



# **A Study of HIV Management, Care & Support Needs among People from Migrant and Mobile Populations in Australia**

A Discussion Paper



# Executive summary

## Background

National HIV surveillance data in the last five years have shown that international migration is shifting the epidemiological landscape of HIV in Australia, as is the case with most parts of the western world. Migrant and mobile populations – particularly those from Sub-Saharan Africa and Southeast Asia – now make up the second largest group affected by HIV, following gay men and men who have sex with men (MSM) (The Kirby Institute, 2017). Of particular concern is the high number of late HIV diagnoses among this priority population. Nonetheless, knowledge on the HIV management, support and care needs of migrant and mobile populations remains poor. Unless the public health system reaches out to *all* priority populations, and ensure that they are linked into appropriate prevention, testing, treatment and care services, Australia's goal to achieve the virtual elimination of new HIV infections by 2020 will fall short.

## Aims

The Australian Research Centre in Sex, Health and Society (ARCSHS) is currently undertaking the project, *A Study of HIV Management, Care & Support Needs among People from Migrant and Mobile Populations in Australia*.

Its aim is to expand the empirical knowledge-base of HIV among priority migrant and mobile populations. Evidence from this project will assist government bodies, health services and community support agencies in the planning and delivery of HIV management and support services that are culturally-sensitive and appropriate to the needs and expectations of people living with HIV (PLHIV) from migrant and mobile populations, as well as their communities more broadly.

Drawing on both published and grey literature, this discussion paper provides the contextual background and rationale for the project by presenting an overview of key international and Australian research surrounding the HIV management, care and support needs among PLHIV from migrant and mobile populations.



## Key Findings

Amid global efforts to achieve the UNAIDS 90-90-90 targets, both international and Australian research have predominantly focused on the quantitative dimensions of HIV, particularly as it relates to the HIV cascade of care (Van Beckhoven et al. 2015).

While the HIV cascade of care has been a useful metric to measure and evaluate intervention strategies to ensure the engagement and retention of PLHIV in care and treatment (Kay et al. 2017; Medland et al. 2015), little is known about its qualitative dimensions. For example, questions concerning the cultural, social and individual circumstances surrounding HIV testing and prevention, as well as how PLHIV from migrant and mobile populations navigate their infection across diverse contexts remains largely unanswered.

### The International Context

International research on HIV in priority migrant and mobile populations – most of which were conducted in high-income countries – have predominantly focused on HIV testing. Less well explored are the later stages of the HIV cascade of care including linkage into, and retention in HIV care and treatment. Research in this area have identified that migrants' willingness to engage with HIV testing services were underpinned by a number of interacting structural, cultural, social and individual factors, which included:

- Legal implications of testing positive such as fear of deportation or having visa or residence applications denied or revoked;
- Restricted access to healthcare services;
- Linguistic and communication difficulties;
- Concerns about stigmatising and discriminatory behaviours from service providers;
- Contexts in which HIV tests were delivered played an important role in test acceptance.

Migrants who travelled frequently, particularly those who travel to and from regions of high HIV prevalence, were identified as being at greater risk for HIV infection.

Among those living with HIV, it has been found that frequent travel increases their vulnerability to treatment disruption due to the following factors:

- Fears of medication side-effects whilst travelling;
- Delaying treatment during travel for fear of unwanted HIV disclosure;
- Logistical and administrative barriers to renewing medication supplies whilst travelling.

### The Australian Context

One of the first qualitative studies to explore the perspectives of PLHIV from migrant populations in Australia was conducted by Korner (2007) over 10 years ago. This study importantly highlighted how the circumstances surrounding diagnosis, including factors contributing to late diagnoses were embedded within a complex set of cultural and social structures in which PLHIV carry out their day-to-day lives.

Since then, only a small number of qualitative studies have responded to this 'emerging concentrated epidemic' (Persson et al. 2014: 252) and explored the social and personal impact of HIV in migrant and mobile populations in Australia. Mirroring the international research trend, most Australian studies have primarily focused on identifying the key barriers and enablers to HIV testing.

Drawing on population samples of mostly Sub-Saharan African and Southeast Asian migrants, these studies have commonly identified the following key reasons behind migrants' willingness to engage in sexual health services, including HIV testing:

- Experiences from birth countries;
- Socio-cultural and religious influences;
- Visibility of HIV;
- 'Safety' in Australia;
- 'Othering' of risk;
- Lack of knowledge, financial and language constraints; and
- Issues of privacy, confidentiality and trust in HIV testing.

Less well explored is an understanding of the HIV management, care and support needs of PLHIV from these populations – especially following the point of diagnosis. Among studies that specifically focus on PLHIV – rather than general members of priority migrant populations, most have focused on the clinical and demographic dimensions (for example, Lemoh et al. 2010), or employed long survey methods that may preclude the participation of some people from non-English speaking migrant communities (Power et al. 2017).



