

# **"I WANT TO TEST BUT I'M AFRAID"** BARRIERS TO HIV TESTING FOR PEOPLE BORN IN SOUTH EAST ASIA & SUB-SAHARAN AFRICA PROJECT PRELIMINARY FINDINGS

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#### **PROJECT TITLE**

Barriers to HIV testing among people born in sub-Saharan Africa and South East Asia

#### **ORGANISATIONS**

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#### FOR MORE INFORMATION

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# GLOSSARY

AIDS	Acquired Immune Deficiency Syndrome
CALD	Culturally and linguistically diverse
GP	General Practitioner
HIV	Human Immunodeficiency Virus
HIVST	HIV self-testing
MSM	Men who have sex with men
NSW	New South Wales
PrEP	Pre-exposure prophylaxis
PLHIV	People living with HIV
SA	South Australia
SEA	South East Asia
SSA	sub-Saharan Africa
VIC	Victoria
WA	Western Australia
WHO	World Health Organization

# **KEY DEFINITIONS**

CD4	A type of white blood cell that protects the body from infection. CD4 cells are the primary target of HIV and CD4 cell numbers decline during HIV disease.
Epidemiology	Deals with incidence, distribution and possible control of disease.
Globalisation	Globalisation is a process in which the people and countries of the world are being brought closer and closer together, economically and culturally, through trade, information technology, travel, cultural exchanges, the mass media and mass entertainment.
Heterosexual contact	The reported sexual intercourse between people of different sex.
High prevalence country	High prevalence countries include those with $\geq$ 1% estimated prevalence in at least one year of the last ten year period.
HIV self-collection testing	Self-collection (or home sampling) involves taking a mouth swab or finger prick and mailing it to a laboratory, which makes the results available either by phone, text message, or online.
HIV self-testing	HIV self-testing (also known as home-based testing) is where HIV testing is conducted in the home or similar environment by a community member and individuals interpret the result. It uses the same technology as rapid tests.
HIV rapid testing	Rapid testing uses a pinprick of the finger (or oral fluid, depending on the test) and returns results within 10 to 20 minutes. Most rapid HIV tests detect HIV antibodies; however some can also test for the presence of the virus itself.
Late diagnosis	Measured by a CD4 cell count of fewer than 350 cells/ $\mu$ l at diagnosis. CD4 cells are a type of white blood cell that fights infection. A normal CD4 count is from 500-1,500 cells per cubic millimetre ( $\mu$ l) of blood.
Migrant	Any person who is moving or has moved across an international border or away from his/her habitual place of residence, regardless of (1) the person's legal status; (2) whether the movement is voluntary or involuntary; (3) what the causes for the movement are; or (4) what the length of the stay is.
Mobile populations	People who move from one place to another temporarily, seasonally or permanently for a host of voluntary and/or involuntary reasons.
Priority population	A group more vulnerable to a health condition.
South East Asia	Countries included in region as per the Australian Bureau of Statistics Standard Classification of Countries (SACC), 2016.
sub-Saharan Africa	Countries included in region as per the Australian Bureau of Statistics Standard Classification of Countries (SACC), 2016.



### EXECUTIVE SUMMARY

#### A CHANGING LANDSCAPE

Over the past decade Australia has seen an increase in Human Immunodeficiency Virus (HIV) notifications among people born in sub-Saharan Africa (SSA) and South East Asia (SEA) (1). People born in these regions have the highest rates of HIV diagnosis by region of birth and are overrepresented in late or advanced presentations of HIV infection (2).

Previous research indicates that migrants from SSA and SEA attend health services in Australia regularly, but only 50% have ever tested for HIV (3, 4). General practitioners (GPs) have a vital role in diagnosing HIV infection through appropriate testing, particularly among migrants.

In addition, new testing technologies for HIV such as rapid testing, self-collecting testing and selftesting have recently been made available in Australia. Little is known about the acceptability of these technologies among people from SEA and SSA.

This report provides a brief overview of the preliminary results from the *Barriers to HIV testing* project – a qualitative research project using focus groups and in-depth interviews to explore the barriers and enablers to HIV testing among priority communities born in SSA and SEA, to better understand the factors influencing late diagnosis.

#### **METHODS**

Eleven focus groups were conducted in Western Australia (n=7), South Australia (n=2), New South Wales (n=1) and Victoria (n=1). Where possible peer facilitators were used to conduct the focus groups to increase cultural security and to provide opportunities for peers to be involved in a large multi-jurisdiction research project.

Focus groups participants (n=77) had diverse experiences and backgrounds and included men who have sex with men, individuals on temporary visas and people who had arrived in Australia recently.

#### RESULTS

Across the focus groups we found that participants' understanding of HIV and readiness to test was influenced by:

- experiences in their home country;
- low visibility of HIV in Australia;
- perception of 'safety' in Australia; and
- low levels of perception of individual risk for HIV.

Eleven interviews were conducted with GPs in Western Australia (n=5), New South Wales (n=2), South Australia (n=1) and Victoria (n=3) on their experiences testing patients for HIV from these two regions. Most GPs reported that they often initiated HIV testing with patients, and often did so during sexual health screenings.

