

# IDENTITY & SECRECY

THE EXPERIENCES OF AFRICAN &  
ASIAN WOMEN LIVING WITH HIV  
IN SOUTH AUSTRALIA



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### **Explanatory Note**

The HIV Women's Program and Positive Life SA acknowledge that no single term can encompass the diversity of the women being discussed in this document. All participants were born in an Asian or African country. For ease of reading and consistency, this document generally uses the word *African* rather than *African-born*, and *Asian* rather than *Asian-born*, or other descriptors. (The terms *Asian-Australian* or *African-Australian* are not relevant in this context, since none of the participants in this study are Australian citizens.) The terms *African communities* and *Asian communities* are intended to broadly include communities, ethnic and language groups, as well as individuals not connected to a particular cultural community. *High prevalence countries* refers to all Asian and African countries with high rates of HIV (a HIV prevalence greater than 1% in the general population).

We recognise the variety and complexity of the many cultural groups and countries within Asia and Africa, and amongst participants in these consultations. Use of these brief, convenient ways to discuss aspects of identity and culture are not intended to suggest homogenous African and/or Asian cultures.

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# Introduction

There has been a significant increase in the number of people with HIV from diverse cultural backgrounds living in South Australia in recent years. In response to this emerging trend, in 2011 the HIV Women's Program consulted women from a variety of cultural backgrounds through a forum entitled *Respect their ways: Listening to HIV positive women from diverse cultural backgrounds*. The findings of this consultation were subsequently published in *HIV Australia* (Price 2012). This Women's Forum produced rich data on the needs of a small group of women from various African, European and Asian backgrounds – some of whom were born in Australia. Participants were selectively invited to participate. This was a deliberate strategy to address the expressed wishes of African and Asian women that other women from their region would not be present.

Since 2011, the number of HIV-positive women from high prevalence countries in South Australia has increased significantly. It is unclear exactly how many Asian and African women are living with HIV in South Australia. **Attachment 1: Epidemiological Data** provides an overview of the available data. In summary, at least 30 African and 20 Asian women are currently known to be living with HIV in South Australia, and total numbers are expected to be higher than this. Nationally, it is estimated that, of the estimated 2,671 women diagnosed with HIV, approximately 18% (approximately 480 women) are Asian and 20% (approximately 535 women) are African.

The HIV sector has recognised the importance of responding to the needs of HIV-positive Asian and African women. In South Australia, this is reflected in the inclusion of strategies related to women from high prevalence countries in the *HIV Prevention in Culturally and Linguistically Diverse Communities in South Australia 2012-2016: Strategic Document* (CHIP 2012). Nationally, the *Seventh National HIV Strategy 2014-2017* also recognises HIV-positive people from high prevalence countries and their partners as a priority population for targeted prevention and treatment, noting that *women from these population groups have a higher risk of HIV than women in the general population* (Department of Health 2014:14).

Accordingly, in 2013, the HIV Women's Program and Positive Life SA decided to more formally document the experiences and insights of women from high prevalence countries - to build on the findings of the 2011 Women's Forum and strengthen the HIV sector's capacity to provide evidence-based service delivery. Further to the Forum, this consultation was designed to include more women, verify the accuracy of Forum findings for women born in African or Asian countries, and focus on additional topics. This consultation was also designed to contribute toward the CHIP strategy, particularly to:

- *Contribute to creating safe, non-isolated, healthy, family and community environments for CALD people affected by HIV. (Objective 2.2)*
- *Increase the confidence of CALD women and children with HIV to articulate their needs and negotiate their safety and wellbeing (Objective 2.3)*
- *Provide support and advocacy to women living with HIV in renegotiating their roles and expectations within their cultural context, families and communities. (Strategy 2.3.3)*
- *Promote and provide knowledge-sharing opportunities ... about CALD HIV issues to service providers in the HIV sector ... (incorporating) lived experiences while protecting client confidentiality. (Strategy 4.3.2)*
- *Identify issues impacting HIV prevention in CALD communities and social, political, physical and cultural determinants of health and wellbeing for CALD PLHIV. (Strategy 5.3.1)*

This consultation aimed to document the perceptions of HIV-positive women from high prevalence countries, with a focus on the realities of living with HIV, women's self-identity and the consequent service delivery needs of Asian and African women. It also gathered participants' insights on what it would take for women to feel better included in their cultural communities, and their advice on how to reduce the risk of HIV transmission within their cultural communities in South Australia.

It appears that this is the first published study focused exclusively on the experiences and needs of Asian and African women living with HIV in Australia.

# Consultation Methodology

This consultation was a joint project between the HIV Women's Program and Positive Life SA. The original intention was that the project should occur in three stages:

1. A Women's Forum for HIV-positive women from high prevalence countries (Saturday 19 October 2013) to gather women's input on a set of questions. The program was designed to concurrently provide an informal peer education/support and health promotion event.
2. Follow-up interviews with other African and Asian women (using the same questions) to augment Forum findings.
3. Verification of the reported findings at a further Women's Forum (Wednesday 14 May 2014) with women who had participated in the consultations.

This process was substantially revised throughout 2013-14, in response to the interests, needs and preferences of participants. The first forum was cancelled due to lack of registrations: all but one woman were clear that they did not wish to attend an event where there was a possibility of meeting other HIV-positive women from their own region. Consultation via individual interviews became the primary data collection tool for the project. It was hoped that, following the individual interview process, women would be willing to attend a second forum to reflect on draft report findings and provide any further feedback and ideas. However, during the interview process, all but one woman were very clear that they would not be willing to participate in a forum. Accordingly, the forum scheduled for May 2014 was also cancelled.

In all, the HIV Women's Program was in contact with 31 women<sup>1</sup> and Positive Life SA with 17 women<sup>2</sup> from high prevalence countries (with most of the latter engaged with both services). A total of 15 women were individually invited to participate in this consultation. Several women responded positively to the invitation, however practical difficulties with scheduling interviews precluded them from the process.