## Next Steps

Taking all this into account, and building on a Victorian-based scoping project conducted by ARCSHS in 2017 – which consisted of a series of focus groups and individual interviews with key stakeholders to ascertain knowledge gaps and areas of focus for future research – ARCSHS, in its current project, will conduct individual interviews with two participant groups: (1) PLHIV from priority migrant and mobile populations and (2) healthcare professionals and community

service providers. To begin to understand the key issues surrounding the HIV management, support and care needs among PLHIV from migrant and mobile populations, this project is directed by the following research questions:

1. How PLHIV from migrant and mobile populations experience their infection across diverse settings including clinical, community and personal settings?

2. What are the perceptions and experiences of healthcare professionals and community service providers in providing HIV management and care to priority migrants and mobile populations?



# Background

The indisputable clinical efficacy of antiretroviral therapy (ART) in the treatment and prevention of HIV propelled the Joint United Nations Programme on HIV/AIDS (UNAIDS) to put forth its 'new, final, ambitious but achievable target' of 90-90-90 by the year 2020.

The target specifies that 90 percent of people living with HIV will know their HIV status, 90 percent of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90 percent of all people receiving antiretroviral therapy will have viral suppression (UNAIDS, 2014:1). The successful realisation of these targets are contingent upon the public health system's capacity to reach out to *all* priority populations, and ensure that they are linked into appropriate care and treatment in order to achieve viral suppression (Higa et al. 2012). However, there are growing concerns that migrants from high prevalence countries including their partners and people from mobile populations such as mobile workers and international students are being left behind in the global push towards the 90-90-90 targets (UNAIDS, 2015).

The United Nations Department of Economic and Social Affairs defines a migrant as 'any person who is moving or has moved across an international border or within a State away from [their] habitual place of residence, regardless of (1) the person's legal status; (2) whether the movement is voluntary or involuntary; (3) what the causes of movement are; or (4) what the length of stay is (United Nations, 2017).

While mobile populations also consist of migrants who take up residence or remain for an extended stay in a foreign country, mobile populations also include people who move from one place to another temporarily or seasonally such as international students and workers on temporary visas. In 2017, there were an estimated 258 million international migrants worldwide, with two-thirds residing in high-income countries in Europe, the United Kingdom (UK), the United States of America (USA) and Australia (United Nations, 2017). While the HIV epidemic remains concentrated among gay men and other MSM in most high-income countries, global epidemiological data in the last decade clearly indicate that the demographic landscape of HIV is changing (Blondell et al. 2015; Kharsany & Karim, 2016; Pendse et al. 2016). In Europe, for example, HIV disproportionately affects migrants from sub-Saharan Africa, Latin America and South Asia while Hispanics or Latinos, Africans and Southeast Asians are identified as priority populations in the USA (Alvarez-Del Arco et al. 2013). In Australia, migrants – particularly those from Sub-Saharan Africa and Southeast Asia – make up the second largest group affected by HIV, following gay men and other men who have sex with men (MSM) (The Kirby Institute, 2017).

Currently, much of HIV-related public health policies, health services and community support programs are predominantly focused on meeting the needs and expectations of gay men and MSM, while knowledge on the HIV management, care and support needs of migrant and mobile populations remains poor. Expanding the empirical knowledge-base in this area will allow government bodies, health services and community support agencies to develop and implement evidence-based, targeted responses to reducing HIV prevalence, vulnerability and risk among migrant and mobile populations.

The aim of this discussion paper is to provide the contextual background for the project, *A Study of HIV Management, Care & Support Needs among People from Migrant and Mobile Populations in Australia*, which is currently being undertaken by the Australian Research Centre in Sex, Health and Society (ARCSHS). In this paper, an overview of the key international literature on HIV in priority migrant and mobile populations is first presented, followed by a discussion of the current state of knowledge surrounding the HIV management, care and support needs among people living with HIV (PLHIV) from migrant and mobile populations in Australia.



# HIV among Migrant and Mobile Populations: A Review of International Research

Knipe et al. (2013) notes that it is not the process of migration, or moving per se that determines the risk and vulnerability to HIV. Rather, it is determined by the circumstances and conditions experienced during the different phases of migration, which include pre-departure, in transit, arrival in host community, and return to country of origin.

It is crucial that any planning and delivery of HIV management and support services are culturally-sensitive and appropriate to the needs and expectations of PLHIV from migrant and mobile populations, as well as their communities more broadly. Doing so requires a comprehensive understanding of the lived experiences of PLHIV from these populations. However, amid global efforts to achieve the UNAIDS 90-90-90 targets, research has predominantly focused on the quantitative dimensions of HIV, particularly as it relates to the HIV cascade of care (Van Beckhoven et al. 2015).