GP expectations about cultural and religious values held by patients presented a challenge at times - noting concern of offending, or making patients anxious or uncomfortable by offering HIV testing. Such assumptions also influenced GP perceptions of patient likelihood of being at risk for HIV, as well as their willingness to test.

#### RECOMMENDATIONS

Findings demonstrate a need to broaden the salience of HIV messages for less visible population groups (beyond Australian men who have sex with men). Opportunities to increase HIV testing include GPs offering testing as part of a general health check-up; and exploring new and novel ways to increase access to testing including consideration of rapid testing or self-collection kits in community-based settings.

#### FUNDING

This project was supported by a Healthway Australian Health Promotion Association Graduate Scholarship and a grant from Gilead Sciences Pty Ltd.

#### WHERE TO NEXT?

This report presents the preliminary findings from the project. Additional results will be upload to the WA SiREN (Sexual Health and Blood borne Virus Applied Research and Evaluation Network) -<u>https://siren.org.au/project-overview-barriers-tohiv-testing/</u>

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# INTRODUCTION

Historically, HIV notifications in Australia have been predominately concentrated<sup>1</sup> among men who have sex with men (5). Over the past decade Australia has seen an increase of notifications among people born in sub-Saharan Africa (SSA) and North East and South East Asia (SEA) (1). People born in these regions have the highest rates of HIV diagnosis by region of birth and are overrepresented in late or advanced presentation of HIV infection<sup>2</sup> (2). As such, people who travel to or from countries of high HIV prevalence<sup>3</sup> are recognised as a priority population in Australia's Seventh National HIV Strategy 2014-2017 (6).

This increase in notifications has been in part attributed to migration and mobility between countries of high HIV prevalence and Australia (1). Migration may increase vulnerability to HIV acquisition, as access to health services and social support is different, and risk behaviour of the individual changes in the host country (7). Individuals from culturally and linguistically diverse (CaLD) populations may experience difficulty accessing health services to test for HIV due to barriers including unfamiliarity with health services, language, stigma and discrimination (8-10). The *HIV and Mobility in Australia: Road Map for Action*, a key document in responding to the rise of HIV notifications among migrant and mobile populations, called for further research regarding migrants' knowledge of HIV, attitudes and behaviour in order to inform strategic policy and program responses (1).

Research regarding migrants' experience and risk of HIV within Australia is limited (5). In addition, new testing technologies for HIV such as rapid testing, self-collection kits, and oral testing have recently been made available in Australia. Little is known about the acceptability of these technologies among people from SEA and SSA. Understanding the barriers to HIV testing, and identifying possible enablers may increase testing to ensure early diagnosis, better care and reduce likelihood of onward transmission.

### OBJECTIVES

The objectives of this project were:

- To identify barriers and facilitators to HIV testing among SSA and SEA populations (including differences and similarities between jurisdictions and region of birth)
- To assess the knowledge and perceived acceptability of new HIV testing strategies (oral tests, rapid testing, self-testing kits and clinical testing) among SSA and SEA populations (including differences and similarities between jurisdictions and region of birth)
- To identify barriers and motivators to offering HIV testing SSA and SEA populations from the perspective of clinical staff and general practitioners

<sup>&</sup>lt;sup>1</sup> A concentrated HIV epidemic refers to a HIV prevalence of less than 1% in the adult population (15-49 years), but greater than 5% in a high-risk subpopulation group

<sup>&</sup>lt;sup>2</sup> Measured by a CD4<sup>2</sup> cell count of fewer than 350 cells/ $\mu$ l at diagnosis. CD4 cells are a type of white blood cell that fights infection. A normal CD4 count is from 500-1,500 cells per cubic millimetre ( $\mu$ l) of blood.

<sup>&</sup>lt;sup>3</sup> Refers to a country with a HIV prevalence below 1% in adults aged 15-49 years

### METHODS

This was an explorative study which aimed to gain a better understanding of barriers and enablers to HIV testing from both the perspective of migrants and GPs. The project received approval from Curtin University Human Research Ethics Committee (HREC2017-0088), ACON Research Ethics Review Committee (RERC reference number: 2017/13) and from Relationships Australia (SA) and has been noted by the Human Research Ethics Committee of the University of New South Wales.

The study components were:

- Interviews with GPs from Western Australia (WA), New South Wales (NSW), South Australia (SA) and Victoria (Vic) who see patients born in SSA or SEA
- Focus group discussions with people born in SSA and SEA living in WA, NSW, SA and Vic

#### STEERING GROUP

This project was overseen by a number of researchers, a policy officer and a program manager across the four sites. The steering group was developed to guide the project and provide input into project methodology. One teleconference was held (March).

The following individuals comprised the steering group:

- Corie Gray (Curtin University)
- Gemma Crawford (Curtin University)
- Dr Roanna Lobo (Curtin University)
- Dr Rachel Thorpe (La Trobe University)
- Dr Praveena Gunaratnam (Kirby Institute)
- Lea Narciso (SA Health)
- Enaam Oudih (Relationships Australia South Australia)

#### PROJECT ADVISORY GROUP

The project was overseen by a number of individuals in WA who work closely with the group. The project advisory group met once (March).