It was intended to invite a further 7 women to participate, particularly women who would require an interpreter to fully contribute, however resource constraints (see *Limitations of Methodology* below) reduced the time available to complete this project. These were generally women who were very recently diagnosed and/or newly in contact with the service(s).

The opportunity for women to participate in the study was also widely promoted to HIV and migrant health services in South Australia, through a variety of means including the CALD HIV Interagency Committee (CHIC) and the HIV sector's Interagency Workers Forum (IWF). All agencies were encouraged to support women within the target group to participate in the consultations. No women new to the HIV Women's Program were referred to this consultation project.

Ultimately, a total of 10 interviews were conducted by HIV Women's Program staff (either separately or together) in Adelaide. A consistent set of questions was asked of each participant. These were grouped under 4 headings:

- *Your identity*
- *Feeling comfortable using HIV and other services*
- *Reducing the risk of HIV transmission in your (cultural) community*
- *Feeling part of your (cultural) community.*

A copy of the questions is included as **Attachment 2: Interview Questions**.

Women were paid \$25 for their time. Most expressly commented on also being motivated by wanting their experiences articulated and heard: for service providers and other community members to understand their situation, experiences, needs and preferences.

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<sup>1</sup> 18 African women; 13 Asian women

<sup>2</sup> 12 African women; 5 Asian women

The consultation was jointly developed, designed, monitored and reviewed by the HIV Women’s Program and Positive Life SA. All interviews were conducted by the HIV Women’s Program. De-identified findings were provided to Positive Life SA who then collated the data, undertook a literature search and wrote this report. This final report was endorsed by staff from both services.

## Limitations of Methodology

Four (4) key limitations impacted this consultation project:

1. **Time and resource constraints.** Moving from primarily consulting with women in a group setting to individual interviews required a substantial additional time commitment. Defunding of the HIV Women’s Program (effective 30 June 2014) meant that the consultation timeline could not be extended to include all prospective participants. Interviews with 5 women who had stated their interest in participating could not be completed within the timeframe (despite multiple attempts to reschedule interview times). Approaching a further 7 women who required a higher level of support to participate (for most, an interpreter) was unable to occur within this limited timeframe. This reduced the opportunity for women, particularly African women from a refugee background, to participate.
2. **Verification of findings.** Cessation of the HIV Women’s Program also meant that there was no opportunity to verify the findings of this report with participants in a culturally appropriate way (that is, through a substantial conversation with each individual woman). Both organisations agreed not to undertake a *nominal* process (e.g. asking participants to sign off on a written report), because this would be inconsistent with the level of English language literacy of some participants.
3. **Varied depth of interviews.** The level of detail of discussion in each interview varied. This reflected the length and nature of the relationship between the woman and interviewer, and the consequent level of pre-existing trust. In particular, some women had become involved with HIV services very recently: it was inappropriate to probe for information with these *new* participants beyond the level of detail volunteered by the woman herself.
4. **Responding to women’s priorities.** Many women, particularly African women, prioritised their family needs and attending English classes ahead of participation in this consultation. The HIV Women’s Program respected women’s decisions, however these competing interests often led to (repeated) cancelled interviews: a number of women who were keen to participate ultimately did not have the opportunity to contribute their ideas to this consultation.

## Participant Profile

Consultation participants represented a cross section of the women from high prevalence countries now living with HIV in Adelaide. A total of 10 women from 8 different countries of origin (4 African countries and 4 Asian countries) participated in interviews. The age profile of participants was also varied, with representation from women ranging in age from their mid-20’s to their late 50’s.

Asian	6
African	4
<b>Total</b>	<b>10</b>

Table 1: Cultural Background of Participants

20’s	3
30’s	2
40’s	2
50’s	3
<b>Total</b>	<b>10</b>

Table 2: Age of Participants

Most participants were relatively recent arrivals in Australia. Five (5) women had been in Australia for 2 years or less, and 8 had been in Australia for less than 5 years. Most had been diagnosed with HIV relatively recently, with 5 women having received their diagnosis during the past 2 years.

Less than 12 months	1
1-2 years	4
3-5 years	3
5-10 years	1
More than 10 years	1
<b>Total</b>	<b>10</b>

**Table 3: Participant Length of Time in Australia**

Less than 12 months	3
1-2 years	2
3-5 years	2
5-10 years	1
More than 10 years	1
Unknown	1
<b>Total</b>	<b>10</b>

**Table 4: Time since Participants' HIV Diagnosis**

For 7 women, the time since their HIV diagnosis was the same as the length of time they had been living in Australia. That is, these women's HIV was diagnosed as part of the immigration process. At least 2 women had acquired HIV through sexual assault in a conflict zone, some years prior to their migration to Australia. Other participants' comments suggested that they had also been living with HIV for a considerable time prior to diagnosis.

Yes - currently	9
Yes - past	1
No	0
<b>Total</b>	<b>10</b>

**Table 5: No. of Participants on HIV Treatment**

All but one participant were currently receiving antiretroviral treatment (ART). This participant was well informed about the benefits of ART and had actively chosen not to maintain treatment due to a combination of her continuing good health and the adverse side effects of past HIV treatment.

Participants' family situations varied. 4 of the 5 women with Australian husbands were from Asian backgrounds, with only one of the Asian women being a parent. All the African participants had at least one child; however 3 of the 4 African women were currently single. (At least one was married upon entry to Australia: the previous relationship status of the remaining African women is unknown.)

