemoh, Baho, Grierson, Hellard, Street, & Biggs, 2010). However, no data could be found to indicate whether exposure in the country of birth is more likely to occur before or after migration.

Federal and government policies have, since at least 2002, identified culturally and linguistically diverse populations from high prevalence countries as uniquely vulnerable to HIV (Australian Government Department of Health and Ageing, 2010), however the high incidence of diagnoses in SSAn migrants has continued (Kirby Institute, 2012). Factors that may contribute to this phenomenon are a lack of HIV-related knowledge among this sub-population and the willingness and/or ability of this community to engage with HIV education and support services. The literature indicates that SSAn communities within developed countries have limited health literacy and face many barriers to engagement with service providers in this area. This raises the question as to the availability and accessibility of HIV education and support services to this population in Australia. Further, if services are available, are they well targeted to this community and what is the level of uptake? The majority of Australia's African born population reside in the metropolitan centres of mainland Australia with approximately one quarter living in each of Sydney (27.7%) and

Melbourne (24.0%) (Australian Bureau of Statistics, 2008). As a major centre for SSAn migrants, this study will review HIV education and support services in Melbourne.

### **3.2 Research Question**

In relation to SSAn migrants, what is the availability, accessibility and uptake of HIV education and support services in Melbourne, Australia?

### **3.3 Study Significance**

This study seeks to understand better the HIV education and support services within Melbourne, Australia as they relate to and impact on the SSAn migrant community. The general thesis of the study being to identify the scope to improve HIV education services as a tool to mitigate against the higher incidence of HIV in this population within Melbourne, and potentially, Australia more widely.

With only a minority of the indigenous population remaining, Australia overwhelmingly comprises migrant populations (Australian Bureau of Statistics, 1995) and, therefore, HIV education must be effective across a diverse range of ethnic groups. Melbourne is home to significant numbers of migrant ethnic populations including the second largest African-born population in Australia (Australian Bureau of Statistics, 2012).

The study will review availability of services in Melbourne, their accessibility to those of SSAn origin, the nature of services provided and level of uptake by members of that community. Evaluation will be based on comparison to documented best practices in delivering HIV services to migrant populations including Australia's human rights obligations under international conventions. The characteristics of successful programs will be identified and, if deficiencies exist at any of those levels, recommendations will be made for improvements in specific areas. The potential significance of this study is that by identifying ways in which the HIV education programs and support services in Melbourne can be enhanced as they relate to SSAn migrants, providers can improve services to better address the infection rates in this community. Further, these findings may be applicable across other regions in Australia and can be communicated more widely.

In addition, a review of services will provide important information to migrant support organisations as to where most appropriate HIV education services can be accessed, potentially enabling a larger number of migrants to engage with effective service provision. Finally, the mapping of service provision may also facilitate collaboration and knowledge sharing between providers.

### **3.4 Aim & Objectives**

The aim of this study was to investigate the availability, accessibility and uptake of HIV education and support services to SSAn migrants in Melbourne, Australia in order to understand the scope for improvement of these services to this high prevalence sub-population.

To achieve this aim the objectives were as follows:

- To review the nature of key HIV education services provided in Melbourne
- To establish the accessibility of those HIV education services to the SSAn migrant population of Melbourne
- To assess the uptake of key HIV education services by the SSAn migrant population of Melbourne

### **3.5 Research Methodology**

This study is a predominantly qualitative design based on content analysis of interview responses received from key individuals working for HIV education service providers. A structured approach was used investigating the availability, accessibility and uptake of HIV education services within a 5km radius of the central business district of Melbourne, in relation to the local SSAn migrant community.

The location and nature of HIV education services in Melbourne was established through a combination of web and literature search and interview with organisations representing and providing services to people living with HIV/AIDS. The interviews facilitated an element of snowball sampling as interviewees identified additional organisations working within the HIV education space that were approached later in the study. Organisations were eligible for inclusion if a fundamental element of their service provision was deemed to be HIV education. Organisations interviewed included primary healthcare facilities, secondary and tertiary healthcare providers, private specialist clinics, and organisations supporting SSAn migrants and/or

PLWHA. Ten interviews were conducted and these organisations included all institutions cited as key service providers within the Victorian HIV/AIDS Strategy (Victorian Department of Human Services, 2006) i.e.:

- Victorian AIDS Council/ Gay Men's Health Centre
- People Living With HIV/AIDS Victoria (now Living Positive Victoria)
- Melbourne Sexual Health Centre
- Victorian HIV/AIDS Service (Alfred Hospital)

The general practitioner (GP) surgeries included in the cohort of interviewees were limited to those including physicians with S100 prescribing status, a designation within Australia awarded to medics trained in the prescribing of certain groups of highly specialised drugs. The prescription of antiretroviral medications to treat HIV in Australia is restricted to physicians with S100 training and therefore, those seeking HIV treatment must attend surgeries or institutions with this capability.

Once HIV education providers had been identified, a key individual(s) was identified and approached to participate in the study. Written informed consent was gained prior to commencing the interview. A structured interview was conducted to establish the nature of the services provided (see Appendix 1). The interview explored general characteristics of the service and more specifically how the services provided are directed to the migrant community, focussing on those from the SSAn region. The structure and content of the interview was designed to understand those elements of service provision that would facilitate or hinder accessibility to services by this sub-population (e.g. language, location, cultural norms etc.). In addition, an indication of uptake by individuals of SSAn origin was gained. The structure of the interview ensured that consistent information was gained across all service providers, while giving the interviewees scope to provide more expansive comments and a narrative to understand the context and nuance of the information provided.

Qualitative information collected during the study interviews was recorded, coded and categorised and six emergent themes were derived relating to the nature and effectiveness of services as they apply to individuals of SSAn origin. These codes, categories and themes were captured in an electronic 'code book' presented in an MS Excel workbook. This thematic approach sought to understand key trends within

and across HIV education service providers relating to the barriers that exist to engaging the SSAn community and successful strategies used to overcome these barriers. Some overlap and duplication existed between themes with some information categories informing multiple themes. A limited quantitative analysis of the nature of services across providers was also conducted.

From the data and information collected, the availability, accessibility and uptake of HIV education was reviewed and compared to best practice protocols related to HIV service provision to migrant populations. Where appropriate, recommendations were made as to how services can be improved.

The study design possesses both phenomenological and ethnographic elements as it seeks to understand the 'lived experience' of the migrant community in Melbourne in relation to engagement with HIV education services (Christensen, Burke Johnston, & Turner, 2011).

### **3.6 Ethical Considerations**

The two key areas for ethical consideration in the conduct of the proposed study related to:

- Engagement with HIV education and support service providers
- The nature and handling of the data obtained from organisations and individuals.

In relation to these areas and to protect the interests of all parties involved in the study, the following principles were strictly adhered to:

**Informed consent:** Written informed consent was obtained from all prospective participants in the study in advance of their participation. Information sheets were prepared detailing the aims of the study, exactly how the study was to be conducted and how the information collected will be used and published.

**Anonymity:** Permission to use the names and affiliation of individuals representing service provider or representative organisations was sought. If declined, these sources are to be referenced anonymously. While, only one individual sought anonymity, the names of all representatives have been withheld in this report.

Individuals are identified only by the organisation they represent and their role within that organisation.

**Confidentiality:** All information has and will continue to be treated confidentially and only published with the consent of the individual involved. No personal information was collected.

**Right to refuse or withdraw:** All participants or prospective participants had the right to refuse to participate or withdraw their participation at any time, without providing a reason and with no consequence. No individuals exercised this right.

**Privacy:** All participants were entitled to and received privacy during the conduct of the study.

**Data Storage and Dissemination:** All research information is stored securely with access provided only to designated researchers. Electronic information is password protected. The results of the research are to be used only for the purposes of the lead researcher's MPhil academic endeavours and not distributed outside of the Faculty of Economic and Management Sciences without prior consent obtained from participants.

The Research Ethics Committee of the University of Stellenbosch approved the research proposal on 21 October 2013 prior to the commencement of the study (Appendix 2).