The HIV cascade of care describes the sequential steps that HIV-infected individuals must undertake to achieve optimal clinical

outcomes (Tanser et al. 2015). These steps include diagnosis, linkage to care, retention in care, adherence to antiretroviral therapy, and viral suppression (Kay et al., 2016). The ultimate goal is to increase population antiretroviral therapy (ART) coverage – a core component of the treatment as prevention strategy – to reduce the rate of onward HIV transmission (Medland et al., 2015).

The HIV care cascade has been a useful metric to measure and evaluate intervention strategies to ensure the engagement and retention of PLHIV in care and treatment (Kay et al. 2017; Medland et al. 2015). However, the disproportionate emphasis on obtaining quantitative data has consequently relegated qualitative understandings to the

margins of research. Questions concerning the circumstances surrounding HIV testing, and how PLHIV from migrant and mobile populations experience their infection following the point of diagnosis remains largely unanswered. This significant gap in knowledge is evident in the following overview of the key international literature on HIV among migrants and mobile populations in high-income countries. The literature are presented in accordance with the key stages identified in the HIV cascade of care: HIV testing, linkage into and retention in HIV treatment and care and HIV prevention.

## HIV Testing

In recent years, a small number of researchers have conducted systematic reviews of evidence on barriers to, and facilitators of, HIV testing among migrant and mobile populations in high-income countries.

While most studies in these reviews were quantitative, they have highlighted a number of significant structural, cultural, social and individual barriers to and, to a lesser extent, facilitators of HIV testing. For example, in a review analysing testing and counselling strategies targeting migrants in high-income countries between 2005 to 2009, Alvarez-Del Arco et al. (2013) identified that while some barriers to testing are commonly shared across diverse priority populations such as those living in disadvantaged socioeconomic situations, other barriers such as those associated with legal, cultural and linguistic issues are often unique to the experience of migrants and mobile populations alone. Studies of migrants in Canada, USA, Spain, Sweden and the UK found that concerns about the legal implications of testing positive prevented them from getting tested for fear of deportation or having their visa or residence applications denied or revoked. For undocumented migrants residing in Europe, restricted access to healthcare services, or lack of knowledge of how to gain access to such services, further heightened their risk of adverse health outcomes.

At the individual level, linguistic and communication difficulties, combined with concerns about stigmatising attitudes and discriminatory behaviours from service providers impeded engagement with medical services. Reluctance to testing were also associated with low perceived HIV risk, despite awareness of community HIV risk, as was the case among Sub-Saharan African migrants in the UK (Young et al. 2014).

Alvarez Del-Arco et al. (2013) further identified that the context in which HIV tests were delivered play an important role in test acceptance among migrants and mobile populations. A study of Hispanic farmers in the USA, for example, found that they preferred testing to be initiated by a healthcare provider while another study of ethnic minority MSM, also in the USA, reported that they were more likely to accept testing outside traditional health settings such as rapid testing at gay pride events. Approaches to testing predominantly fell into two categories: (1) general population approaches in healthcare settings such as routine antenatal screening, which was identified as an effective strategy for achieving good coverage of HIV

testing among migrant and ethnic minority women; and (2) targeted approaches aimed at priority populations, which was not always endorsed by the targeted population, as illustrated by a Canadian study of migrant women from HIV endemic countries. Most of these women preferred non-targeted strategies integrated within health services. It is important to note that Alvarez Del-Arco et al.'s review identified no studies from Australia – a gap which was also observed by Blondell et al. (2015), who pointed out that while migrants from Southeast Asia are recognised as a priority population in Australia, not much is known about their HIV testing behaviour.

Building on Alvarez Del-Arco's (2013) review, Aung et al. (2017) extended their analysis beyond migrants in high-income Anglo-Saxon countries to include international migrants from low to middle-income countries. In their review and evaluation of the effectiveness of intervention strategies aimed at increasing HIV testing uptake in migrant populations, Aung et al. reported that only a small number had undergone evaluation and were readily available through a systematic search of the peer reviewed and grey literature.

## HIV among Migrant and Mobile Populations: A Review of International Research

Of the 6511 papers published between January 1985 and December 2016, only 10 met their inclusion criteria – most investigated migrants from Mexico residing in the USA and along the U.S.-Mexican border (n=7) and the remaining three studies were conducted in Australia, Belgium and Uganda with migrants from Sub-Saharan Africa (n=1), Dominican Republic (n=1) or mixed origin (n=2). Three types of interventions were identified: (1) exposure to HIV prevention messages; (2) interactive HIV education programs; and (3)

direct offer of HIV testing. With the exception of one, which targeted health professionals, all interventions directly targeted migrants. Aung et al. (2017) identified mixed reports of success in increasing HIV testing uptake. One limitation observed was that most interventions were based on individual models of behaviour change and while the authors acknowledged that the articles reviewed may have been part of a broader multilevel intervention package, it is suggested that future interventions move beyond one

dimensional approaches that only focuses on how migrants engage in healthcare services. Rather, Aung et al. emphasised that interventions should include 'an examination of the various interactions between individual migrants, health system determinants and the broader socio-cultural and economic enablers and barriers of HIV testing and healthcare use' (2017: 2854), something that increased qualitative methods will help achieve.