One child	2
More than one child	3
No children	5
<b>Total</b>	<b>10</b>

**Table 6: Parenting Status of Participants**

Single	4
Australian husband – HIV-positive	2
Australian husband – HIV-negative	2
Australian husband – HIV status unknown	1
Non-Australian husband	1
<b>Total</b>	<b>10</b>

**Table 7: Current Relationship Status of Participants**

Participants entered Australia by a variety of means – most commonly, through a Spouse Visa:

Spouse Visa	4
Humanitarian (Refugee)	1
Skilled Migration	2
Student Visa	1
Other temporary visa*	1
Unknown	1
<b>Total</b>	<b>10</b>

**Table 8: Original Immigration Status**

\* details precluded to protect participant privacy

Spouse Visa	2
Humanitarian (Refugee)	1
Student Visa	1
Other temporary visa*	1
Permanent Resident	5
<b>Total</b>	<b>10</b>

**Table 9: Current Immigration Status**

\* details precluded to protect participant privacy

All the women who have lived in Australia for 4 or more years now have Permanent Residency.

# Consultation Findings

## What women said about their identity

Participants indicated that their HIV status played a very small part in their *identity*. When asked the open-ended question – *How do you see yourself?* – 8 of the women described their self-identity in relation to others.

Eight (8) women primarily identified themselves in the context of their family - as a *wife, mother, sister* and/or *grandmother*. All 4 African women mentioned their role as a *mother* first. Only one woman mentioned being a *friend* as part of her identity. Only 2 women, both single Asian women, did not describe themselves in familial terms: one described herself as *a strong woman and healthy*, and the other, as an *international student*. Only 4 women mentioned being HIV-positive as part of their identity, and all were very clear that it was a small part.

*I see myself as a worker, wife, sister. I have only been diagnosed with HIV in last few months and it is a small part of who I am and I hope to keep it that way. I am still the same person. (Asian Woman)*

0%	1
5%	2
10% - 20%	2
40%	1
50%	3
80%	1
<b>Total</b>	<b>10</b>

**Table 10: How much (%) of your identity is being HIV-positive?**

Women were later asked: *How much of your identity is being HIV-positive?* This question produced widely varying results (from 0% - 80%).

Interviewers found this question difficult to explain and several women found it difficult to answer. It was clear from participants' flanking comments (combined with the fact that they did not mention their HIV status when responding to the earlier open question) that most were describing the impact of HIV on their day-to-day life rather than its place in their identity (e.g. one woman said: *Can vary on good and bad days.*)

The impact attributed to HIV in women's lives tended to parallel their length of diagnosis and state of health. The more recently diagnosed women and/or women facing significant health challenges were more likely to indicate a higher percentage. For example:

*About half my life – positive 1 year. (Asian Woman)*

*Treatments did enable me to move on. It doesn't play on my mind. You must be mentally, physically, emotionally strong to achieve this rating – stay strong and positive. (African Woman)*

*I am the same person and often forget being HIV positive. (Asian Woman)*

**HIV has a significant impact on most women's lives, choices and decisions.** For many participants, living with secrecy has been the greatest impact: other women noted the impact of various fears and anxieties associated with HIV. Several women talked about the practical impacts of HIV on their lifestyle, employment and immigration options. Most imagined that their life would have been better if they hadn't had HIV – they could have more easily met new people or a partner; felt *happier, freer* and more relaxed around other people; been more conversational about their health; been healthier; been able to travel more easily; been able to focus more on the future; and/or felt less obliged to practice safe sex.

Most (7) women focused on their need to keep their HIV status a **secret**, and the impact of this on their quality of life. Two (2) participants had not told immediate family members about their HIV diagnosis – in one case, her partner; in another, one of her children. Another lived with the constant fear of people finding out. For others:

*My husband is also HIV-positive and he does not want me to tell anyone about us, but I have told a friend. She has known me for a long time and has been very supportive. We talk through email and*

*my friend will send me information that she thinks may be helpful. I feel guilty for asking her to keep this secret. (Asian Woman)*

*I would prefer people not know and continue to treat me the same. (African Woman)*

*Once you trust and disclose then get hurt, (it) makes it harder to do again. (Asian Woman)*

Most women focused on the emotional impact of HIV, with both an African and an Asian woman worrying about the possibility of an early death. Two (2) talked about trying to overcome their fear associated with HIV so they could move forward:

*What can I do? ... accept it. Sometimes it is hard, I get scared – but I keep moving on. (Asian Woman)*

*I try not to think about having HIV. If I think too much that I will get sick and die, then I am overwhelmed with negative thinking and it means that I do nothing. I can't deny it, but I want to put it behind me and move on. (Asian Woman)*

One woman who acquired HIV in a war zone is impacted by both her experience of violence and the hidden stigma of HIV:

*As a woman of rape and that's how I got my HIV, it has affected many aspects of my life. Sometimes I feel I don't fit in society like other mothers. (African Woman)*

A number of women also talked about dealing with illness (particularly those with multiple co-morbidities), the ongoing risk of ill-health, the life-long commitment to treatment and taking daily pills. The practical constraints arising from attending medical appointments – particularly in a hospital setting, where long waits are often involved – had wider implications. Three (3) women talked about how keeping their doctors' appointments precluded them from employment.

Several women talked about the more practical impact of HIV on their lifestyle choices, residency and access to work.

Three (3) women raised the impact of being HIV-positive on international travel and immigration - particularly accessing a partner bridging visa, permanent residency and, ultimately, Australian citizenship.

One woman had found having HIV a barrier to working in the health industry in Australia. Another had been precluded from working in hospitality in her country of birth: HIV testing is required and social attitudes preclude working with food. Another felt she no longer had the energy to do physically demanding work.