## Chapter 4. Results and Discussion

### 4.1 Identification of HIV Education and Support Service Providers

The process of identification of HIV education and support service providers was initially conducted through a web search and continued as additional service providers were identified by interviewees. Through this process 16 providers were identified that include HIV education as a fundamental element of service delivery and are based within a 5km radius of Melbourne's central business district (Table 1)

**Table 1: Organisations Identified as Providing HIV Education and Support Services within Melbourne, Australia**

Organisation	Website
Victorian AIDS Council/Gay Men's Health Centre	<a href="http://www.vicaids.asn.au">www.vicaids.asn.au</a>
Living Positive Victoria	<a href="http://www.livingpositivevictoria.org.au">www.livingpositivevictoria.org.au</a>
Positive Women	<a href="http://www.positivewomen.org.au">www.positivewomen.org.au</a>
Straight Arrows	<a href="http://www.straightarrows.org.au">www.straightarrows.org.au</a>
Multicultural Centre for Women's Health	<a href="http://www.mcwh.com.au">www.mcwh.com.au</a>
Multicultural Health and Support Service	<a href="http://www.ceh.org.au/mhss">www.ceh.org.au/mhss</a>
Melbourne Sexual Health Centre	<a href="http://www.mshc.org.au">www.mshc.org.au</a>
Northside Clinic (Fitzroy)	<a href="http://www.northsideclinic.net.au">www.northsideclinic.net.au</a>
Prahran Market Clinic (Prahran)	<a href="http://www.prahranmarketclinic.com">www.prahranmarketclinic.com</a>
Victorian HIV Consultancy (Victorian HIV/AIDS Service – Alfred Hospital)	<a href="http://www.alfred.org.au">www.alfred.org.au</a>
HIV CALD Service (Victorian HIV/AIDS Service – Alfred Hospital)	<a href="http://www.alfred.org.au">www.alfred.org.au</a>
HIV Service (Victorian Infectious Disease Service – Royal Melbourne Hospital)	<a href="http://www.vids.org.au">www.vids.org.au</a>
HIV Disease Unit (St Vincent's Hospital)	<a href="http://www.stvincents.com.au">www.stvincents.com.au</a>
CatholicCare's Catholic HIV/AIDS Ministry	<a href="http://www.ccam.org.au">www.ccam.org.au</a>
Royal District Nursing Service (HIV/AIDS Team)	<a href="http://www.rdns.com.au">www.rdns.com.au</a>
Youth Empowerment Against HIV/AIDS	<a href="http://www.redaware.org.au">www.redaware.org.au</a>

Of these 16 providers, key personnel were identified in 12 organisations and each was contacted by telephone and/or email and invited to participate in the study. Ten organisations participated in the study (62.5% of organisations identified), one did not respond to the approach and one was unable to arrange a convenient time for an interview. Nine of ten interviews were conducted in person with the remaining interview conducted by telephone. The duration of interviews ranged between 25 and 105 minutes with the mean duration being approximately 75 minutes.

While it would have been preferable to interview members of every organisation identified, the organisations that participated in the study are considered a representative sample of the HIV education service providers in Melbourne. These organisations comprise education/support/advocacy organisations for PLWHA and primary, secondary and tertiary healthcare providers; represent organisations addressing specialist HIV/AIDS needs and those providing mainstream healthcare; and involve organisations representing all interest groups (e.g. gay men, women, heterosexual PLWHA), including all identified services specifically directed to culturally and linguistically diverse (i.e. migrant) communities.

#### **4.2 Characteristics of HIV Education and Support Services**

Through web search and the structured interview process, core information was obtained from all organisations with regard the general nature of service provision and some specific details in relation to services directed toward to the SSAn community. These profiles are summarised in Table 2 and Table 3.

Of the ten organisations interviewed, seven organisations (60%) provide services only directed to people living with or affected by HIV/AIDS, while all others have broader healthcare agendas. Five of the organisations (50%) have services specifically targeting to the welfare of migrant communities (including the SSAn community) all of which offer interpreter services and outreach programs to these communities. Some other strategies used by these organisations to facilitate service provision to the SSAn community include the provision of multilingual educational and information materials, and the employment of staff from the community.

**Table 2: Profile of HIV Education and Support Service Providers in Melbourne (General Service Provision)**

Organisation	Interviewee (Role in Organisation)	Services Provided	Focus of organisation	Specialist HIV Provider
<b>Victorian AIDS Council/Gay Men's Health Centre</b>	Partnership Program Leader	<ul style="list-style-type: none"> <li>- Testing &amp; counselling</li> <li>- Financial &amp; legal assistance</li> <li>- Peer education &amp; outreach</li> <li>- Medical services</li> <li>- Resources and links to other service providers</li> </ul>	All PLWHA in Victoria with a strong focus on gay men	Yes
<b>Living Positive Victoria</b>	Executive Officer	<ul style="list-style-type: none"> <li>- Health promotion &amp; advocacy</li> <li>- Peer education &amp; support</li> <li>- Financial &amp; legal assistance</li> <li>- Resources &amp; links to other services and groups</li> </ul>	All PLWHA in Victoria	Yes
<b>Positive Women</b>	Executive Officer	<ul style="list-style-type: none"> <li>- Health promotion &amp; advocacy</li> <li>- Prevention through education</li> <li>- Peer support</li> <li>- Resources and links to other organisations</li> </ul>	Women living with HIV	Yes
<b>Multicultural Centre for Women's Health</b>	Health Promotion and Research Project Officer	<ul style="list-style-type: none"> <li>- Advocacy &amp; social action</li> <li>- Multilingual education</li> <li>- Research</li> <li>- Capacity building</li> </ul>	Wellbeing of immigrant and refugee women across Australia	No

Organisation	Interviewee (Role in Organisation)	Services Provided	Focus of organisation	Specialist HIV Provider
<b>Multicultural Health and Support Service</b>	- Manager - Sector Development & Policy Officer	- Community support (information, counselling, links to services) - Community education - Community engagement - Training to mainstream health providers	Refugee and migrant communities in the areas of sexually transmissible infections and blood-borne viruses	No
<b>Melbourne Sexual Health Centre</b>	Physician	- Testing and treatment of STIs - Information resources and education	All PLWHA	No
<b>Northside Clinic</b>	General Practitioner x 2	- General medical practice - Specialisation in HIV/AIDS and STIs	All community members	No
<b>Victorian HIV Consultancy</b>	Clinical co-ordinator	- Care of PLWHA	All PLWHA with focus on those less connected to mainstream services (e.g. rurally located, aging, CALD PLWHA)	Yes
<b>HIV CALD Service</b>	Co-ordinator	- Individual support of CALD PLWHA	CALD community members living with HIV/AIDS	Yes
<b>Royal District Nursing Service (HIV/AIDS Team)</b>	Clinical Nurse Consultant	- Support for PLWHA, family and carers - Nursing care & links to other healthcare providers - Information and education	All PLWHA	Yes

**Table 3: Profile of HIV Education and Support Service Providers in Melbourne (Services to SSAn Community)**

<b>Organisation</b>	<b>Specific Service to SSAn Community</b>	<b>Multilingual educational materials</b>	<b>Dedicated Multicultural staff</b>	<b>Use of Interpreters</b>	<b>Outreach to SSAn Migrant communities</b>	<b>Uptake by SSAn Community</b>
<b>Victorian AIDS Council/Gay Men's Health Centre</b>	No	Limited	No	No	No	Limited
<b>Living Positive Victoria</b>	No	No	No	No	No	Limited
<b>Positive Women</b>	No	No	No	No	No	Limited
<b>Multicultural Centre for Women's Health</b>	Yes	Yes	Yes	Yes	Yes	Yes
<b>Multicultural Health and Support Service</b>	Yes	Yes	Yes	Yes	Yes	Yes
<b>Melbourne Sexual Health Centre</b>	No	No	No	No	No	Limited
<b>Northside Clinic</b>	No	No	No	Yes*	Yes	Yes
<b>Victorian HIV Consultancy</b>	Yes	Yes (via HIV CALD service)	Yes (via HIV CALD Service)	Yes	Yes	Yes
<b>HIV CALD Service</b>	Yes	Yes	Yes	Yes	Yes	Yes
<b>Royal District Nursing Service (HIV/AIDS Team)</b>	Yes	No	No	Yes	Yes	Yes

\* Statewide interpreter service employed but reportedly never used by SSAn patients due to confidentiality concerns.