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### Linkage into, and Retention in HIV Care and Treatment

In comparison to HIV testing, the barriers and challenges associated with the later stages of the HIV cascade of care are less well researched. Even less well explored is an understanding of these barriers and challenges from the perspectives of PLHIV from migrant and mobile populations themselves.

One of the most comprehensive reviews of key studies linking migrants and mobile populations with HIV treatment was conducted by Tanser et al. (2015), which drew on studies from countries of all income levels – from Nigeria and South Africa to France and the USA. It was found that migrants who travelled frequently, either in the form of work-related travel, travel for care and circular migration, were particularly vulnerable to treatment disruption. Fears of medication side-effects whilst travelling, or having family or friends in home countries finding out about their HIV status often resulted in individuals delaying treatment uptake until they were back home in host countries.

Barriers to renewing medication supplies whilst travelling was another theme identified in the review. Specifically, the administrative and logistical challenges of locating new health services to access medication affected treatment adherence. In the context of intervention strategies aimed at improving migrants and mobile populations' retention in HIV care, Tanser et al. found that a centralised health database that 'seamlessly' linked medical records across space and time had the potential to capture infected migrants who would normally be declared as loss to follow-up in the healthcare system. Studies in the USA and Sub-Saharan Africa, for example, found that a high proportion of individuals

who had initiated ART often reengaged in HIV care following migration to a different location. Mobile health technology was also identified as a critical tool in improving adherence to ART through text messaging, and facilitating interaction between healthcare providers and patients. However, the use of mobile health technology in the management of HIV is associated with many challenges such as difficulties with scaling mobile technology, dependency of funding sources, unreliable infrastructure, fast-evolving technology and ensuring harmonisation with existing healthcare systems.



## HIV among Migrant and Mobile Populations: A Review of International Research

### HIV Prevention

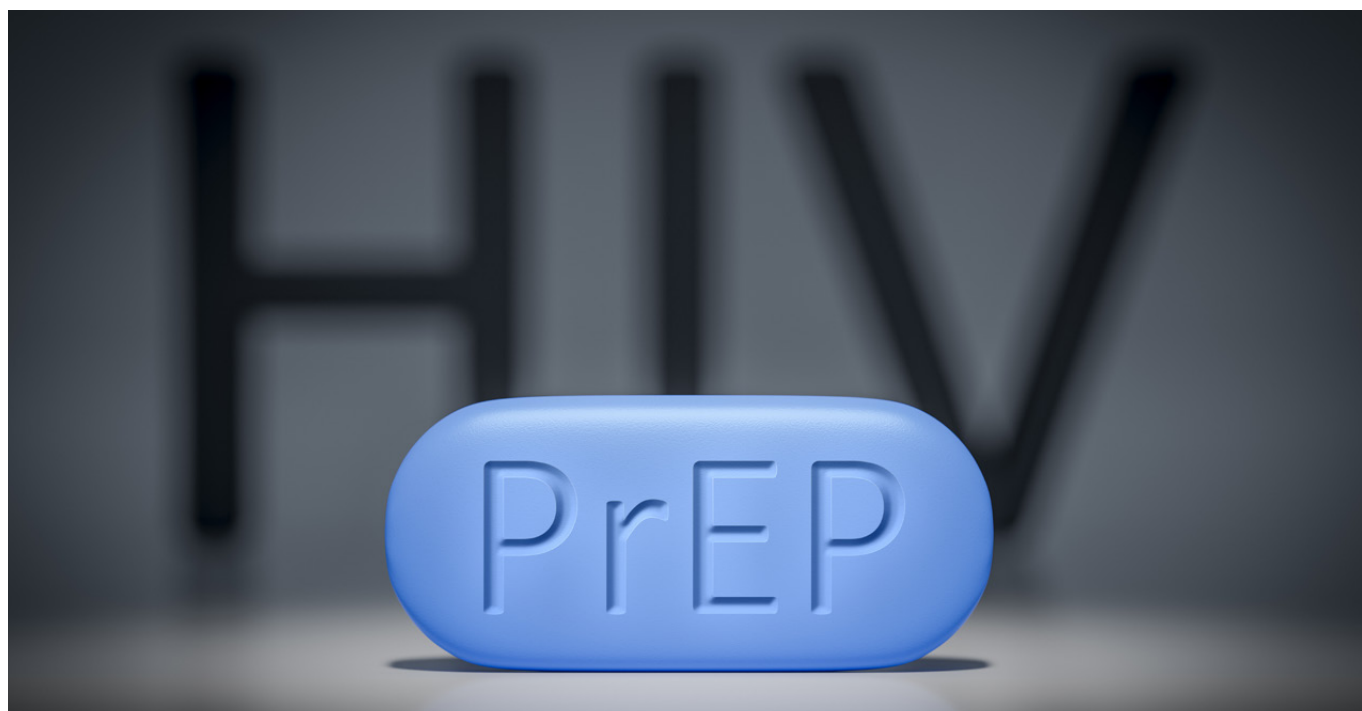
Recent biomedical developments in the prevention of HIV transmission – notably pre-exposure prophylaxis (PrEP) – has transformed global responses to the HIV epidemic, and inspired confidence in achieving 90-90-90 targets.