*... if I did not have to think about HIV then I would not have to focus on health forever – the rest of my life. It may have made immigration and residence to Australia much harder. Lawyer needs speciality knowledge ... it's expensive – no HIV would make it easier I believe. (Asian Woman)*

Several women aspired to a life less impacted by HIV. One African woman saw the support that she had received as helpful in seeing life *from a positive angle*. Another participant was one of several women who looked forward to a time when HIV would not affect their lives:

*I have been very unwell since diagnosed but not just with HIV and it has changed my focus in life for a while – I have not been able to return to work this year yet, I have taken a while to get used to treatments and we had to cancel a planned overseas holiday as the doctors told me that I need to stay near medical support. I get tired very easily now – maybe that is the HIV. ... I don't think it will change any life plans that we will make together. Once I get past this current illness then I expect to go back to doing all my normal things. I am confident that it will be OK. (Asian Woman)*

On the other hand, one woman perceived HIV as having a limited impact on her life decisions and choices:

*(Being HIV-positive) mostly does not influence my decisions – but I do check if being HIV is OK to study or work. It doesn't stop me doing anything, in fact, sometimes I forget. I look and feel well and stay on my treatment ... one pill per day, easy. (Asian Woman)*

Only one woman had experienced no impact:

*HIV doesn't affect any of my decisions. I just live a normal life – same as if I didn't have HIV.*  
(African Woman)

And, another believed her life had been enriched by her experience of HIV:

*I am stronger, wiser, appreciate life more.* (African Woman)

## Women's service delivery needs

Nine (9) of the 10 women named the specific HIV services they are currently using. The remaining woman received *doctors, oral hygiene, nursing support and community support*, but did not name the particular agencies providing these services. Note that most women used more than one service:

Service	No. of Women
HIV Women's Program	9
Royal Adelaide Hospital	7
Royal District Nursing Service	6
Positive Life SA	4

**Table 11: HIV services currently being used by participants**

Three (3) women commented on how they valued the services and support received from these agencies, and felt encouraged to return.

*In Australia services are good. I keep going back to a service if they listen to me and my problems and if they follow up on what they say they will do for me ... I like that. If what they do for me makes me feel better. And if I feel more educated and informed. If they are thoughtful and considerate I would go back.* (Asian Woman)

Another woman clearly distinguished between these HIV services and mainstream services.

*I find services in the HIV sector friendly, helpful. Other services treat you less respectfully.* (Asian Woman)

Some women suggested possible improvements in the range of services available to them. This included access to (free or affordable) migration assistance and personalised assistance navigating the income support system. Some women also sought assistance in accessing education, employment and housing. **Table 12** details the service delivery needs of the 7 women who sought further services. Again, several women sought more than one service:

Area of Need	No. of Women	Includes ...
Migration Assistance	3	Migration lawyer; HIV/AIDS Legal Centre (NSW).
Income Support	3	Centrelink (x 3) ... A dedicated worker (same person); housing.
Education & Employment	3	Access to tertiary education; support & information re study and employment opportunities; support to re-enter workforce (building networks).
Other	1	Health (RAH, RDNS); Housing (Anglicare); Resettlement Program (Migrant Resource Centre).

**Table 12: Additional services sought by participants**

One Asian woman found the services she needed accessible already, commenting that cost and language are not barriers for her.

Six (6) women talked about how services could be more accessible to them. Cost was a barrier to accessing services for 2 women - one Asian woman sought free immigration legal advice and an African woman said help with travel costs would improve her access to services. Two (2) would have liked means to connect with HIV-positive women from their own cultural community in a safe and anonymous way online. Individual women also preferred:

- HIV services to be delivered via home visits from a female worker.
- Access to systemic advocacy officers for assistance with housing-related issues (e.g. complaints about neighbours).
- The capacity to access services online.
- More use of interpreters at Migrant Resource Centre.
- To be able to bring their young children with them to services.
- Retention of some specialist HIV services.

Not all women sought additional services. For example, 2 participants for whom the HIV Women's Program was the only non-medical service they used, said:

*We prefer to keep our information to ourselves and don't see need to use any other services ... I trust the confidentiality of the services I use and that is important to me.* (Asian Woman)

*I only go to the hospital and see (the) women's program. It is good to have this place to talk. I ... don't need to use any other services and I would never tell them about my problem.* (Asian Woman)

**Women consistently identified three key criteria which would encourage them to continue to use a service:**

1. **Confidentiality & Privacy.** Being confident that workers understand and respect their need for confidentiality and privacy, was the single highest priority for women. Every participant implied its importance at some time during the interview, and 6 women explicitly identified this as central to whether they would return to a service. For 2 women, this was the single determining factor as to whether or not they would return to a service.
2. **Supportive Attitude, Approach & Environment.** The 7 women who commented on the importance of attitude approach and environment variously described supportive service delivery as *warm, thoughtful, considerate* and *welcoming*.

*(I'd willingly go back to a service depending upon) how they treat me and my husband. My privacy and confidentiality is respected – supportive environment and welcoming people.* (African Woman)

*(I'd willingly go back to a service) if I felt that a worker is listening to me and being supportive then I like to keep going – but I have no choice with the hospital.* (Asian Woman)

3. **Responsive & Reliable.** Four (4) women highlighted the importance of services listening to their needs, following up on agreed actions, and/or providing the services women need.

## Women's experience of living with HIV within their cultural communities

The Asian and African HIV-positive women in Adelaide who participated in this consultation are isolated from their cultural communities, and often their families, too. Women's individual comments speak for themselves. The following includes **one quote from each of the 10 women** who participated in this consultation:

*Still a secret - only my parents know, not my siblings. I have fear of being judged by them (siblings) and others – we keep it a secret. Don't think even a famous person coming out would change it – due to lack of accurate HIV knowledge and information, the community is so judgmental.*

*I am not involved in my community – I don't trust them not to talk behind my back. I felt like this before the HIV – I wouldn't talk about personal things with them. There is a lot of infighting in my community. If anyone in my community knew about my HIV then they wouldn't want to know me because they would be frightened of getting it. They would judge me and think it was my fault. They are very gossipy.*

*When my ex-sister in law told me that I'm a bad woman or dirty woman because of health but apart from that no-one told me that I'm a dirty woman .... nobody knows.*

*They forget no one should be punished for trusting or falling in love or having pleasurable sex.*

*(I have) not told anyone yet, only my husband – but when I have had time to maybe come to terms I may tell family, I may not.*