The following individuals comprise the project advisory group:

- Corie Gray (Curtin University)
- Bernadette Masbayi (Office of Multicultural Interests)
- Tony Bober (WA AIDS Council)
- Sue Laing (Sexual Health and Blood-borne Virus Program)
- Dr Indi Pattni (Multicultural Services Centre of WA)
- Professor Donna Mak (Communicable Disease Control Directorate)
- Sue Lee (Women's Health and Family Services).

#### SUPPORT AND COLLABORATION

This project has received support from a number of individuals. The following people have been involved in recruiting for and/or conducting focus groups: Amira Hosny (Masters student), Gita Warsito (peer), Agni Manggali (peer), Tony Bober (WA AIDS Council), Matt Bacon (WA AIDS Council), Majok (peer), Victoria Sande (peer), Mabor Chadhuol (North Richmond Community Health, peer), Lea Narciso (SA Health), Enaam Oudih (PEACE SA), Dr Praveena Gunaratnam (Kirby Institute) and Adrian Banks (peer).

Josephine Shearer (volunteer) and Melissa Evans (volunteer) were involved in recruiting and conducting interviews with GPs.

#### FOCUS GROUP AND INTERVIEW GUIDE

The focus group and interview guides were developed based on previous studies reported in the peer reviewed literature, in line with the project's objectives. The guides were refined with consultation from the project advisory group, from the steering group and the peer facilitators involved in the project. The focus group guide was developed to be semi-structured, to encourage facilitators to explore topics of interest as they arose. The focus group and interviews were designed to be informal and conservational in nature, providing an opportunity to understand participants' terminology and world view.

#### FOCUS GROUP FACILITATORS

The decision was made that, where possible, a peer would help recruit for and conduct the focus group. This helps to ensure that the focus group is conducted in a culturally appropriate manner, with a view to capturing more useful data. A guide book has been developed to assist sites to appropriately train peer facilitators. An honorarium (\$100 cash) was provided to facilitators to acknowledge the important role that they played in the success of this project.

#### FOCUS GROUP RECRUITMENT

Peer facilitators, as well as people who work closely with the target group, developed targeted recruitment strategies. Recruitment was conducted via advertisements on social media (Facebook), e-lists for multicultural services, at clinics for men who have sex with men, and through individuals' networks.

#### DATA COLLECTION

Eleven focus groups (n=77) were conducted to capture diverse experiences among different groups. All focus groups were audio-recorded, and lasted between 45 minutes to 90 minutes. Demographics were captured through a self-administrated paper-based questionnaire. Number of participants per group ranged from between 4 - 12. Participants were offered refreshments to acknowledge the time taken to participate, as well as a \$20 gift card.

Eleven GPs were recruited through word of mouth, advertisements in online newsletters, and social media posts. Phone interviews with GPs were semi-structured and ranged between 25 minutes to 50 minutes. Demographics were captured via an online survey, produced in Qualtrics.

#### DATA ANALYSIS

Audio recordings were transcribed verbatim in English by the lead researcher and checked against recordings for accuracy. Transcripts were first read through, then coded initially using NVivo software. From there, codes were organised into overarching themes. Literature was read concurrently throughout data analysis to better explain and further refine themes. Themes were discussed with two members of the steering group.



#### FOCUS GROUP PARTICIPANTS

A total of 11 focus groups were conducted over a four-month period. This involved three SEA men who have sex with men (MSM) groups, three mixed gender African groups, one male African group, one female African group and three SEA women groups.

Countries represented from South East Asia included – Indonesia (14), Malaysia (4), Philippines (3), Viet Nam (3), India (2), Hong Kong (2), Myanmar, Pakistan, Sri Lanka, Taiwan and Thailand. Sub-Saharan African countries were – South Sudan (19), Somalia (5), Botswana (2), Tanzania (2), Nigeria (2), Congo, Djibouti, Ghana, Kenya and Zambia.

CHARACTERISTICS	NUMBER OF PARTICIPANTS			
	Sub-Saharan	South East	All participants	
	Africa (n=35)	Asia (n=42)	(n=77)	
Gender*				
Male	12	19	31 (40%)	
Female	22	23	45 (60%)	
Age**				
18-24	6	5	11 (15%)	
25-29	2	22	24 (32%)	
30-34	6	7	13 (18%)	
35-39	3	4	7 (9%)	
40-44	7	2	9 (12%)	
45+	11	2	13 (18%)	
Years lived in Australia				
<1 year	6	11	17 (22%)	
1-5 years	6	15	21 (27%)	
6-10 years	3	8	11 (14%)	
>10 years	20	8	28 (36%)	
Status in Australia***				
Citizen	23	9	32 (43%)	
Permanent resident	4	6	10 (13%)	
Student visa	6	22	29 (39%)	
Other temporary visa	0	5	5 (7%)	
Education Level****				
Primary school	4	0	4 (5%)	
High school	6	1	7 (9%)	
Year 12 or equivalent	4	2	6 (8%)	
TAFE certificate/diploma	4	2	6 (8%)	
University bachelor degree or higher	15	37	52 (69%)	
Sexuality****				
Heterosexual	18	21	39 (54%)	
Homosexual	1	17	18 (25%)	
Bisexual	0	2	2	
Pansexual	0	1	1	
Other (not disclosed)	4	1	5 (7%)	