All organisation representatives were asked for their opinion as to the whether they saw meaningful uptake of their service by the SSAn community. The opinion of all representatives was that engagement with this community was challenging and uptake sub-optimal, however six representatives (60%) felt that there was substantive uptake of the services of their organisation by the SSAn community. Not unexpectedly, this included all organisations targeting their services to migrant communities and also the Northside Clinic, a general practitioner surgery that includes the management of HIV/AIDS and STIs as a specialty service. Those specialised HIV/AIDS and sexual health service providers that direct their activities only to a broader HIV/AIDS community are least successful in engaging the SSAn community.

### **4.3 Thematic Analysis**

Analysis of the interview responses revealed seven overlapping and linked themes describing key elements of the HIV education and support service provision to the SSAn community in Melbourne.

1. Structural barriers to SSAn migrants accessing HIV education and support service providers exist at multiple levels.
2. Cultural norms within the SSAn migrant community inhibit individuals engaging with HIV education and support service providers.
3. HIV education and support service provision to the SSAn community within Melbourne is fragmented, under-resourced and lacks co-ordination or collaboration.
4. The nature of the HIV epidemic in Australia can lead SSAn individuals towards more risky sexual behaviours.
5. Effective service provision to SSAn migrants recognises the contextual needs of the individual in their specific situation.
6. Service provision to SSAn migrants benefits from working within the community and using staff from multicultural backgrounds.

The themes identified are inherently interlinked but can be separated broadly into the barriers preventing effective engagement with the SSAn community in regard to HIV education and support (themes 1-4), and strategies that are successful in minimising or overcoming those barriers (themes 5-6).

## **Theme 1: Structural barriers to SSAn migrants accessing HIV education and support service providers exist at multiple levels**

### **A. MSM Focus of Key HIV Education and Support Service Providers**

As previously stated, the HIV epidemic in Australia has very different characteristics to that which exists in SSA. A key differentiator is that the Australian epidemic is highly centralised among the male homosexual community with 86% of newly acquired infections diagnosed between 2007-2011 attributed to exposure through sexual interaction between men (Kirby Institute, 2012). Not unexpectedly therefore, the service provision to people infected and affected by HIV/AIDS living in Melbourne is necessarily directed to the MSM community.

*“Our clients are overwhelmingly gay men”*

*“Most of our services are directed towards gay men”*

This focus is most obviously reflected in the name of the largest HIV education and support service provider within Melbourne and the state of Victoria, the Victorian AIDS Council/ Gay Men’s Health Centre. While this organisation acts as the overarching body within Victoria, providing services to all people affected by HIV/AIDS, its name, employees, marketing materials and activities reflect a clear focus toward supporting the gay, lesbian, bisexual and transgender (GLBT) community. In relation to this study, it is notable that the most recent strategic plan (2012-2016) of the organisation makes no reference to addressing the needs of the CALD community. Similarly Living Positive Victoria, the peak education, support and advocacy body for PLWHA, acknowledges that the majority of services target gay men.

As would be expected, funding to support HIV education and support services is correspondingly directed to those agencies focusing on the MSM community. If we consider the HIV education, health promotion and advocacy organisations interviewed (as opposed to the treatment and care services) – all of which rely on state or federal governmental grants - the latest publicly available annual reports indicate that the Victorian AIDS Council/ Gay Men’s Health Centre and Living

Positive Victoria receive significantly greater funds than those organisations representing other community sectors (Table 4).

**Table 4: Revenue of HIV Education, Health Promotion and Advocacy Organisations as Stated in the Most Recently Published Annual Reports**

Organisation	Revenue (AU\$)
Victorian Aids Council/ Gay Men's Health Centre (2013)	\$6.1 million
Living Positive Victoria (2013)	\$960,000
Multicultural Centre for Women's Health (2012)*	\$1.1 million
Positive Women (2012)	\$303,000
Straight Arrows (2008)	\$164,000

\* This funding covers a wide range of non-HIV/AIDS related health services for CALD women.

It is clear that a national HIV/AIDS response must be targeted towards the groups most at risk and therefore, this MSM focus of service provision and associated funding distribution is fully justified. However, while it is understood that no service provider interviewed actively excludes individuals from migrant communities, it must be recognised that services that are culturally appropriate to a largely Caucasian and male homosexual community are unsuitable or unattractive to most individuals from those migrant communities. And this is particularly true when considering those individuals of SSAn origin.

Most recent data (2007-2011) indicates that infections within the Australian SSAn community occur approximately equally between men and women and are overwhelmingly attributed to heterosexual contact (Kirby Institute, 2012). Therefore, services directed towards MSM are practically inappropriate for most people from the SSAn community.

In addition, and perhaps more importantly, a service that overtly links to the gay community is not sensitive to the cultural norms within communities of African origin. Many SSAns link homosexuality or same-sex sexual interactions with immorality, promiscuity and criminality, a perspective often embedded through the political, cultural and/or religious norms of their country of origin (Dodds, 2006). Therefore, for any individual, engagement with such services is unlikely for fear of the stigma that may be experienced if this association became known within their community.

*“We would like to work with more members of the migrant community, but our GLBT focus acts as a deterrent”*

Further, and as a result of these cultural perspectives, MSM of SSAn origin often do not identify themselves as homosexual, will also have sex with women and may be married and have children (Anova Health Institute, 2011). As such, they do not identify with the term “gay” or the associated culture, and their sexual activities with other men remain clandestine and hidden (Rebe, De Swardt, Struthers, & MacIntyre, 2013). This perspective contrasts with the culture of the homosexual community presented within MSM focussed service providers (and more broadly across public Australian life), which promotes an open community where individuals are supported in disclosing their sexual orientation (i.e. the “Gay Pride” culture). Therefore, while these service providers focus on the MSM community, they do not present an attractive environment to SSAn MSM.

The barriers to better engaging with the migrant community are well understood within the MSM focused service providers, and there is a desire to address the issues. For example, consideration is being given to removing “Gay Men’s Health Centre” from the title of the Victorian AIDS Council. However, the greater obligation seems to reside with providing a service to the majority of PLWHA i.e. MSM. As a result, a degree of frustration towards this specific focus was expressed during interviews with some representatives of organisations supporting other community sectors.

## **B. HIV/AIDS Focus of HIV Education and Support Service Providers**

Similar to the issues facing providers linked with the homosexual community, but perhaps more fundamental still, is that many providers explicitly and, not unsurprisingly, reference their focus on HIV/AIDS. Stigma towards HIV is endemic in many SSAn countries and remains highly prevalent within Australian communities of SSAn origin (Lemoh, Biggs, & Hellard, 2008). As such, the reference to HIV/AIDS services in the name or mission of an organisation can present a major structural barrier.

All providers understood this issue and recognise that many individuals are reluctant or refuse to engage with HIV-related services for fear of disclosure of their HIV-positive status or, in the case of preventative programs, others thinking, by association, that they are HIV-positive or engage in perceived 'immoral' behaviours.

It is interesting to note that four of the six organisations from which representatives felt there was substantive uptake of services by individuals from the SSAn community (Multicultural Centre for Women's Health, Multicultural Health Support and Services, Northside Clinic and the Royal District Nursing Service) provide a wider range of health services and do not reference HIV/AIDS in the organisation name.

*"A culturally sensitive HIV/AIDS program [to the SSAn community] would not include HIV or AIDS in its title"*

Representatives from these organisations all felt that the ability of an individual to attend and use the services without any obvious association to HIV/AIDS (if recognised by another member of the community) was a key element, providing confidence and comfort to clients and patients.

The other organisations successfully engaging with SSAn individuals (Victorian HIV Consultancy and HIV CALD Service) have a HIV focus, however both take multiple precautions to restrict public awareness of the nature of the services and protect individuals e.g. discreet signage, business cards that avoid reference to HIV/AIDS, home or external visits and meetings. Even so, the HIV CALD service is considering

removing HIV from its official title. Similarly, an understanding of this issue was a contributory reason for Living Positive Victoria changing its name from People Living With HIV/AIDS Victoria in 2012.

The Royal District Nursing Service has experience that stigma of association with HIV sometimes presents difficulties in maintaining contact with clients. Therefore, the team will link individuals to non-related services (e.g. nutrition or housing programs) in order to retain a path of communication to be able to continue to monitor the wellbeing of clients.