*I know that if I told one person about my problem then everyone would know ... You have to understand how things are in my culture. When we came to Australia we started to mix with the many cultural groups, but then we stopped because of the attitudes and gossip about others (not just about HIV). There is a lot of infighting.*

*I have not experienced stigma, I think because I have not taken risk to tell anyone – only my best friend. The fear of stigma has affected my life and who I talk to and my work – it has affected everything. I don't let anyone get too close otherwise they will ask why I am going to the hospital and things like that. I am very cautious.*

*I am open to a select few close friends, not all my family. ... The fear of being condemned is too big a risk.*

*It (HIV) is very hidden in the ... community. I do not have a connection with my community. I belong to a church community but would not tell them.*

*I hear people talk about it, without them knowing I am HIV positive. I listen to 'unbelievable gossip' and misinformation being bandied around – but I will speak out passionately if I feel safe. I pick my times. My community have not been supportive or really care – my community is inside my house now.*

*Nobody knows.*

## Reducing HIV transmission within women's cultural communities

All Asian participants noted that limited accurate information about HIV and how to reduce the risk of transmission was available within their cultural community – in both Australia and their country of birth. They saw HIV information as very hidden (along with talking openly about sex). Most saw little difference in community attitudes between their country of birth and Australia. However, one woman did note changes in the younger generation living in Australia:

*The young people in my community in Australia have been educated to use condoms I think – they have taken on local values and the girls would have a condom in their bags.* (Asian Woman)

Another saw levels of HIV awareness and education within her cultural community in Australia as lower than in her country of birth. One Asian woman highlighted the need for gender equity within her community and more widely, and saw this as the best pathway to enabling women to negotiate safer sex. Another noted that, even where women are aware of the female condom, it is *easier for the male to wear the condom*.

All African participants saw HIV as hidden within their cultural communities in Adelaide, and, as in Asian communities, noted that it is unusual for people to talk about HIV. Two (2) of the 4 African women had experienced very different levels of understanding of HIV in their country of birth.

One African woman felt that there *was good gender equity* in her country of birth, and that this makes it easy for women to negotiate safer sex. She talked about ease of access to support groups, counsellors, billboards and female condoms free of charge. However, this same woman is largely secretive about her HIV status within her cultural community in Adelaide.

Another African woman also noted very different attitudes toward HIV in her country of birth compared with her cultural community in Adelaide. Gender inequity continues to play a role in her country of birth – with women finding it difficult to negotiate safer sex if a male partner is against condom use. However, attitudes toward HIV make it normal to tell the partner if *you are sick*:

*If man loves her they will both look to keep safe and have safe sex. In (her country of birth) men understand it is men and not blaming women. ... Men will look for a positive partner if positive.*  
(African Woman)

This woman, too, has found limited understanding of HIV and HIV transmission, and is secretive about her HIV status within her cultural community in Australia.

A third African woman talked about the lack of gender equity within her cultural community, the belief that women *don't realise they are meant to be pleased* and the critical role these play in women's limited confidence about negotiating safer sex.

Both Asian and African participants talked about the central role of community education in reducing stigma, and empowering men and women to make informed personal choices. One African woman thought it would be good to have *an open discussion as a community*. However, most participants advocated a wider mass education approach:

*They don't understand about HIV – there is much ignorance. So education is needed, as they think you can get (HIV) just by touching. I think they need education but I know that they wouldn't go to anything that says (it's) about HIV.* (Asian Woman)

*Mass serious education to the African men, and women being given the support to make personal choices.* (African Woman)

An Asian woman also felt that women were a little more open to information than men. She proposed that free outreach testing should be available to members of her community.

Asian women particularly focused on promoting the need to always use a condom. An interesting incongruence emerged from Asian women's response. Despite comments about community members' disinclination to talk about sex, most felt that both men and women were confident with the use of condoms (mainly male condoms), but that this was seen exclusively as a means of protection from pregnancy, rather than HIV or other STIs. Whilst condom use is not universal, Asian women implied that common use of condoms made it relatively easy for women to negotiate condom use in order to prevent pregnancy – with protection from STIs being a useful secondary benefit.

Most participants saw the need for a change in community attitudes toward HIV and people with HIV as central to enabling women to feel more confident about negotiating safer sex and thereby reducing any risk of HIV transmission.

## What would it take for women to feel part of their (cultural) communities?

Participants were invited to share any experiences of **stigma or discrimination** due to their HIV status. Most said that they had not experienced direct stigma or discrimination from their cultural community in Adelaide solely because they had told no-one, one other person, or very few select individuals about their HIV diagnosis. One African woman named this as *hidden discrimination* – hearing people talk negatively about HIV has led to her choice not to disclose her HIV status within her community. Two Asian women had told *close friends* and a family member respectively about their HIV status: this was a negative experience for both, with stigma leading to feelings of anger and betrayal of trust.

A couple of participants commented on their experience with Australians. One had experienced stigma from a doctor; another had a very positive experience with both her doctor and a close friend:

*When I was diagnosed, my GP told me that I had to choose someone to tell so that I would have one person to talk to and someone would know what my health problems are if I needed to go to hospital. I chose this friend who I worked with and studied with for many years. It was a good choice for me.*

(Asian Woman)

Another was recently married when diagnosed, and was very scared that her Australian husband would reject her. Instead, *he was supportive and understanding and said 'it's not your fault'. We then planned together to get me to Australia.*

All felt that their community could, and should, be more supportive of its HIV-positive members. Women aspire to a day when community behaviours change:

*Not discriminate or judge or treat different – the stigma is hard.* (Asian Woman)

*Re-educate; less judgemental; have a greater awareness.* (African Woman)

*I don't know - it feels too hard to imagine that day when we can just be open about this problem. They would have to change their thinking a lot.* (Asian Woman)

However, none were confident about the likelihood of an imminent change in community attitudes:

*Africans still see HIV as a bad killer and anyone with it is considered to be a prostitute.* (African Woman)

*I don't think education would make any difference.*

(Asian Woman)

Two women missed the community support which would have been available to them in their country of birth:

*Support here is clinical only – in my country peer and social support would be excellent. The support groups (in Adelaide) often focus on treatments or how you get it and are mostly gay or MSM<sup>3</sup> which I have no issue, but only a few women are open at the hospital where we meet.* (Asian Woman)

<sup>3</sup> Men who have sex with men

*In (her country of birth) when the community know your HIV status they help you find a partner who loves you, and who may also have HIV. (African Woman)*

In the absence of community support, several women looked to other HIV-positive women outside their community, to give them strength. Two (2) participants saw the internet as the most viable means of accessing support from other HIV-positive women: they suggested developing an online support group and using Facebook as a *safe and good way to share accurate info and stories*.

When asked **What would it take for women to be able to be open about being HIV-positive within your community?** most women saw this prospect as too far into the future, or too difficult to achieve, to comment.

Two participants saw this possibility as generations away:

*Not a lot now but in future, maybe change over several generations. (Asian Woman)*

*A new generation – otherwise, cultural shock. (African Woman)*

*A long time of other people being educated, and then it still may not stop rumours or fear. (African Woman)*

The best prospect was seen as building trust through greater quality and quantity of community education, including *more accurate education and awareness*. But, ultimately, women expressed little hope of a significant change in community attitudes, and, consequently, their capacity to be open about their status and fully participate in their cultural community in Adelaide. One African woman proposed that the best approach was to *hope and pray*. An Asian woman reflected the sentiments of most participants in this consultation:

*I am fearful to be open because I can see the stigma and the attitude about HIV. I would have to see people in my community talking about HIV with some understanding. My community has old fashioned ways and I may just try and test the waters and talk about a friend with HIV or something, and see what the responses are like. (Asian Woman)*

## Discussion

### The wider research context

It appears that this is the first published study focused exclusively on the experiences and needs of Asian and African women living with HIV in Australia.

The lack of dedicated research on these groups of HIV-positive women is both surprising and disappointing. Women from high prevalence countries are a significant and growing minority within the HIV-positive community in Australia. As detailed in **Attachment 1**, at least 450 African-born women are living with HIV in Australia. It is unclear how many HIV-positive Asian women are living in Australia. However, 22% of the 1,364 new *heterosexual diagnoses* between 2008 and 2012 were born in Asia (approximately 300 people), and it is reasonable to assume that a significant proportion of these were women, given the epidemiology in high prevalence Asian countries.

Since 2009, the Australian Federation of AIDS Organisations (AFAO) has been consulting with African community leaders, HIV-positive African community members and other stakeholders about HIV-related issues for African communities (AFAO 2013:1). AFAO acknowledges that: *There have been no studies of gender-specific issues affecting HIV positive Africans in Australia*, although a small number of Africans were

included in one study (Asante et al 2009), and two interviews with individual African women have been published (AFAO 2011a & 2011b). Some findings of the Australian Human Rights Commission consultations on the (broader) health and social needs of Africans in Australia (AHRC 2010) are relevant to Africans living with HIV.

No research appears to have been published which focuses on HIV-positive Asian people living in Australia – let alone Asian women living with HIV. See for example, a systemic international review of 178 studies published in the *European Journal of Medical Research* (McMahon & Ward 2012), where the limited Australian data was primarily epidemiological and/or focused on HIV prevention in migrant communities more widely.

Many experiences, needs and concerns were shared by both African and Asian women who participated in this consultation. Participants frequently reflected themes that have emerged from the limited literature looking at people from (particularly non-individualistic) minority cultural communities living with HIV in Australia (Forbes & Godwin 2011; Körner 2007; McMahon & Ward 2012; McMahan & Luisi 2011). Consultation participants consistently reinforced the themes which emerged at an earlier South Australian Women's Forum with HIV-positive women from a variety of CALD backgrounds, conducted by the HIV Women's Program in 2011. The article based on this event by Pam Price (2012) provides the only documented commentary on HIV-positive women from minority cultural communities in Australia.

## What we know about HIV-positive African women

Based on 5 years of consultation, the Australian Federation of AIDS Organisations (AFAO) has concluded that key issues affecting African people living with HIV in Australia are:

- Stigma & discrimination – *from services, the wider Australian community and their own community*
- Late diagnosis
- Comorbidities
- Immigration status
- Medicare/Pharmaceutical Benefits Scheme (PBS) ineligibility<sup>4</sup>
- Financial issues
- Language
- Gender & sexuality (AFAO 2014a:1-3)

Several of these issues resonate with the findings of this consultation and the epidemiological data. African women particularly highlighted their experience of stigma and discrimination *from their own community* (rather than from services and the wider Australian community<sup>5</sup>) however the limited focus on responses of the wider Australian community and service providers may have been influenced by the questions asked, and the fact that interviews were conducted by non-African service providers. Two (2) of the 4 African participants already had permanent residency (PR) in Australia: one of the remaining women was anxious that her HIV diagnosis might limit her access to PR. Two (2) African women raised financial and associated issues including housing, travel/transport costs and difficulties with Centrelink. As detailed in *Methodology* (above), a key limitation of this study was the inability to include women with limited English language skills, due to resource constraints. Several Asian participants identified similar issues.

AFAO identified, but did not elaborate on, several issues for African women with HIV:

- Diagnosis during pregnancy.
- Concerns about breast feeding, and the stigma associated with bottle-feeding.
- Issues related to mothering/parenting.

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<sup>4</sup> Ineligibility for health services does not apply in South Australia, where the State Government ensures that anyone who is Medicare/PSB ineligible has access to HIV treatment.