Table 1. Socio-demographics of focus group	p participants by region of birth
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\*One gender missing

\*\*Three ages missing

\*\*\*Two statuses missing

\*\*\*\*Two levels of education missing

\*\*\*\*\* Five sexuality missing

#### **INTERVIEW PARTICIPANTS**

A total of eleven interviews with GPs were conducted. This included five in WA, one in SA, two in NSW and three in Victoria. All had over ten years' experience working as a GP.

Table 2. S	Socio-demogra	phics	of GPs
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CHARACTERISTICS	NUMBER OF PARTICIPANTS		
Gender			
Male	4		
Female	7		
Country of birth			
Australia	3		
Overseas	8		
Language spoken other than English			
No	4		
Yes	7		
Current workplace*			
Bulk-billing practice	1		
Community health centre	2		
Private practice	6		
Sexual health clinic	4		
Years practicing as a GP			
10 – 19 years	5		
20 – 29 years	2		
30 – 39 years	3		
40 or more years	1		

\*Able to select more than one option

Table 3. GP frequency of seeing and testing patients for HIV

CHARACTERISTICS	NUMBER OF PARTICIPANTS	
Frequency of conducting a HIV test (overall)		
Daily	3	
Weekly	6	
Monthly	2	
Frequency of seeing patients from South East Asia		
Daily	7	
Weekly	2	
Monthly	1	
Yearly	1	
Frequency of testing patients from South-East Asia	a for HIV*	
Weekly	7	
Monthly	3	
Frequency of seeing patients from sub-Saharan Africa		
Daily	3	
Weekly	2	
Monthly	3	
Yearly	3	
Frequency of testing patients from sub-Saharan Africa for HIV *		
Weekly	1	
Monthly	6	
Yearly	3	

\*One response not recorded

# PRELIMINARY FINDINGS

Results are summarised here in brief. The barriers and motivators of people born in SEA and SEA to HIV testing, the acceptability of testing methods and opportunities to increasing testing among communities respectively are described. Barriers and motivators for GPs in testing patients for HIV are also described, with their recommendations to increase testing.

#### BARRIERS TO HIV TESTING - FOCUS GROUPS

This section reports barriers and motivators to HIV testing identified in focus group discussions. The key themes and sub-themes are described below with examples from the discussions. An overall list and short description of the main themes is provided in the table below.

THEME	OVERVIEW
Accessing health services	<ul> <li>Participants described low engagement with health services for some international students due to feelings of not being 'eligible'.</li> <li><i>"The cover we have is just too complex Then they charge you, like you're fined to be sick"</i> – M, Botswana</li> <li>Some people from Africa (particularly males) described the need to be visibly unwell before they would attend health services.</li> <li><i>"here for 10 years and I don't have malaria or anything, I don't go to a doctor. So this is a common thing with us, you only see the doctor when you are sick"</i> – M, South Sudan Low levels of engagement with health services limit opportunities to test for HIV.</li> </ul>
Experiences from home country	<ul> <li>Experiences of AIDS epidemic in home country can create fear and reluctance to test.</li> <li><i>"…the fear of the unknown is better than…the benefits of testing…I'd rather not know</i></li> <li><i>…the fear associated with…the perception of how people with HIV are still treated</i></li> <li><i>within the African community… there's this other layer of fear upon fear, and they feel</i></li> <li><i>like the unknown is better than… testing" –</i> F, Africa</li> <li>For MSM, expectation of homophobia in relation to accessing HIV information and</li> <li>testing creates barrier.</li> <li><i>"I never really checked in Indonesia… because it's better not to know…once you get HIV,</i></li> <li><i>there is nothing you can do. You die…people still afraid of it, and also – gay and LGB</i></li> <li><i>communities…you can be arrested for being you" –</i> M, Indonesia.</li> </ul>
Visibility of HIV	<ul> <li>HIV not seen often in mass media.</li> <li><i>"I've been in Australia for 14 years now and I've never seen anything on HIV" –</i> M, South Sudan</li> <li>When it was seen, it was frequently negative (i.e. HIV criminal cases or media stories on migrants) contributing to HIV-related stigma.</li> <li><i>"I remember one of my friends asked "so what if you find HIV positive, what do you do?"…"you get locked up, isolated areas" …you find you're HIV positive, you get isolated, you don't stay in the community, that's what they say, you don't see your family and stuff" –</i> M, South Sudan</li> </ul>
Risk perception	HIV often attributed to gay men, sex workers and people who inject drugs. People did not see themselves at risk of acquiring HIV, limiting uptake of testing. <i>"…because its only for bad people you know like bad people like drug people and</i> <i>prostitutes or … people who have free sex, I'm a good girl…I think that there is no</i> <i>chance I get that issue [HIV]"</i> – F, Indonesia
Safety in Australia	<ul> <li>Participants described a perception that HIV was not an issue in Australia, which limiting uptake of testing and increased risk taking behaviour.</li> <li><i>"…people think Australia is so safe, it is a safe place…people think it's okay, I can do anything I want even if I don't check with the doctor I am okay"</i> – M, South Sudan</li> <li>For MSM, peer led testing increased perception of feeling safe to test.</li> <li><i>"[in Australia] it's okay to know about testing, it's okay to know about the gay community"</i> – M, Asia</li> </ul>