*“We will link with people in any possible way to keep contact. This is not always through the HIV sector – in fact may Africans refuse to use these services”*

### **C: Concerns Regarding Legal Status**

The health requirements relating to HIV for immigrants are complex and confusing and many members of SSAn community (and Australian health care workers) do not fully understand the mechanism used to grant or deny visas to PLWHA (HIV/AIDS Legal Centre, 2012). Indeed, many believe that all PLWHA are excluded from settling in Australia (Victorian Department of Human Services, 2006). As a result, individuals will not engage with services for fear of jeopardising their right to remain in the country.

Most service providers recognise this issue and can provide or link to services that assist individuals through the requirements of the process. Treatment service providers such as the Melbourne Sexual Health Centre are able to provide medical reports to support visa applications while others can help with financial or legal assistance.

*“We have an important role to support clients from a legal perspective”*

However, providers agreed that the complexities of the process and the limited understanding within the SSAn community stand as a substantial deterrent to individuals seeking testing, treatment or other support services.

## **D: Concerns Relating to Cost of Services**

Many SSAn migrants enter Australia as refugees or with limited resources and have a low economic status in the community. Therefore, concerns exist about the financial burden of seeking healthcare, particularly in relation to the costs of antiretroviral drugs. Further, many individuals are unaware of their eligibility for Medicare, the Pharmaceutical Benefits Scheme or other government support that may be available.

In addition, there was a consensus among providers that many SSAns place their health as a lower priority than other financial obligations, particularly at a time of great turmoil such as migration and resettlement in a new country. Therefore, costs for other necessities, such as housing, food and clothing, may well be prioritised. This may be particularly true for women, who culturally are often expected to first attend to family “duties”.

*“Women’s health can be secondary to other settlement issues...required to meet the needs of the family.”*

Those providers involved in providing treatment and care services expressed particular concern towards this issue with many seeking to limit the cost burden to migrants.

*“There are issues around eligibility to Medicare...some local arrangements can be made, like compassionate supply of drugs, but no national mechanism of support exists.”*

*“We attempt to reduce costs by limiting the number of tests we do and scheduling joint visits with clinicians.”*

Some individuals seek their own solutions by attempting to obtain medications outside of the formal sector in Australia, which has obvious concerns relating to quality and counterfeit supplies.

*“People will import drugs online or have drugs sent from their home country.”*

The Melbourne Sexual Health Centre (MSHC) is the only service provider that is able to offer free medications and other physicians will often refer patients to the facility for that reason. However, as previously discussed, the sexual health focus of the MSHC and the preponderance of clients from the homosexual community can act as a deterrent to SSAn individuals attending the clinic.

*“Patients won’t go to the Melbourne Sexual Health Centre to collect their drugs”*

For some SSAn patients, care nurses are able to collect medications from the clinic on their behalf, however this is not seen as an adequate or sustainable solution.

Therefore, while *ad hoc* local solutions can sometimes be found, interviewees emphasised that difficulties remain in assisting SSAn individuals in this regard and improved systems of financial support for the poorest members of migrant communities are required.

#### **E: Language and Literacy Issues**

English is often not the first language of many SSAn migrants and English language skills are often absent or poor. Therefore, to provide effective HIV information and educational materials, it is necessary to use the first language of the individual.

However, only four of the providers interviewed (40%) provide multilingual educational materials and employ bilingual staff. The Multicultural Centre for Women’s Health has compiled the largest publicly available multilingual library of health information in the country (including HIV/AIDS related material), however no other providers of HIV education and support services have accessed this material.

Six providers (60%) use interpreters to deliver information. These services are mostly conducted by telephone to maintain the confidentiality of the individual. However, the small size of communities from SSA and the high degree of concern about disclosure ensure that concerns remain about recognition.

*“Our African patients will not use the interpreter service in case the interpreter knows them”*

In some cases this fear seems to be well founded as a number of service providers expressed concerns over the difficulties involved in recruiting interpreters that fully appreciate the importance of and adequately respect confidentiality.

*“It is difficult to find bilingual co-workers who understand confidentiality”*

*“Interpreters can feedback to the community...this maybe out of concern – ‘this child is sick, I must tell [her] Auntie’”*

*“Professionalisation of bilingual educators is required”*

Additionally, communities from SSA speak a number of different languages and dialects, compounding the difficulties in providing services in a first language. Further, members of the SSAn community may have low levels of formal education and so literacy may also be an issue. Positive Women reported some success with highly pictorial materials (with limited text) that reflected the experiences of women living with HIV. The Royal District Nursing Service has also used these materials effectively.

*“The stories...worked nicely with pictures...and allowed them to learn to read at their own pace.”*

#### **F: Location of services**

The location of services was recognised as an important issue, with the priority for SSAn individuals seen to be the ability to attend the service discreetly without the likelihood of meeting someone from their own community. As an example, the Northside Clinic had considered offering the convenience of a regular local clinic within a suburb where a number of their SSAn clients live. Patients rejected the proposal insisting that attending a clinic some distance from the local community was essential to maintain confidentiality.

*“This community doesn’t want a local service...for fear of recognition.”*

This was further emphasised as clinic staff reported SSAn clients actively seeking weekend or after-hours appointments in an attempt to avoid meeting other SSAns while attending the clinic.

*“There is a Somali – he never wants to see an African face”*

However, those services directed specifically to the multicultural community emphasised that the long-term solution was not to simply accommodate this perspective, but to work with communities to change these attitudes. This requires working physically within and in partnership with the community, while being respectful of cultural norms and perspectives. This will be discussed further in relation to theme 6.

**Theme 2: Cultural norms within the SSAn migrant community inhibit individuals engaging with HIV education and support service providers.**

It is clear throughout the discussion relating to structural barriers to the SSAn community (Theme 1) that most do not operate in isolation. Rather, it is that these aspects of the service provision combine with the characteristics of and perspectives within the SSAn community to present roadblocks to addressing the needs of the community. In particular, cultural norms and perspectives relating to HIV/AIDS, sexual practices, healthcare and gender roles differ markedly from those of the wider Australian community and influence decision-making and health-seeking behaviours.

**A: Stigma**

All providers of HIV services interviewed cited a pervasive stigma within the SSAn community as the greatest barrier to engaging with members of this community living with or affected by HIV/AIDS.

*“Stigma within the African community is our biggest issue”*

Stigma exists on a number of levels, however it is relation to HIV and homosexuality that has the greatest impact. Within the SSAn community, both HIV/AIDS and homosexuality are widely associated with immoral behaviour and promiscuity, and can lead to discrimination and ostracism by other community members (Victorian Department of Human Services, 2006). This is combined with close familial and social networks that rapidly facilitate the spread of ‘gossip’ within the community (Dodds, 2006). Consequently, there is a deep-rooted fear among PLWHA that engagement with services will lead to disclosure of their status within their

community, and this in turn often leads to a wider social isolation and associated mental health issues. This fear of disclosure extends to interactions between PLWHA within the same community.

*“We are aware of five Ethiopian HIV-positive women who all know each other and yet none are aware of the status of the others.”*

*“This is a contrast with Caucasians who will actively seek out people in a similar situation.”*

Also, for non-infected individuals there are concerns that through association with service providers, they will be presumed to be HIV-positive or accused of an ‘immoral’ lifestyle. The latter has significant implications in delivering HIV education and prevention services.

It is therefore not unexpected that those service providers that openly direct their activities towards PLWHA and/or the MSM community all reported minimal engagement with the SSAn community. Conversely, the specialist service providers to multicultural communities adopt an approach more sensitive to the ‘local’ culture, and seek to avoid and reduce the associated barriers.

*“It is important to understand what ethnic groups do at home. This allows us to introduce differences in a culturally sensitive way. For example, many African women do not understand why regular antenatal visits are required.”*

The Multicultural Centre for Women’s Health (MCWH) and Multicultural Health and Support Service (MHSS) both mainstream their HIV/AIDS services into a wider healthcare provision. This is effective in allowing individuals to safely attend the service locations without any obvious association with the disease. Similarly, the Northside Clinic is a general medical practice serving the whole community and is therefore able to effectively and discreetly offer and deliver specialist HIV services to SSAn individuals. The MCWH takes this concept further and does not offer education or information sessions that explicitly address the subject of HIV/AIDS (or other aspects of sexual health). These subjects are woven into broader topics such as

'Healthy Living' or 'Healthy Relationships'. In this way there is no deterrent to members of the SSAn community attending the sessions and the topics can be introduced "naturally" into the discussion and in terms that are comfortable to the attendees. Indeed, the attendees may choose to raise the subject themselves.