<sup>5</sup> There is certainly reason to expect that African women may experience stigma and discrimination from the wider Australian community. The *Challenging Racism* study found that up to 30.7% of respondents in some States expressed *concern* about *black Africans* (cited in AFAO 2014d:1).

- Pre-migration trauma.
- Problems related to gender inequity in intimate relationships and more widely.

(AFAO 2014a:1-3; AFAO 2014b:1-2)

These were not dominant themes in women's feedback during this consultation process. Most women in this consultation were diagnosed as part of the immigration process, and none raised concerns about pregnancy, breast feeding or parenting – despite the fact that 2 of the Asian women hoped to become pregnant in the near future. Two (2) African participants contracted HIV as a result of sexual assault in a war zone: one of these women reported its life-long impact on her life, particularly her role as a mother. Whilst several women commented on wider gender inequity within their cultural community in Australia, none focused on issues within their intimate relationships. (This may, in part, reflect the relationship status of participants – with only one participant being married to a member of her cultural community.)

## Secrecy & identity

Secrecy about one's HIV status amongst African women is not unique to the Australian context. A significant 2012 study involving interviews with 929 adult patients (of whom 78% were women) in sub-Saharan Africa found high levels of secrecy amongst people living with HIV. Of the 72% of participants in a stable partnership, 67% had declared their HIV infection status to their partner, 59% were aware of the status of their partner and 34% did not know the HIV status of their partner. (Carter 2014)

This consultation has found that HIV takes disproportionate 'space' in women's lives. Whilst, for many, their HIV status was a small part of their identity, women reported feeling under constant pressure to identify as HIV-positive in order to access services. However, most women primarily identified in relation to their family – firstly (for those who were mothers) as a *mother*, then in terms of other familial relationships (*wife, sister and/or grandmother*).

Two Sydney studies looking at HIV and minority cultural communities in Sydney (Asante et al 2009 & Körner 2007), *found that HIV-positive people expected and experienced stigma and discrimination from their families and within their communities* (Körner 2007). In particular, Körner found variations in disclosure decisions which were influenced by gender, sexual orientation and cultural background:

*Heterosexual women disclosed to no one outside the health care system and were anxious to avoid any disclosure in the future. For all participants, voluntary and involuntary disclosure caused potential and actual disruption of relationships with their families and ethnic communities.*

(Körner 2007)

Similarly, the Australian Federation of AIDS Organisations (AFAO) has highlighted the importance of recognising the wider familial and community implications of disclosure:

*For people from African communities, disclosure '... is not an individualized action. [They] are not only considering the personal ramifications of disclosure, but also the possible impacts on their immediate families, their communities, and their extended families "back home".'*

(African and Caribbean Council on HIV/ AIDS in Ontario 2010 cited in AFAO 2014e:2)

These implications can be both practical and social. At a practical level, for example, the *one fails, all fail* migration policy means that one HIV-positive family member can preclude their whole family from settling permanently in Australia<sup>6</sup>. All the services interviewed for an AFAO paper on stigma within African

<sup>6</sup> The *one fails, all fails* criterion is included in the Migration Regulations 1994. Despite the advent of individual assessment of the future cost of treatment and care in 2008, it appears that the Health Requirement still precludes most people living with HIV (other than on-shore applicants for permanent protection visas) from obtaining permanent visas unless they are able to secure a waiver. Generally, a person and all family members included in a permanent visa application must satisfy the Health Requirement. Where any member of the family fails the Health Requirement, the whole family will be refused permanent residence. (Forbes & Godwin 2011:3-4) This *can place an enormous burden on the person diagnosed with HIV, in terms of guilt and shame, and in terms of the reaction of the rest of their family – if they disclose the diagnosis* (Forbes & Godwin 2011:7).

communities reported that *their clients were extremely concerned about discrimination from within their own communities:*

*Service providers often stated that their clients had told no-one at all from their community about their HIV status, refused to have interpreters from their community, and sometimes refused even to meet other HIV-positive people from their own country. (AFAO 2014d:2)*

As one woman told AFAO:

*I used to go straight to the clinic and go into a [private] room and shut the door, and told them to call me when they want me, or come in, because I thought if [an African worker at the clinic] sees me then everybody knows. (AFAO 2014d:2)*

This is consistent with the feedback of HIV-positive women from a variety of CALD backgrounds who participated in the 2011 Women's Forum:

*The decisions about disclosure of their HIV status can be especially complex for women from CALD communities. Women spoke about the dynamics of being part of a collective culture where one person's business is everyone's business. For many women this has meant choosing not to disclose to their family and community in order to protect themselves, their families and children from stigma and social ostracism. These are complex decisions as women try to balance their own needs for privacy with the strong need for support from their community. Most women have dependent children and the protection of their children is a strong consideration in the disclosure process. Their choices are often also influenced by the degrees of knowledge about HIV in their community and the prevailing attitudes to HIV-positive people. (Price 2012)*

Like the African and Asian women participants in this consultation, most 2011 Women's Forum participants saw the need for secrecy about their HIV status as the single biggest impact on their *day to day life and health*. For example, women said:

*We make decisions together, celebrate together and we are responsible for each other ... So for me to keep to myself and keep this big secret ... it attracts unwanted attention.*

*It means living a secret. I don't encourage my community to visit and if I am sick I keep it quiet – it is very hard not having support from my own people.*

*I have to be two faced. I get to know people but it is always in the back of my mind and I feel uncomfortable.*

*Being HIV-positive has meant that I don't follow up friendships especially in my community. I am very lonely sometimes.*

*If you have too many friends then they will get nosy and want to know your business. I can't risk that. It's a very hard journey. I have to live in secrecy ... always being on watch for my community members who may see me when I visit the hospital or places like that.*

*I was in hospital recently and the community women started to say it must be true about the HIV. If there are more people in my life it is more stressful for me. I have to hide my pills and any information on HIV.*

*After I told my cousin they stopped coming to my house, they wouldn't share my food or cups and then she told all my relatives back in my country.*

*I have not told my new partner about my HIV. I am afraid of what would happen but we always use condoms.*

*I am worried about who will look after me when I get sick and especially who will be there for my kids.*

(CALD HIV-positive women cited in Price 2012)

These comments are consistent with African and Asian participants' self-reported attitude toward disclosure of their HIV status in this consultation, and the experiences of the HIV Women's Program and

Positive Life SA more widely. For example, it was hoped that, following individual interviews, participants in this study may be willing to meet each other to discuss the findings: only one woman was willing to even consider this option. Every participant in these consultations had a high level of secrecy about their HIV status – with 7 women identifying the stresses associated with keeping this secret as the major impact on their quality of life. The single highest determinant of whether women would willingly use a particular HIV service was their confidence in workers' understanding of this need, and their willingness to respect women's privacy and maintain the highest level of confidentiality about their HIV status.