Table 4. Overview of barriers to HIV testing identified in focus groups

#### MOTIVATORS AND FACILITATORS TO HIV TESTING - FOCUS GROUPS

Participants were asked for what reason people would test for HIV, and what helped facilitate that. An overview is provided below.

Table 5.	Overview	of motivators	and fa	cilitators to	HIV testing

MOTIVATORS AND FACILITATORS TO TESTING	DESCRIPTOR
Community and partner health	Participants from Africa described the importance of knowing personal status to keep community and partners healthy. <i>"It is very important otherwise you are so selfish to pass it onto others"</i> – M, South Sudan
Individual health	Participants from Asia described the benefits of knowing personal own status to better look after their own health. <i>"I just really, really want to know whether or not I'm healthy so I don't mind [testing] at all"</i> – F, Indonesia
Peer education (informal or formal)	Asian MSM described being associated with the gay community as a facilitator to testing. <i>"I think for me most of the information is from [name] I mean</i> <i>for me about a couple of months ago, [name] took us to test</i> <i>also with partner, just to see, also to see what we do and just</i> <i>also gain assurance"</i> – M, Asia

#### **RECOMMENDATIONS TO INCREASE HIV TESTING – FOCUS GROUPS**

Participants were asked to discuss opportunities to increase HIV testing among communities. Overall, there was a strong sense that 'something needed to be done':

#### "We don't need to hide it, we need to talk about it [HIV]" - F, Africa

An overview of barriers and possible strategies to address these as discussed by participants are presented below. It is important to note that at the heart of all these recommendations was the need for community to be involved. One African woman described people from outside her community coming in to deliver education without consultation:

"They just come in with a PowerPoint... it would be good to have more employed staff from similar cultures because they would understand how to communicate the message" – F, Africa



3 11 1	3
BARRIER	RECOMMENDATION
Lack of awareness of HIV "Until this thing is put out there in the open they can't achieve what we [Africa] have achieved" – M, Botswana	<ul> <li>Community or religious leaders to have positive conversations about HIV and the benefits of regularly testing</li> <li>Social media to be used to promote benefits of testing regularly and promote locations to receive HIV tests (using posts, infographics, short videos etc.)</li> <li>Mass media campaigns on HIV (or STIs in general) encouraging the broader Australian community to test (<i>Note: MSM were strongly against this</i>)</li> <li>GPs to encourage HIV testing in patients by providing accurate information</li> <li>Community forums on HIV</li> <li>Inclusion of people born overseas in HIV-related material (such as pamphlets, online information)</li> </ul>
Patients not regularly engaging with primary	HIV testing to be conducted at community locations
healthcare	or events
"[You go] when the symptoms are full-blown like	<ul> <li>Community leaders to offer HIV testing to</li> </ul>
some physical evidence of what they are feeling" –	community members
F, Alrica	• GPs to offer HIV testing as part of a 'general health
"They don't do it I routinely come to the clinic and	check' and when doing sexual health screening or
they don't say anything about HIV" – F, Indonesia	pap smears (for women)
	GPs to provide HIV testing when requested
	<ul> <li>Increased availability of rapid testing</li> </ul>
	Home-testing kits to be permitted for use in Australia
HIV related stigma	<ul> <li>PLHIV to openly share their status and stories</li> </ul>
"I know a neighbor who works as a sex worker,	PLHIV to offer peer testing
know" – M. Philippines	<ul> <li>More positive reporting on HIV by the media</li> </ul>
- , , , , , , , , , , , , , , , , , , ,	
Unsure of where to test	More advertising of HIV testing locations or pop-up
"The problem here is when you arrive is how,	testing centres in key locations
where do you access?" – M, Nigeria	<ul> <li>Information for international students on where to</li> </ul>
	access testing
Fear of testing positive	<ul> <li>Address HIV-related stigma and myths</li> </ul>
n m ajraia oj naving HIV" – F, Myanmar	<ul> <li>Eroo HIV testing to be promoted (particularly for</li> </ul>
<i>Cost</i> <i>"I'm sick and tired of being ripped off by everything here I just don't go," –</i> F, Indonesia	<ul> <li>Free niv testing to be promoted (particularly for international students)</li> </ul>
	<ul> <li>Discounted or free home-testing kits</li> </ul>
	<ul> <li>Universal access to HIV treatment if necessary<sup>4</sup></li> </ul>

Table 6. Focus group participants' recommendations to increase HIV testing

While these are presented as opportunities to increase HIV testing, there was fear that overall increased messaging about HIV testing would in fact lead to increased HIV related stigma, and 'blame' for communities 'bringing in HIV'. This fear of blame was most noticeable among African participants, who expressed concern that HIV was already seen as an 'African disease'.