In addition, these providers adopt strategies to maintain confidentiality and provide the individuals with the confidence that their status will not be disclosed. These include ensuring that business cards and written materials provided to clients do not reference HIV and conducting visit at home or outside of the clinics (with some organisations also using unmarked vehicles).

The Royal District Nursing Service does not use the term 'HIV' internally but adopts a code – A100 – to maintain confidentiality while some organisations provide clients with cover stories to explain behaviours associated with managing their HIV. For example, the Victorian HIV Consultancy works closely with pregnant women and nursing mums who are HIV-positive. As part of the prevention of mother-to-child transmission protocol, HIV-positive mothers are required not to breastfeed. However, breastfeeding is expected in the SSAn community and serves as an indicator of status. Therefore, the consultancy looks to overcome questions that may arise by providing stories to explain the situation.

*"African women feel a sense of loss at not being able to breastfeed. We provide cover stories – their milk is not letting down or they are suffering from anaemia – to help her through this."*

Also, the HIV CALD Service employs bilingual co-workers to link with those individuals that feel socially isolated due to the fear of disclosure and discrimination. This provides someone who can, if necessary, communicate in their own language and also allows them to meet with someone from their own community and be open about their status without drawing unwanted interest. Any SSAn individual meeting with a Caucasian, say for coffee, may draw attention from other community members, whereas someone from same community does not attract the same interest. Of course, as with the use of interpreters, co-workers must be properly trained to maintain confidentiality.

A related aspect to the stigma within the SSAn community is the views that exist in the wider Australian community. Service providers acknowledged that racism remains prevalent within society and can be an added factor in excluding migrant community members from integrating more widely, including in terms of the use of community services.

### **B: Gender Inequality within the SSAn Community**

Communities of SSAn origin can be characterised by gender inequality reflecting the culture of their home countries. Male concepts of masculinity can be linked *inter alia* to dominance, power, sexual prowess and control. Consequently, women will fill subservient roles, may be subjected to sexual violence and will feel disempowered, particularly in relation to sexual encounters (WHO, 2013). These cultural characteristics present challenges to service providers in engaging with male members of the community and difficulties in effectively delivering safe sex messages.

*“It is a problem – how do these women disclose safely to potential sexual partners?”*

The empowerment of women in the migrant community to maintain their own health is central to the gender-specific focus of the Multicultural Centre for Women’s Health, and in the wider community, a focus for Positive Women. Also, the Northside Clinic ensures patients are gender-matched to their doctors to facilitate more open communication.

However, it is clear that challenges remain in overcoming gender inequality in SSAn communities and while it persists, the effectiveness of efforts to address HIV/AIDS will be significantly compromised.

### **Theme 3: HIV education and support service provision to the SSAn community within Melbourne is fragmented, under-resourced and lacks co-ordination or collaboration.**

Examination of the service provider organisations identified in Melbourne suggests that collectively a comprehensive suite of HIV-related services is available that addresses the needs of most community sectors (Table 5). However, the interviews

conducted during this study indicate that many service providers operate in relative isolation and collaboration is limited.

There is recognition by most providers that partnerships are beneficial and service provision could be enhanced through collaboration, and effective collaborations do exist. Living Positive Victoria, Positive Women and Straight Arrows achieve efficiencies by operating from the same location and have recently implemented a Joint Health Promotion Program. In addition, the HIV CALD service work closely with the Multicultural Health and Support Service and Positive Women are assisting with the training of bilingual educators at the Multicultural Centre for Women's Health.

The HIV treatment services are, perhaps, best connected, with hospital infectious disease clinics strongly linked to outreach services such as the HIV Consultancy, HIV CALD service and Royal District Nursing Service, however there is scope for much improvement in this area. The representative from the Multicultural Centre for Women's Health provided an example. The centre has identified that their education materials would be improved if content was added addressing elements relating to the treatment and management of HIV/AIDS, however this expertise was not available at the centre. This could be addressed relatively simply by linking with one of the treatment service providers, but no collaboration with providers in the sector currently exists. Perhaps most emblematic of this issue is that the Victorian AIDS Council chair a bi-annual inter-agency forum aimed at co-ordinating services, but the representative from the council expressed disappointment that its effectiveness was limited by poor attendance.

It is also interesting to note that organisations such as the Multicultural Centre for Women's Health, Multicultural Health and Support Service and the Royal District Nursing Services link effectively with other health and non-health services, while not collaborating extensively within the sector. The linkages outside the sector were emphasised as an important aspect, as many SSAs and their families will be experiencing multiple issues. For example, refugees may have difficulties dealing with past experiences (conflict or long periods in detention centres), financial challenges or even poverty are common, there may be uncertainty relating to migration and frequently settlement and housing issues must be addressed. This is in

addition to other health issues that may co-exist. Co-ordination with these service providers allows prioritisation of issues, assists in identification of inter-related problems and facilitates delivery of a more comprehensive, effective and efficient response. All benefits that could be further achieved by better links within the sector.

Another key issue is that most organisations interviewed operate with limited funding and resources. For example, the HIV CALD service has one only part-time (0.8FTE) employee and otherwise uses casual staff, Positive Women operates with only four part-time employees and Straight Arrows reportedly have only three staff. As a result, organisations are under-resourced, time-poor and the weight of core activities may not allow time and effort to be applied to establishing collaborative partnerships. This seems particularly true for those providers representing minority sections of the HIV community, such as the SSAn community. In addition, a view was expressed that some funding opportunities, particularly from the state government, are competitive and lead to organisations working separately to retain access to funds.

*“Competition among state funded organisation leads to vulnerability among organisations”*

However, representatives of other organisations felt this not to be the case and that collaborations would be favoured by funders.

*“Partnerships attract more funding...we must work together.”*

Also, and as previously discussed, there is some frustration that services directed to the MSM community dominate resources and public awareness.

*“HIV services are guarded by the homosexual community”*

**Table 5: Target Populations of HIV Education and Support Service Providers in Melbourne**

Organisation	Target Population
Victorian AIDS Council/Gay Men's Health Centre	All those affected or infected by HIV/AIDS Strong focus on MSM community
Living Positive Victoria	All those affected or infected by HIV/AIDS Strong focus on MSM community
Positive Women	Women living with HIV/AIDS
Straight Arrows	Heterosexual people affected or infected by HIV/AIDS
Multicultural Centre for Women's Health	Multicultural women
Multicultural Health and Support Service	Multicultural community members
Melbourne Sexual Health Centre	People living with STIs and/or HIV/AIDS
Northside Clinic (Fitzroy)	All community members
Prahran Market Clinic (Prahran)	All community members
Victorian HIV Consultancy (Victorian HIV/AIDS Service – Alfred Hospital)	All PLWHA with a focus on: Outreach and ambulant care and support Aged and continuing care HIV-positive children Pregnant HIV-positive women
HIV CALD Service (Victorian HIV/AIDS Service – Alfred Hospital)	PLWHA from CALD backgrounds
HIV Service (Victorian Infectious Disease Service – Royal Melbourne Hospital)	PLWHA
HIV Disease Unit (St Vincent's Hospital)	PLWHA
CatholicCare's Catholic HIV/AIDS Ministry	PLWHA
Royal District Nursing Service (HIV/AIDS Team)	PLWHA
Youth Empowerment Against HIV/AIDS	Young people affected or infected by HIV/AIDS

Some representatives suggested that those with the specialist MSM services did not recognise that their strategies were ineffective to other sectors of the community and/or were not willing to modify services to be sensitive to those needs.

*“My biggest stressor is the sector”*

In summary, the interview responses provided an impression that the sector was fragmented and could easily present as confusing to vulnerable community members such as those within the SSAn community. Given the limited resources available, improved co-ordination and collaboration would likely better address this issue.