Evidence from key clinical trials of PrEP has shown that if taken daily by HIV-negative people, the risk of HIV acquisition reduces by more than 90 percent – making it one of the most efficacious HIV prevention methods available today, alongside latex male condoms and access to sterile syringes (Auerbach et al., 2015). However, the public health impact of PrEP remains limited as a result of poor adherence levels, slow uptake among key affected populations and increase in risk behaviour. Auerbach et al. (2015) argued that among clinical and advocacy communities, the two commonly addressed questions are: 'Is it clinically effective?' and 'What are the structural and policy factors that impact its effectiveness when implemented?' According to the authors, these lines of inquiry do not consider the social and cultural dimensions of PrEP, which is more than just 'getting drugs into bodies'. From a social science perspective, Auerbach et al. argue that 'PrEP embodies a range of interacting physiological, psychological and social realities that

together affect not only an individual's risk or avoidance of HIV infection but also relationship dynamics, sexual cultures and social arrangements that have influence beyond HIV' (2015:1).

To date, only a small body of qualitative research has investigated the acceptability of PrEP among migrant and mobile populations. The study population in most PrEP research – which have typically been in the form of clinical trials and demonstration projects – are gay and bisexual men, and other MSM more generally. PrEP research among heterosexual populations are predominantly conducted in low-income regions such as Africa (see, for example, Eakle et al. 2018; Govender & Karim, 2018). In the context of Europe, Loos et al. (2016) observed that PrEP research among heterosexuals at risk of HIV infection – most of whom are migrants from sub-Saharan Africa, South America and Southeast Asia – are 'overlooked'. This is despite recent data showing that up to 31 percent of migrants from sub-Saharan Africa

living with HIV acquired the infection in host countries. A Scotland-based study conducted by Young et al. (2014) was the first, and continues to be one of few qualitative studies to investigate migrants' perspectives on the barriers to uptake and use of PrEP. Alongside a population sample of 20 MSM, Young et al. also explored the acceptability of PrEP among 14 men and women from migrant African communities, eight of whom were HIV-positive. The inclusion of HIV-positive participants as potential or existing partners of PrEP users was driven by evidence that serodiscordant sexual partnerships may be an important factor in PrEP acceptability. Psychological and social barriers underpinned participants' responses, which included low self-perceived risk of HIV infection, uncertainty or confusion surrounding the efficacy rates of PrEP, and concerns about managing adherence. Additionally, fears that PrEP would reduce condom use, and lead to the spread of other STIs was also identified as a barrier to its acceptability.



# HIV among Migrant and Mobile Populations: The Australian Context

In Australia, there is a national commitment to achieve the virtual elimination of new HIV infections by 2020 (Commonwealth of Australia, 2014). The state of Victoria has further set out to achieve 95-95-95 targets for diagnosis, treatment and viral load by 2030 and for the first time, the elimination of HIV-related stigma and discrimination has been identified as a priority outcome, with the aim to have 0 percent of people experiencing and reporting HIV-related stigma and discrimination by 2030 (Victorian Government, 2017).

In response to recent HIV notification trends, combined with projected demographic modelling, Australia's Seventh National HIV Strategy, along with the Victorian HIV strategy, have identified people from high prevalence countries and their partners, travellers, mobile workers and international students as key priority populations who may benefit from targeted responses to HIV (Commonwealth of Australia, 2014).

People born overseas make up the second largest group most affected by HIV in Australia, following MSM. While the HIV notification rate was stable among Australian-born people from 2007 to 2016 (between 3.3 and 4.0 per 100 000), the HIV notification rates for those born in Southeast Asia have sharply increased between 2014 and 2016 (from 11.5 per 100 000 to 17.1 per 100 000). In 2016, the highest notification rate were in people born in North and South America (17.3 per 100 000) and while the rate of HIV notification has fallen among people born in Sub-Saharan Africa in the last 10 years (from 22.2 to 10.9 per 100 000), they still made up one of the highest proportion of HIV notifications in 2016. The proportion of HIV notifications with late diagnoses in the last five years was highest among people born in Central America (45%), sub-Saharan Africa (43%) and Southeast Asia (43%). Further investigation of late diagnoses in 2016 among people born in Southeast Asia and sub-Saharan Africa identified that approximately 60 percent arrived in Australia in the last five years, suggesting that they most likely acquired HIV prior to arriving in Australia (The Kirby Institute, 2017). In Victoria, 42 percent of new diagnoses in 2015 were among people born overseas – in comparison to an average of 37 percent over the past five years (Victorian HIV/AIDS Targeted Surveillance Report, 2017).