<sup>&</sup>lt;sup>4</sup> Currently, PLHIV who are not eligible for Medicare or the Pharmaceutical Benefit Scheme cannot access subsidised **HIV treatment** 

#### BARRIERS AND MOTIVATORS FOR TESTING PATIENTS FOR HIV - INTERVIEWS

This section reports on the interviews conducted with GPs. This section presents an overview of the barriers and motivators to testing patients for HIV, and an overview of the recommendations to increase testing presented by GPs.

GPs reported initiating HIV testing on most occasions, with few direct requests from patients. While several factors increased the likelihood, others impeded upon GPs readiness to test a patient from SSA and SEA for HIV. An overview of the main themes are identified in the table below.

THEME	DESCRIPTOR
	DESCRIPTOR
Interest and experience in HIV testing	GPs who had a number of years of experience testing patients from these two regions reported feeling more confident than those that didn't. GPs who were either involved in research or read frequently had a greater knowledge of priority groups. <i>"I have an interest in sexual health, women's health so I'm always thinking about it [HIV] as much as I can"</i> – GP05
Opportunities for testing	GPs reported that a patient's request for sexual health screen helped facilitate offering of test, while they perceived that it wasn't as appropriate to offer testing for patients who came for other concerns (such as a cold). <i>"Obviously you don't pounce on someone when they have a</i> <i>cough and say 'oh by the way what about your HIV status'"</i> – GP 03
Language and interpreters	GPs experienced difficulty in securing an interpreter who was of the appropriate gender and who was confident in discussing sexual health. Interpreters who they worked with often and had a good working relationship with helped facilitate testing. <i>"Using a phone interpreter can be hit and miss… sometimes</i> <i>you can tell that someone isn't very comfortable talking</i> <i>about sexual history of a client… Having someone that you</i> <i>see regularly who then understands the types of questions</i> <i>that you ask and why you ask them… that actually makes a</i> <i>big difference"</i> – GP 06
Cross-cultural communication	GPs expressed concerns about approaching people from these regions about HIV, due to fear of offending or causing fear. <i>"…I'm a little bit more delicate I suppose of how I go about that conversation… I don't want them to think I'm making assumptions about them"</i> – GP 08
Pre-test counselling	Spending time on counselling provided an opportunity to provide information on HIV and to address patient concerns. <i>"Patients won't get tests with informed consent unless they</i> <i>feel that they have enough education about the testing they</i> <i>are getting and I don't think it's fair to just test I think there</i> <i>is a lot of fear around HIV testing there is a lot of stigma" –</i> GP 02

Table 7. GP barriers and motivators to testing patients for HIV



#### RECOMMENDATIONS FOR INCREASING HIV TESTING AMONG PATIENTS - INTERVIEWS

GPs were asked what could be done to increase HIV testing among people born in sub-Saharan Africa and South East Asia. An overview of the barriers and recommendations are provided below.

Table 8. GP recommendations to increase HIV testing

BARRIERS	RECOMMENDATIONS
GPs not aware of HIV priority populations or	Vearly potification rates of HIV and other STIs at
unsure how to approach sexual health screenings "some updated resources about prevalence in different communities in Australia because I don't really know that" – GP 04	<ul> <li>rearry notification rates of Fiv and other Sris at national and jurisdictional level to be sent to GPs</li> <li>Increased opportunities for GPs to attend information sessions on sexual health and blood borne viruses</li> </ul>
SEA and SSA communities are 'hard to reach' "I can only understand how hard it is to break through in that community and make them aware of these [sexual health] things" – GP07	<ul> <li>Availability of testing at community-based settings (e.g. multicultural centres, religious centres)</li> <li>Roll out HIV self-testing kits</li> <li>Widening of focus of HIV community organisations beyond Australian gay men</li> </ul>
<b>Patients with low knowledge of HIV</b> "People don't understand [HIV] and the translators don't necessarily understand either it's quite a medical consultation to try and break down some of those myths as well" – GP06	<ul> <li>Culturally appropriate and translated resources to be available to give patients</li> </ul>
<b>Patients not requesting HIV testing</b> "I think making the community aware will be easierMy barrier is that I'm not able to pick a patient and say that they should be tested it can be missed" – GP07	<ul> <li>Interventions to increase HIV testing among communities, delivered by communities (e.g. community info sessions held by community leaders or religious leaders)</li> <li>Advertising free and confidential HIV testing centres</li> </ul>
<b>Gender</b> <i>"If there was a male in the room I would not saying anything about my genitalia but I would a female doctor" –</i> GP05	<ul> <li>Clinics to offer both male and female staff</li> <li>Receptionist to offer choice of male or female doctor to patient</li> </ul>
Language or cross-cultural communication "It's more of an issue for me because I haven't asked her the question because I haven't known how it would go down I was anxious about how she would cope with me asking that through a male interpreter" – GP 08	<ul> <li>Training of interpreters to feel confident asking sexual health questions</li> <li>Increase availability of interpreters (both male and female), particularly for small language groups</li> <li>Clinic support staff pre-booking interpreters</li> <li>Availability of bicultural workers to support GP</li> <li>Research to better capture communities understanding of health, HIV, same sex relationships, etc. and terminology used to describe these concepts</li> </ul>
<b>Fear of offending patient</b> "To say that I do it for you [HIV test], maybe they get offended" – GP10	<ul> <li>Offering HIV routinely (i.e. for all new patients)</li> <li>Promoting a HIV test as something everyone is offered</li> </ul>
<b>Short consultation times</b> <i>"It's easier to offer them a urine test rather than</i> <i>taking a detailed sexual health history [for HIV]. You</i> <i>have limited time"</i> – GP04	<ul> <li>Increase consultation times during some sessions to promote wider participation</li> </ul>