**Theme 4: The nature of the HIV epidemic in Australia can lead SSAn individuals towards more risky sexual behaviours.**

There was a consensus among providers that a distorted view of the Australian HIV epidemic can be formed within SSAn communities based on their specific experiences in migrating to Australia. Specifically, providers have observed the following erroneous perspectives:

- There are few signs or media messages relating to HIV in Australia, therefore it must be a ‘clean’ country. (This derives from the experience of individuals in in home countries where, due to the scale of the epidemic, HIV prevention messages via television, radio, signs and posters and through workplace and community health programs are ubiquitous.)
- The HIV testing program during immigration does not allow anyone with HIV to enter the country.
- References to HIV in Australia relate to the MSM, so HIV exists only in the homosexual community.

*“There is double trouble as MSM [from the SSAn community] perceive Australia to be clean, while heterosexuals either believe the country to be clean or see HIV only as a gay disease in Australia.”*

Consequently, SSAns do not believe that safe sex measures are necessary and take fewer precautions against HIV transmission than they would previously have used in their home country. This presents a challenge to HIV education providers in

overcoming the misperceptions gained about Australia and effectively reinforcing HIV prevention messages.

**Theme 5: Effective service provision to SSAn migrants recognises the contextual needs of the individual in their specific situation.**

There is a danger in the course of this discussion in representing the SSAn community as a single homogenous demographic group, rather than recognising the reality of a diverse collection of peoples comprising separate cultures, traditions, religions and languages. The same appreciation of this diversity is required when considering the nature of HIV education and support services to be provided to members of this community. The service providers successfully engaging with the SSAn community strongly emphasised this diversity and the need for flexibility in service provision to accommodate these variations.

*“It is important to recognise the variations between countries and regions...sub-Saharan Africa is made up of 50 countries, every one different.”*

These organisations also recognised the challenges that this diversity presents when putting together materials and campaigns around HIV prevention and awareness. Numerous languages may be involved and differences in cultural nuance must be considered. Again, the limited capacity of organisations was raised as an issue in adequately meeting these demands.

Further emphasis was placed on the requirement to consider the needs of each individual separately in the context of their own and the wider Australian community. For example, refugees from areas of conflict (e.g. Sudan or Somalia) have suffered turmoil and destabilisation of their lives, which gives an “*added layer*” if compared to skilled migrants settling in the country.

*“Look at the person in the context of their community”*

*“See the whole picture, and the individual”*

The Multicultural Centre for Women’s Health often provides group information education sessions on wide range of healthcare subjects, but always makes

provision for one-to-one follow-up to meet the needs and address the concerns of the individual.

While it is evident there is a clear recognition of this aspect among those providers working closely with migrant communities, it was suggested that this wasn't uniform across all providers.

*“People are categorised by their demographic, not as an individual...services are boxed.”*

This commitment to the individual was most strongly reflected by the representative from the Royal District Nursing Service (RDNS). This, perhaps, reflects the clear institutional focus publicly presented by the RDNS towards meeting the requirements of “clients and carers with diverse needs and from diverse backgrounds”. This was articulated in the recently implemented Diversity Framework: Policy, Planning & Practice 2012-2017 (RDNS, 2012), a document that presents a conceptual framework to allow staff to “think about the holistic needs of your clients and how best to meet these” and a plan and priorities to achieve this goal. The general elements of this document could be usefully applied across the HIV education and support sector.

**Theme 6: Service provision to SSAn migrants benefits from working within the community and using staff from multicultural backgrounds.**

The difficulties in engaging with individuals from the SSAn community have been discussed at length and the organisations interviewed accept that many challenges must be met to improve this situation. However, those organisations focussed on multicultural communities agreed that a critical element was to establish long-term relationships with the communities and gain the trust of its members.

*“Services must engage the community...build relationships”*

There are some consistent elements of the services provided by the Multicultural Centre for Women's Health (MCWH) and the Multicultural Health and Support

Service (MHSS) that appear to be key to achieving effective and lasting engagement with the SSAn communities:

- Adopt a long-term approach that allows the development of relationships and trust.
- Work with the community leaders and members to develop educational materials and programs.
- Use workers from the community.
- Deliver information in the first language of the community.
- As appropriate, use multiple means to provide education and information e.g. written materials, electronic media, group and individual sessions and the involvement of other healthcare workers.
- Link with other agencies working within the community to provide a co-ordinated approach e.g. settlement agencies, housing services and employers.

All workers from the MHSS and most from the MCWH are bi-cultural and both organisations use bi-lingual co-workers to effectively deliver their health education programs. The MHSS train volunteers from SSAn communities over a long period and use these individuals to deliver HIV-related (and wider sexual health) educational messages that are both in the first language of the community and culturally sensitive. Similarly, the MCWH use bi-lingual educators who implement programs and also advocate for their communities. As a result, both the MHSS and MCWH use the strength of these relationships as a basis to engage with individuals who live on margins of society and may be most vulnerable to HIV. These include prison inmates, young offenders and individuals with mental health issues and/or who are socially isolated.

Considering themes 5 and 6 together shows that service providers effectively working with the SSAn community must establish broad links with the community to establish functional relationships and build trust, yet retain the ability to meet the needs of individuals. This balance seems best achieved by providers that have broad health remit and do not suffer the stigma associated with a specific HIV/AIDS focus.

#### **4.4. Discussion**

This study has identified a diverse range of HIV education and support service providers within Melbourne. Collectively, these organisations offer a range of services that target many sectors of the community including multicultural and migrant groups. While these services exist, the evidence from the interviews conducted in this study is that there remain significant deficits in addressing the needs of the SSAn community. It is clear that those groups working with the SSAn and other migrant communities have an intimate understanding of the issues, recognise the needs of the communities and are able to implement culturally sensitive and appropriate service programs. However, the groups constitute a small proportion of the sector and limited resources and funding, funding insecurity and a lack of collaboration within the sector restrict their effectiveness.

Unsurprisingly, the majority of funding available to HIV service providers is directed to those organisations focusing on addressing the needs of the Caucasian MSM community, the group overwhelmingly most severely affected by the epidemic in Australia. These services are largely unavailable to the SSAn community (including the MSM within the community) due to the stigma associated with HIV/AIDS and homosexuality. Indeed, there is a view that the consistent association in the public sphere between services and the GLBT community acts as a deterrent to other groups seeking services, particularly migrant community members.

However, similar to the difficulties faced by migrant groups in other developed countries, this is only one of a number of barriers identified that impede SSAn migrants accessing and engaging HIV service providers within Melbourne. These challenges result in an increased vulnerability of this community to HIV, with many providers reporting that late diagnosis and poorer health outcomes were common in this sub-group.

As identified in other regions, the barriers can broadly be divided into structural elements that obstruct or prevent engagement (such as the nature and capacity of HIV service provision, legal or administrative limitations and linguistic or financial issues) and the cultural norms within the SSAn community that inhibit or deter individuals from linking to service providers (such as stigma and gender inequality).

The cultural norms stem from deeply ingrained beliefs borne of traditional, social and religious perspectives held in the country of origin. It is clear that many of these views are intractable and considerable efforts and time will be required to change these norms across communities. For example, one representative interviewed felt that a generational change would be required for individuals from the SSAn community to understand fully the concept of confidentiality. The HIV service providers specialising in multicultural health are best placed to effect this change, yet these same cultural barriers prevent or limit their engagement with the community. Hence, something of a 'Catch-22' situation exists.

However, the structural barriers would appear to constitute "lower hanging fruit" in terms of the challenges to be met to improve service provision and increase community engagement. A reduction or removal of these barriers (through modifications to approaches used by service providers, improving capacity and financial support and a reduction in legal and administrative burdens) would seem to be more readily achievable if a co-ordinated effort can be mobilised across government and support agencies. Therefore, a strategic approach can be envisioned where resources are directed to sequentially address structural and cultural barriers to incrementally grow the sector, increase community engagement and address the vulnerability of the SSAn community to HIV (see Recommendations and Figure 1).