Mirroring the international research trend, the current knowledge-base on the lived experiences of PLHIV from priority migrant and mobile populations in Australia remains empirically thin. Nonetheless, researchers have slowly begun to fill this qualitative gap in response to national surveillance data which indicates an 'emerging concentrated

epidemic' (Persson et al. 2014: 252) among this population. Korner (2007) was among the first to investigate the perspectives of PLHIV from migrant communities in Australia. The 29 participants in Korner's study consisted of 22 men (15 gay, 6 heterosexual, one provided no information) and seven women (all heterosexual). All but one participant were born overseas (16 in Asia, eight in South America and four in Southern Europe). In addition to understanding participants' perceptions of risk and the circumstances surrounding diagnosis, it was found that ethnicity and country of birth alone could not explain the high proportion of late diagnoses among this population. Rather, factors contributing to late diagnosis were embedded within a complex set of cultural and social structures within which PLHIV carry out their day-to-day lives. For most participants, for example, HIV testing only occurred following a health crisis and was other-initiated. Among some women participants, delayed diagnosis was attributed to male partners' control over their access to healthcare services.

Since Korner's research more than 10 years ago, the number of HIV notifications among people from migrant and mobile populations remains on the rise. This increase is occurring alongside significant scientific advancements and understandings of HIV treatment and testing technologies. The dissonance between the direction of scientific knowledge and HIV prevalence among migrant and mobile populations led Persson et al. (2014) to call into question current HIV responses in Australia, asking 'whether we can afford to continue to conduct business as usual' (2014: 252). In the same period, the discussion paper *HIV and mobility in Australia: Roadmap for Action* was released to mobilise key stakeholders including government bodies and policy makers, community organisations, health services and research institutions, in an effort to build evidence-based policy and program development (Crawford et al., 2014). The complexities surrounding HIV in migrant and mobile populations were highlighted, with a particular emphasis on the interacting issues of 'stigma, racism, marginalisation as well as historical contexts

such as colonisation, evolving economic and migration policies and labour mobility' (2014).

More recently, a small number of researchers have built on, and extended previous literature on the barriers and enablers to sexual health help-seeking including HIV among African and Asian-born migrants living in Australia (Agu et al. 2016; Collaboration for Evidence, Research and Impact in Public Health [CERIPH], 2018). Participants in these studies represented a cross-section of migrants including women and men who entered Australia on a student, humanitarian, family, or 457 temporary work visa. Two of these studies drew on a broad sample of migrants from the targeted regions to explore community perceptions and experiences with sexual health services, including motivations for HIV testing. Factors that influenced help-seeking behaviour in Australia included: (1) experiences from birth countries; (2) socio-cultural and religious influences; (3) visibility of HIV; (4) 'safety' in Australia; (5) 'othering' of risk; (6) lack of knowledge, financial and language constraints; and (7) and issues of privacy, confidentiality and trust in HIV testing (Agu et al. 2016; Collaboration for Evidence, Research and Impact in Public Health, 2018). CERIPH's study also explored the perspectives of GPs on HIV testing, and found that HIV tests were predominantly GP-initiated. Multiple challenges underpinned GPs' willingness to initiate testing, which included poor knowledge of priority populations, discomfort in discussing sexual health issues, low perceived risk of HIV among patients from Sub-Saharan Africa and Southeast Asia, language and cultural barriers as well as short consultation times. In another recent study by Mullens et al. (2018), community forums with sub-Saharan African community members in Australia – including community/cultural health workers, leaders and elders – revealed a strong assumption that Sub-Saharan African migrants were at less risk of transmitting HIV in Australia based on the belief that all Sub-Saharan African migrants had been tested for HIV prior to arrival in Australia. Participants in this study also expressed less concern about acquiring HIV based on psychological and psycho-social



processes such as avoidance of people with HIV and denial that HIV is a problem in Australia. The researchers identified that further research is required on understanding the role of international travel as a risk factor for HIV acquisition.

To date, not much is known about the lived experiences of PLHIV from migrant and mobile populations – especially following the point of diagnosis. One exception is Herrmann et al.'s (2012) qualitative study, which explored the experience and clinical outcomes of mostly East-African and Asian-born, temporary visa holders with HIV infection in Western Australia (WA). Contrary to previous studies of migrants on temporary visas, Herrmann et al. found that despite their lack of citizen's rights, participants in their study engaged with WA's healthcare system, via a simple chain of clinical care delivery from MHS screening to Specialist Tertiary HIV Services. In terms of the personal and social impact of HIV, timely post-testing discussions and education attenuated distress as well as frequent connection to family ties in countries of origin, despite most families not being aware of participants' HIV status.