### DISCUSSION

This project highlights the complexity of late HIV diagnoses among people born in sub-Saharan Africa and South East Asia. It has identified a number of barriers to accessing testing, both structural and sociocultural, and is consistent with previous research in Australia (3, 11, 12).

What this work adds to the available research is a number of recommendations to increase HIV testing, as proposed by community members. Considering this and the current literature, the following recommendations are proffered in brief with a focus on interventions to increase HIV-testing that are multi-strategic and community-led.

It is important to note that these recommendations are broad and may not be appropriate for all groups. It is acknowledged that while challenging, it is important to recognise the heterogeneity of migrant groups and as far as is practicable segment migrant groups in order to identify and respond to their unique needs. Further, this project identified a critical need for communities to see themselves represented in the HIV-response, while avoiding putting 'blame' on specific groups. Striking a balance here will be difficult. In line with good health promotion practice, consultation and engagement with community is necessary to ensure that the community has buy-in to forthcoming projects and a voice on issues that most affect them.

#### **RECOMMENDATIONS FOR POLICY**

**Recommendation 1:** Universal access to HIV treatment for Medicare ineligible people living with HIV. The Australian Government provides subsidised antiretroviral treatment (ART) to PLHIV eligible for Medicare through the Pharmaceutical Benefit Scheme (PBS). Temporary residents who are ineligible for Medicare must therefore pay the full treatment cost, source treatment from their home country or import generic drugs from oversea suppliers. Without access to effective HIV treatment, health outcomes for these individuals are further complicated and present the risk of onwards HIV transmission to their partners (13). Universal access to treatment allows people to test without fear of not being able to afford treatment and subsequently either not accessing treatment, or returning to their home country (14, 15).

### **Recommendation 2:** HIV self-testing (HIVST) kits to be approved for use in Australia by the Therapeutic Goods Association

Availability of HIVST may increase testing among groups who are concerned about confidentiality, are embarrassed about discussing their sexual behaviour with health professionals, or who are concerned about judgment on behaviour from health professionals (16, 17). Currently the only option in Australia is to purchase unregulated HIVST online, raising concerns about the quality of such tests, and the lack of health information available, such as local HIV counselling (18). Necessary support needs to be made available through adequate funding to ensure patients who receive a reactive test are linked into appropriate care (18). Opportunities to subsidise HIV testing kits, or to collect for free, should be considered by government and/or other funding bodies.

#### **Recommendation 3:** Assess benefits of increasing availability of rapid HIV testing

Consider the appropriateness and effectiveness to expand rapid testing sites including new locations and providing rapid testing to populations other than gay and bisexual men in jurisdictions where this is not available (19). Rapid testing provides fast results, and can address some of the anxiety around waiting for a test result, or patients not returning for follow up appointments to receive results.

**Recommendation 4:** Inclusion of PrEP (Pre-Exposure Prophylaxis) in the Pharmaceutical Benefit Scheme PrEP is recommended for at-risk groups by guidelines in the United States, Europe and Australia, and globally through the WHO (20). The ASHM guidelines recommend daily use of PrEP for both men who have sex with men and heterosexual populations who meet high or medium risk criteria. This includes sexual intercourse with a partner from a high HIV prevalence country, or for individuals who are travelling to a high HIV prevalence country and are likely to be sexually active (20). PrEP trials are currently underway in some jurisdictions and will add more evidence to the effectiveness of PrEP.

#### Recommendation 5: Remove criminal prosecutions of the sexual transmission of HIV

For many people outside the gay community, the media is often a significant source of information on HIV (21). Criminalisation of HIV transmission only adds to HIV-related stigma, and is inconsistent with UNAIDS policy guidelines<sup>5</sup> and public health messaging. Fear of prosecution may deter people from disclosing their status to a sexual partner. Criminalisation of HIV is not believed to contribute to a reduction of onwards transmission<sup>5</sup>.