Perhaps of greatest concern is that the findings of this study differ little from the findings of previous investigations. Specifically, two studies conducted in Victoria in 2006 investigated reducing the risk of transmission of HIV/AIDS in African communities (Victorian Department of Human Services, 2006) and assessing access to HIV prevention information among CALD communities (Australian Research Centre in Sex, Health and Society, 2006). Many elements regarding structural and cultural barriers to effectively addressing these issues are consistent between the 2006 and current studies. This study does not allow conclusions to be drawn as to why the situation remains largely unchanged and, perhaps, simply emphasises the difficulty of the task. However, immigration into Australia continues at a rapid pace with the increase in overseas-born residents per year (3.1%) three times that of

Australian-born residents (1.0%). The estimated size of the SSAn community alone has grown 17.8% in just four years (2006-2010). Without improved services, and while generalised epidemics persist overseas, the elevated incidence of HIV seen in many migrant communities, and most notably the SSAn community, will continue to threaten the low prevalence status of Australia.

As such, there should be a well-resourced and comprehensive HIV service provision directed to the migrant community, possessing the flexibility and capability to accommodate the cultural and linguistic needs of all community groups (including those of SSAn origin). The services would extend from educational, awareness and health promotion campaigns through to integrated treatment and care for PLWHA, and should aim to build capacity and resilience into these communities to meet the needs of future migrants. While this may be a utopian view in the near term, there are achievable improvements that can be made to remove obstacles to better community engagement and developing better services. Recommendations to achieve this goal are made in the following chapter.

## **Chapter 5: Limitations and Recommendations**

This chapter examines the limitations of the study and makes recommendations related to both the provision of HIV education and support services to the SSAn community within Melbourne and areas of possible future study.

### **5.1 Limitations of the study**

#### **a) Study Sample**

Representatives from only a subset of organisations identified within the selected sample area were interviewed. Those organisations included represent a convenience sample dictated by the time available to conduct the interviews and the willingness of the organisations contacted to participate. Inclusion of all identified organisations would have been preferred, however the sample used represents a diverse range of organisations across the sector.

In addition, with one exception (the Multicultural Health and Support Service), only one representative of each organisation was interviewed. In all cases, a key individual with strong understanding of the organisation was selected. However, it may have been preferable to interview a second or third individual from each organisation, to triangulate and validate the information received as accurate.

#### **b) Location**

The area selected for study was that determined by a 5km radius around the central business district (CBD) of Melbourne. However, during the course of the study it became clear that the largest SSAn communities within Melbourne are located outside of the selected area (e.g. Dandenong and the Western Suburbs). While many services are located within the CBD and individuals travel to gain access, added benefit may have been gained by expanding the study to include these areas.

#### **c) Inclusion of Individuals from the SSAn Community**

Within the cohort of representatives interviewed from service providers, only one was a member of the SSAn community. It is recognised that inclusion of feedback from SSAn community members, in particular people affected by HIV/AIDS, would have been a valuable addition to the study. Indeed, an early study design proposed either interviewing or surveying individuals from the SSAn community. However, as with engagement with services, difficulties would have been encountered in recruiting

individuals to an HIV-related study within the required timeframe. Also ethical concerns (in relation to stigmatisation) were identified in respect to selecting only a single ethnic group for participation in the study.

**d) Quantitative Data**

With the exception of some basic descriptive statistics relating to service offerings, the study is entirely qualitative in nature. Some quantitative analysis relating to service delivery and uptake (e.g. number of educational sessions delivered to SSAn community groups or number of SSAns attending services within a particular time period) would have provided valuable data to objectively assess engagement of an organisation with the SSAn community. This type of information can also usefully serve as a baseline against which to measure future improvements in service delivery.

**e) Role of Government**

State and/or federal governments fund all organisations included in this study and are pivotal to providing resources, setting policy directions and creating the environment in which HIV education and support service providers operate. There is evidence from this study that stated objectives of government policy outlined in the literature review are not being achieved within Melbourne, however, this study did not consider this aspect in any depth. Further investigation of the role and influence of government in this area would certainly add usefully to the knowledge base.

In summary, the restrictions in time and resources available to complete this study necessitated certain compromises to the study design and consequently, the scope of the study, the data collected and conclusions that can be drawn are limited. However, it is hoped that the information and analysis contained in this report retains significant value and provides a useful insight into the HIV education and support services available to the SSAn community in Melbourne. In addition, the limitations identified may be valuable in guiding future study designs.

## **5.2 Recommendations**

**a) Capacity**

Resources and funding should be increased and/ or redistributed to enable a HIV education and support service provision that is tailored towards and has the capacity to meet the needs of Australia's growing migrant population. This is likely to require

increased funding from federal and state governments, however public-private partnerships should also be considered.

**b) Co-ordination and Collaboration**

The current service provision within Melbourne is fragmented and the sector would benefit from improved co-ordination of and/or collaboration between services. The inter-agency forum, chaired by the Victorian AIDS Council, would seem to be an appropriate mechanism, but is not currently sufficiently effective in this regard. Also, the specific needs of the SSAn community (and other migrant groups) may warrant services to multicultural communities to be independently co-ordinated from the wider HIV service provision. The Victorian Multicultural Commission (VMC), established by the state government in 2011, has a stated objective of “developing and maintaining partnerships between community organisations that provide...service delivery for diverse communities”. As state government funds most service providers, the VMC seems well placed as the agency to establish mechanisms to co-ordinate and improve collaborative networks within the sector.

**c) ‘Professionalisation’ of Multilingual Workers**

The study has identified the importance of developing programs and services with the target community and employing workers from that community to deliver services. However, there are difficulties in identifying individuals from those communities that understand the standards required to operate in the sector, particularly in relation to confidentiality. A standardisation of training through the establishment of a specific qualification scheme has been suggested by the Multicultural Centre of Women’s Health. This approach would have the benefit of raising minimum standards, helping to set a consistent standard across providers and developing a career path for individuals in this area.

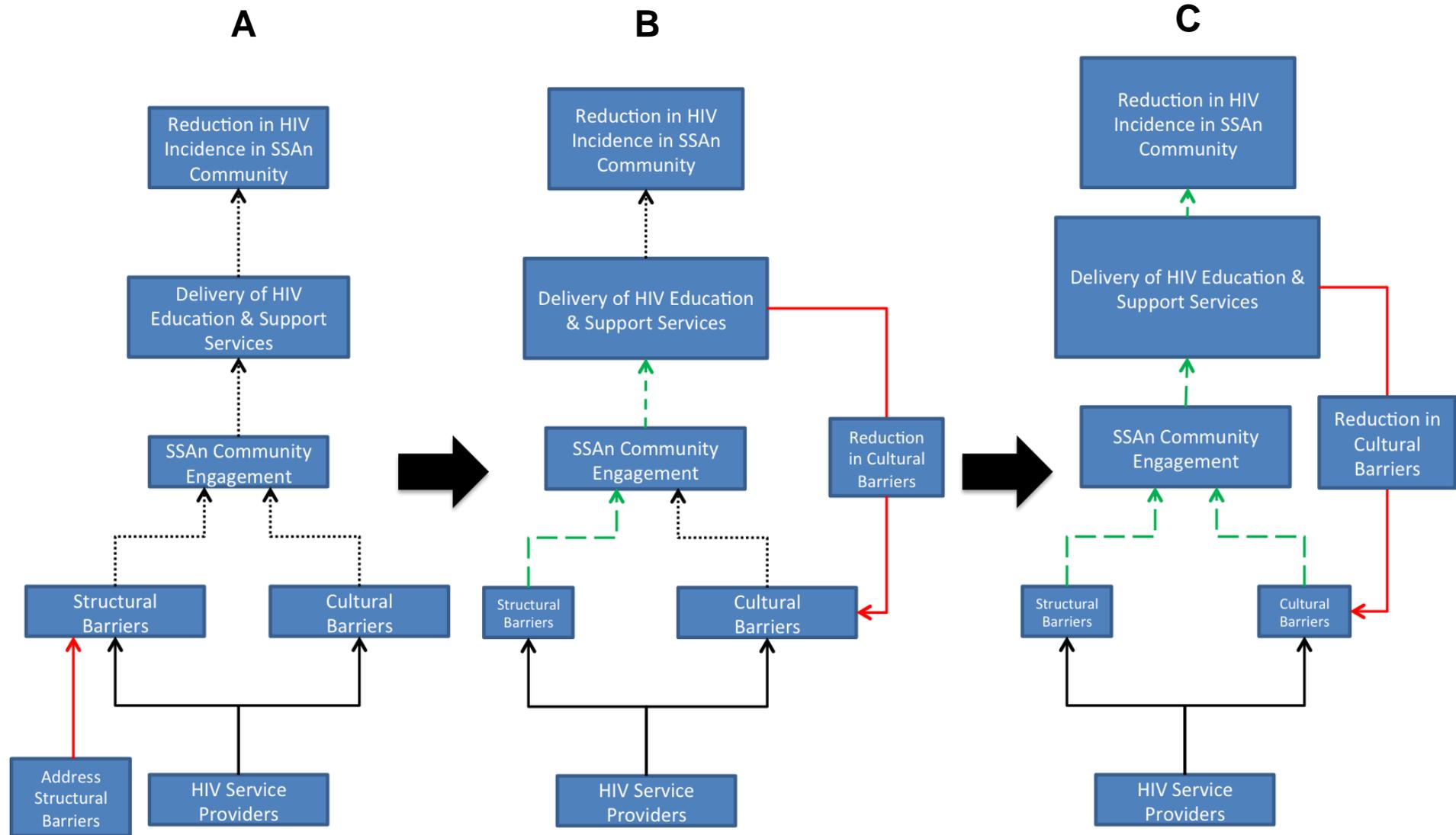
**d) Simplifying Migration and Benefits Procedures**