To prevent disclosure within participants' 'cultural' communities for fear of stigma and discrimination, participants only informed selected members of their immediate families. Participants on 457 visas also expressed fears of stigma and discrimination within the workplace given that applications for continuation requires disclosure of HIV status.

Among other studies that specifically focused on PLHIV – rather than on non-HIV infected members from priority migrant populations, most have explored the demographic and clinical dimensions such as Lemoh et al.'s (2010) case series of African Australians living with HIV in Australia. In other examples, such as HIV Futures – which is the largest and longest -running study of the health and well-being of Australians living with HIV – the use of long survey instruments, which requires a high level of English literacy, precludes the participation of some people from non-English-speaking migrant communities (Power et al. 2017). In an effort to fill this significant research gap, ARCSHS is currently undertaking a qualitative project which aims to explore the HIV management, support

and care needs among PLHIV from migrant and mobile populations in Australia. This project builds on a Victorian-based scoping project conducted by ARCSHS in 2017, which consisted of a series of focus groups and individual interviews with representatives from the state Department of Health and non-government organisations, HIV clinicians, epidemiologists and HIV support workers. The scoping project specifically sought key informants' perspectives on the current state of knowledge on PLHIV from migrant and mobile populations, with a particular focus on identifying knowledge gaps and areas of focus for future research. Its objective was the provision of information that could assist the government, as well as services and programs to reduce the gap in treatment outcomes (90-90-90) between mainstream populations and people from migrant and mobile populations. Presented below is an overview of key findings from the scoping project.



## HIV among Migrant and Mobile Populations: The Australian Context

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### Scoping project method

Data collection involved interviews and a group discussion with key stakeholders from Victoria. Key stakeholders were identified by the project team and included representatives from the state Department of Health, HIV clinicians, epidemiologists, representatives from non-government organisations and HIV support workers.

Recruitment strategies included contacting the Victorian branch of the Community of Practice for Action on HIV and Mobility (CoPAHM), an alliance of over 80 stakeholders from government and non-government organisations, research institutions, community groups, and national peak bodies in Australia, and inviting members to participate in a recorded focus-group discussion, and inviting other individuals to participate in a

face-to-face interview. The interview schedule included questions such as: what information about culturally and linguistically diverse (CALD) PLHIV do we not currently have? what information about CALD PLHIV do you think we need to know? what information would be useful for the sector? what do you believe are the main barriers and enablers to CALD PLHIV accessing management, care and support among CALD/migrant communities?

and what do you think is changing or has changed in terms of the ways in which CALD/migrant communities are affected with HIV or the kinds of communities that are affected? The focus group and interviews were recorded and notes of the key points made from the recording. Key themes were identified prior to data collection and updated during the process of data analysis.

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### Scoping Project: Key Findings

*Need for better documentation of existing knowledge.* A major finding of this study was that there is a need to consolidate, translate and exchange existing knowledge about the needs of migrant and mobile populations in relation to HIV in a form that is accessible, meaningful and comprehensive to the end user.

Policy-makers, healthcare providers, community support agencies and researchers were all asking for greater access to existing knowledge. In discussing the core issues around HIV management among migrant and mobile populations, participants commonly drew a distinction between formal and informal knowledge. Formal knowledge, or academic knowledge, was identified as research-based evidence that had been formalised through publication in academic journals or presented at conferences. Informal knowledge was identified as practice-based knowledge obtained through working directly with clients across diverse contexts such as clinics, support services and community organisations. Some participants questioned the applicability of formal, academic knowledge to community organisations, stating that it was not translated into a form that was useful or meaningful. In this context, it was believed that the generation of academic knowledge was often focused towards meeting university priorities rather than serving the needs of those that would benefit most from the research. At the same time, representatives from HIV support organisations expressed the need to formally document informal knowledge that was already widely 'known' and practiced within the HIV sector. Without a formal evidence-base that can be widely accessible through peer-reviewed journals

or conference papers, these organisations are unable to make informed decisions about future planning for service delivery. The strong need to formally identify and document unpublished knowledge was exemplified by one participant's discussion of key findings derived from interviews with clients from migrant populations. Whilst most had received a late diagnosis, it was found that once these clients were linked into appropriate HIV care and support services, they continued to engage in the service and returned for follow-up appointments. Among the few that did not return for follow-ups, immigration status was believed to be the key reason. Fundamental to improving access and retention in care was to link clients into a support system that had bilingual support workers on hand, who can provide HIV-related support and assistance in a culturally-sensitive and appropriate manner.