#### RECOMMENDATIONS FOR PRACTICE

**Recommendation 6:** Increase positive conversations on HIV through community settings Community organisations to identify appropriate methods to increase positive conversations about HIV and regular testing among community, led and delivered by community and religious leaders. This may be through seminars, after religious ceremonies, or through drama or story-telling. Community and religious leaders are uniquely poised to 'break the silence' on HIV, by welcoming and accepting people living with HIV, and encouraging community members to know their status (22).

**Recommendation 7:** Addressing HIV-related stigma and sharing positives stories by people living with HIV Organisations to encourage people living with HIV from these communities to share positive living stories (not necessarily disclosing their own status) where they feel safe to do so. Identify platforms for people living with HIV to share with community groups, such as through community forums, videos, social media, written stories or through drama. This involvement of PLHIV needs to be meaningful and be led by PLHIV, as outlined in the UNAIDS "Greater Involvement of people living with HIV"<sup>6</sup>.

#### Recommendation 8: Advertise locations of where to test

Advertise (through social media, online sites, etc.) locations where HIV testing can be conducted – particularly where it may be free (including for international students) and confidential. Community organisations and health services to identify, work with and promote GPs, clinics or other community-based centres where staff have undertaken cultural competency training, and are comfortable and willing to test patients for HIV.

**Recommendation 9:** GPs to routinely offer HIV testing and be more aware of emerging priority populations People from high HIV prevalence countries, or who travel to high HIV prevalence countries, are considered priority groups for HIV testing<sup>7</sup>. Peak bodies and/or state governments should encourage GPs to offer HIV testing as part of a general health checkup; when a patient first joins the practice; or is requesting blood tests, rather than waiting for patient self-disclosure of 'high risk'. The ASHM HIV testing policy states that a detailed sexual behaviour and/or drug use history is not necessary for testing; and patients who request a HIV test should be tested<sup>7</sup>. Opportunities to increase GPs knowledge of priority populations for HIV should be identified, such as through short emails or mailouts of national and jurisdictional epidemiology. This work can be targeted to GPs who work in locations where there are a high volume of patients from these regions.

#### **Recommendation 10:** Make HIV-testing information sheets available for use by GPs

Peak bodies, community organisations and/or research centres to consolidate useful information sheets on HIV, HIV transmission, and HIV testing process (including contact tracing, length of time for results, treatment options if diagnosed, etc.), translated into priority languages, for GPs to deliver to patients who are unfamiliar with testing. Information sheets to be developed in consultation with GPs and patients, and housed online to be available for download. Have a particular focus on GPs in locations where priority communities frequently visit.

<sup>&</sup>lt;sup>5</sup> http://www.unaids.org/sites/default/files/media asset/jc1601 policy brief criminalization long en.pdf

<sup>&</sup>lt;sup>6</sup> http://data.unaids.org/pub/briefingnote/2007/jc1299 policy brief gipa.pdf

<sup>&</sup>lt;sup>7</sup> http://testingportal.ashm.org.au/images/HIV Testing Policy Feb 2017.pdf

# **Recommendation 11:** Identify opportunities to test for HIV outside sexual health clinics and general practices.

Opportunities include 'pop up' testing in community-based settings using rapid testing, or self-collection oral samples collected by peer workers (23). Such initiatives could be delivered by multicultural organisations using peer workers or people living with HIV. There are also opportunities for primary health services to be made available at multicultural organisations that include HIV testing.

# **Recommendation 12:** Ensure international students are provided relevant information on accessing health services in Australia, including sexual health services and HIV testing

This could be delivered during orientations, clear information made available on university's website, at international student social events, or using other students as 'peer educators' during the semester. Advertise free health services on campus where available.

# **Recommendation 13:** Ensure communities are well informed about new HIV prevention measures, such as PrEP

This is particularly important for those who are traveling to high HIV prevalence countries. Community organisations to work with GPs, community health workers and community and religious leaders to ensure they are aware of new prevention methods, and are able to support individuals in finding further information. This may be via forums or workshops or evidence updates. As PrEP trials continue, we expect more information will be made available to key groups.

#### RECOMMENDATIONS FOR RESEARCH

# **Recommendation 14:** Evaluate interventions and campaigns to increase HIV testing among people born in sub-Saharan Africa and South-East Asia

Interventions or campaigns such as 'pop up' testing or use of social media, should be appropriately evaluated and reported on by community and government organisations. With support from research centres, develop core indicators that measure success beyond knowledge increase and report on HIV-related stigma, cultural and religious barriers to testing. Information should be published in the peer reviewed literature and disseminated via open access tools such as case studies or reports and community fora.

# **Recommendation 15:** Ensure that people born in sub-Saharan Africa and South-East Asia are accurately and appropriately represented in all HIV-related research (such as current PrEP trials).

Identify processes to facilitate participation for these communities (e.g. peer recruiters, community involvement from onset of research), and address barriers to non-participation.

# **Recommendation 16:** Implement a national surveillance survey on HIV knowledge, testing and HIV testing barriers for priority migrant communities.

In order to accurately capture critical data on often hidden populations a national, periodic survey should be conducted, to be delivered in partnership between government, research centres and community organisations. This will assist in identifying at-risk sub-populations, and track success in addressing barriers to HIV testing.



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