The migration procedures for immigrants from SSA entering Australia are complex and confusing. Uncertainties around legal status to remain in the country and to entitlements such as Medicare and the Pharmaceutical Benefits Scheme (PBS) are fundamental structural barriers deterring SSAn individuals engaging with services. A key element of this is the mandatory HIV test required as part of permanent resident and some temporary visa applications. While many potential migrants testing positive during HIV screening are able to gain entry into Australia through the health requirement waiver scheme, the process is bureaucratic, time-consuming and

daunting for applicants. Further, many, if not most, migrants do not fully understand the criteria applied when assessing HIV status as part of the visa process and a common misperception is that all HIV-positive applicants are excluded from the country. As such, it acts as a deterrent to engagement with services. In addition, the cost burden of accessing services is a concern. A contributory factor in this regard is that some temporary migrants are ineligible for Medicare and PBS, while others are unaware of their eligibility. Therefore, a simplification of the migration and benefits application process should be considered and the requirement for mandatory HIV testing removed. The extension of medical benefits to temporary residents should also be considered.

**e) Strategic Approach**

It is likely that structural barriers to the engagement of individuals from the SSAn community are more readily addressed in the near term than achieving widespread changes in the cultural norms of the community. Therefore, when looking at the fundamental issue of elevated HIV incidence in the SSAn community in Australia, a strategic approach is proposed whereby emphasis is placed on reducing those structural barriers (Figure 1A). A reduction in structural barriers would lead to an improvement in community engagement by service providers and an increased delivery of services (represented by the increased box sizes in Figure 1B). As education, awareness and support within communities increases, cultural norms can be better challenged and adapted to breakdown the cultural barriers (Figure 1B). A reduction in cultural barriers further improves community engagement, delivery of services and, in time, begins to positively impact on the vulnerability to HIV within the community (Figure 1C).



**Figure 1: Strategic Framework to Improving Engagement of HIV Education and Support Service Providers by the SSAn Community in Australia**

## **Chapter 6: Conclusion**

Melbourne is served by a number of HIV education and support service providers offering assistance to many sectors of society. A limited number of these services target multicultural (including SSAn) populations offering culturally sensitive approaches to HIV education, advocacy, management, support and care. Key factors that underpin their successful engagement with these groups are a community-centric approach that fosters long term relationships and trust, use of bilingual workers and first language materials, the ability to mainstream HIV services into broader healthcare services and the adoption of strategies to maintain confidentiality and avoid unintended disclosure.

However, the effectiveness of these organisations is restricted due to funding and resource limitations and a lack of collaboration between providers. Other structural barriers to effective engagement with the SSAn community include the complexities of the migration process and cost issues. Specifically, migration rules are complicated and there can be fears among the SSAn community that a positive HIV test will jeopardise residency rights, while the low economic status of many members of the community leads to concerns around affordability of services. The latter is compounded by uncertainty with regard to eligibility for benefits such as Medicare. Both factors act as a deterrent to engagement with services.

Cultural norms among the SSAn community also impact greatly on service delivery, with stigma related to the fear of disclosure universally accepted as the most significant issue. Hence, accommodating and overcoming these cultural barriers presents the greatest challenge to the HIV education and support service community.

A focus on addressing structural issues is recommended to increase the capacity of providers and facilitate greater engagement. This in turn will increase the ability of organisations to modify cultural norms, build capacity and resilience within communities and reduce the vulnerability of the community to HIV. This approach will require increased support from federal and state governments and a more collaborative ethos between HIV service providers.

Net migration into Australia is forecast to increase over the next decade and the observed growth in the SSAn African community is set to continue. Without improvements in HIV education and support service provision to this community, the threat that the elevated HIV prevalence within this group poses to both the low prevalence status of the wider community and the ability of this community to integrate into society will remain or grow.

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## Appendix 1: Interview Structure



AFRICA CENTRE FOR HIV/AIDS MANAGEMENT  
Stellenbosch University



### INTERVIEW STRUCTURE – HIV EDUCATION SERVICE PROVIDERS

**Project Title: A review of the availability, accessibility and uptake of HIV education service provision to sub-Saharan African migrants in metropolitan Melbourne, Australia**

As interaction with a range of HIV education service providers is envisaged, this document provides a broad interview structure intended to accommodate all organisations contacted. The nature of the discussion may vary within these parameters depending on the characteristics of the organisation.

1. Name and location of organisation
2. Description of organisation (e.g., specialist health centre, GP surgery, representative/ advocacy organisation)
3. Position/role of interviewee within the organisation
4. Does the organisation provide HIV education services?
5. What is the nature of the services provided? (e.g. printed information, educational sessions, counselling etc.)
- 6a. How is this information/service offered (e.g. advertised, on request of the individual, when an individual engages other services etc.)?
- 6b. How does an individual engage with these services/obtain this information?

7. Who within the organisation provides the information/services?
8. Are specific or tailored services provided to culturally and linguistically diverse (CALD) groups?
9. If yes, how are the services tailored towards CALD groups (e.g. translators, multi-lingual education materials etc.)?
10. Does this include the sub-Saharan African community? If so, please explain.
11. Does the organisation produce its own educational materials and programs? If yes, how are these produced and approved? If no, from where are the materials and program content obtained?
12. Does the organisation have systems to review and improve HIV education services and materials? If so, please explain.
13. What proportion of people that engage with HIV education services are from CALD groups and specifically, from the sub-Saharan African community
14. Do you think the HIV education needs of the sub-Saharan African community are adequately catered for? Please elaborate.
15. If not, how do you think these services can be improved?
16. Is there anything else that you would like to add?

## Appendix 2: Research Ethics Committee Approval



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### Approval Notice Response to Modifications- (New Application)

21-Oct-2013  
LAMBERT, Peter

**Proposal #: HS977/2013**

**Title:** A review of the availability, accessibility and uptake of HIV education service provision to sub-Saharan African migrants in metropolitan Melbourne, Australia

Dear Mr Peter LAMBERT,

Your **Response to Modifications - (New Application)** received on **14-Oct-2013**, was reviewed by members of the **Research Ethics Committee: Human Research (Humanities)** via Expedited review procedures on **21-Oct-2013** and was approved.  
Please note the following information about your approved research proposal:

Proposal Approval Period: **21-Oct-2013 -20-Oct-2014**

Please take note of the general Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

Please remember to use your **proposal number (HS977/2013)** on any documents or correspondence with the REC concerning your research proposal.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Also note that a progress report should be submitted to the Committee before the approval period has expired if a continuation is required. The Committee will then consider the continuation of the project for a further year (if necessary).

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) registration number REC-050411-032.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 0218839027.

**Included Documents:**

Revised DESC form  
Revised questionnaire  
REC letter  
Revised informed consent  
Revised Research proposal  
Research proposal  
DESC feedback  
letter of response  
Revised REC Application  
Consent form  
REC Application  
DESC form  
Questionnaire

Sincerely,