*Lack of knowledge about specific communities.* Most participants reported that they had a comprehensive understanding of the key issues surrounding African communities but lacked knowledge about newly arrived or emerging communities such as migrants from China and India. Drawing on both formal and informal knowledge, and speaking predominantly within the context of African migrants, the following factors were identified as key barriers to accessing and remaining engaged in HIV care and treatment, and

health services more generally:

- HIV-related stigma, combined with clients' low perceived risk of HIV infection within their communities.
- Concerns about the personal and social implications arising from HIV disclosure, not only to the infected individual but also to their families in both Australia and home countries.
- Competing priorities associated with the process of migration and resettlement often meant HIV, and other health-related issues were not given top priority.
- System barriers, such as the decoupling of HIV services from other mainstream health services was identified as a problem for migrant populations.

Participants acknowledged that redressing system barriers would require a structural reform of health services, in which HIV-specific services would be embedded within broader community issues. One participant, for example, highlighted that successful sexual health programs with CALD communities were not framed around sexual health per se but implemented within the broader issues of migration, experiences and challenges in Australia.



## Next Steps: Aims and Rationale for the Current Project

As indicated earlier, national HIV surveillance data in the last five years have shown that international migration is shifting the epidemiological landscape of HIV in Australia. This new emerging pattern of HIV prevalence among migrant and mobile populations in Australia raises important questions about their pattern of healthcare service utilisation as well as the impact of the infection on their overall quality of life.

A key challenge identified by key informants in the scoping study, and one that the current project seeks to address, is the lack of empirical knowledge about the HIV management, support and care needs among three key migrant sub-populations: (1) 'newly arrived' migrants who have lived in Australia for less than 10-15 years; (2) women from migrant and mobile populations; and (3) migrants on temporary visas such as international students and those on the 457 visa. While these sub-populations are distinguished by specific social categories – migration status, gender and age – it is important to recognise the 'intersectionality' of these categories whereby people can belong to one or more of these sub-populations and therefore be impacted by multiple barriers. Additionally, other important social categories to consider among the targeted sub-populations are culture, language, socioeconomic status and sexuality. It is also important to recognise the heterogeneity that exists within and between migrant populations to avoid making culturally essentialist assumptions – particularly in the context of planning and implementing support services for migrant and mobile populations (Agu et al. 2016).

In addition to speaking to PLHIV from migrant and mobile populations, this project will also interview healthcare professionals and

community service providers about their experiences and perspectives in providing HIV management and care to priority migrant and mobile populations. It is anticipated that service providers of HIV-specific clinics and community support services will provide a more comprehensive understanding of the key clinical, cultural, social and personal issues surrounding PLHIV post-diagnosis, including enablers and barriers to service engagement. The project will also target community-based healthcare services, including private general practices in geographical areas with a high concentration of residents from HIV endemic regions. This decision was informed by the recommendation put forward by the UNAIDS, which posited that ending the AIDS epidemic by 2030 requires a more targeted public health response driven by the location-population approach. As UNAIDS Executive Director Michel Sidibe stated: 'ending the AIDS epidemic is achievable if we focus on people accessing the right services delivered in the right place' (UNAIDS, 2015). In the context of migrants and mobile populations, previous research identified that irrespective of time in the host country, people from these populations prefer to access community-based healthcare, and with ethnically and culturally concordant healthcare professionals (Henderson & Kendall, 2011; Leong et al. 2010). This was further observed by key

informants in the scoping project, in which there was a consensus towards expanding HIV care and services from specialist HIV or sexual health services to mainstream primary healthcare services.

All these factors combined highlight a strong need for HIV experience and expertise outside HIV-specific services but to date, there remains limited research investigating the perspectives and experiences of service providers outside HIV-specific services. Although many community-based healthcare professionals, especially general practitioners (GPs), will rarely diagnose and care for a person with HIV, they have a critical role in offering appropriate testing and counselling to high-risk patients. Doing so will reduce the number of delayed diagnosis and late care for HIV patients and thereby reducing the number of onward transmission. Understanding the key issues and concerns surrounding provider-initiated testing and counselling (PITC) in this context will better inform governments, policy-makers, community organisations and researchers on how best to support those at the frontline of HIV management and care. Such information can also be leveraged to increase early testing and diagnosis and link patients into appropriate care and treatment.



# Key Research Questions

To begin to understand the key issues surrounding the HIV management, support and care needs among PLHIV from migrant and mobile populations, this project is directed by the following research questions:

1. How PLHIV from migrant and mobile populations experience their infection across diverse settings including clinical, community and personal settings?
2. What are the perceptions and experiences of healthcare professionals and community service providers in providing HIV management and care to priority migrants and mobile populations?





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### Suggested citation:

Le Gautier, R, Thorpe, R and Power, J (2018). A Study of HIV Management, Care & Support Needs among People from Migrant and Mobile Populations in Australia. Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University