There is, indeed, a danger that fear of stigma and discrimination could result in both Asian and African women living with HIV in Adelaide ...

*... becoming extremely isolated, getting support solely from clinical service providers (if at all), rather than from HIV-positive peers, family and friends, their community and religious leaders. (AFAO 2014d:2)*

## Community attitudes toward women living with HIV

The Australian Federation of AIDS Organisations (AFAO) has identified myths within African communities which may contribute to stigmatisation of people living with HIV, including:

- *HIV always leads to illness and death*
- *People who are HIV-positive cannot have children*
- *All people with HIV are prevented from entering Australia, therefore HIV does not exist here*
- *HIV can be caught via casual social contact*
- *Religious faith may 'cure' people with HIV. (AFAO 2014c:1)*

These are consistent with findings of a NSW study with 4 communities in Sydney (Thai, Cambodian, Sudanese and Ethiopian) which found that, based on participants' knowledge and experience of HIV/AIDS in their country of birth, *HIV was perceived as a terminal illness which meant a short life expectancy* (Asante et al 2009:1). This study reports the view of health care professionals that:

*... there is a perception in some communities that HIV is a problem primarily in their countries of birth and is less of a problem in Australia. There is also a perception among refugees who have been tested for HIV in refugee camps before coming to Australia that they are now safe from HIV infection. Such perceptions and misconceptions can lead to behaviours that make people more susceptible to HIV infection. They can also serve as barriers to HIV testing and contribute to stigmatisation of people living with HIV. (Asante et al 2009:1)*

Similarly, one participant in the 2011 CALD HIV-positive Women's Forum said:

*My community does not understand that I am not going to die soon... to them it is always death very soon.*

*The community do not understand... there is still so much stigma and discrimination... many in my community don't understand English and have no way to hear other things about HIV in Australia.*

(CALD HIV-positive women cited in Price 2012)

A number of Asian and African participants in this consultation believed that understanding of HIV was even lower amongst their cultural community in Australia, than it was in their country of birth. Whilst engagement with services has provided participants in this consultation with a better understanding of their prognosis than other community members, the fear of an early death continues to impact on a few of the women – particularly those with significant comorbidities and ongoing health issues. For 2 participants, this fear continues to have the greatest impact on their lives and choices.

The NSW study found that approximately 1/3 of all participating community members indicated that people living with HIV/AIDS should be treated with respect, and the majority believed rather that people living with HIV/AIDS should be treated with sympathy: however, 8% of participants indicated that people living with HIV/AIDS should be treated with disrespect, isolated and not be allowed to participate in

community activities (Asante et al 2009:11). Participants were asked whether they *thought people with HIV brought shame to themselves and their families*, and more answered *yes* (43%) than *no* (32%) (ibid:12). These incongruous findings suggest that, at the very least, people living with HIV in their communities were viewed as *less than equal* – whether worthy of sympathy, or justifying outright exclusion.

Since the beginning of the epidemic, HIV has been associated with ‘immoral’ behaviour, and with stigmatised groups such as gay men and sex workers. This applies equally in Africa and many other countries. AFAO reported that HIV-positive Africans interviewed during community consultations identified *fear of gossip, stigma and breaches of confidentiality within their community as a major issue for them*. According to one African woman:

*My friend who used to drive me to hospital started spreading rumours that I was HIV-positive. People in the community started calling me a ‘husband snatcher’. You know in many African communities, single women are viewed as prostitutes.* (AFAO 2014d:2)

Both African and Asian women participants in this consultation talked about the perceived association between HIV and promiscuousness within their cultural community. One Asian participant raised precisely the same fear as experienced by the African woman– that allowing anyone within her community close enough to know about her regular hospital visits would lead to speculation, rumours and exclusion from her community. Another talked about concerns that if her HIV status were known, she would be assumed to be unfaithful to her husband (despite the fact that she became HIV-positive prior to marriage).

Similarly, during the 2011 Women’s Forum participants said:

*I felt like dirt in my community... this feeling is with me everyday.*

*Many positive CALD women live in silence and darkness.*

*I have had a bad experience when I was open about my HIV... my community is very quick to judge. They are not able to be compassionate.*

*There is always blame for women. Where did you get it? What did you do wrong?*

*In my country it is called “the sickness from the man”... They are afraid to even say the word AIDS ... now all my family back home know that I have HIV they have let me know that I am not welcome to go back.*

*My ex husband used my HIV as a weapon against me ... he wrote a letter about me and read it to the Elders back in my home country. My mother had a heart attack when she heard. After that no one in the community here wanted anything to do with me and my children.*

*My pain is for my children who do not see their family here in Australia.*

(CALD HIV-positive women cited in Price 2012)

The evidence continues to suggest that women’s fear of stigma and discrimination from their communities, should they disclose their HIV status, is well-founded. It is hardly surprising that every participant in this consultation continues to keep her HIV status very private – with one having (literally) told no-one outside the health system, and the remainder having only told one or a few close friends or family members.

## Implications for community development

Asian and African women who participated in this consultation agreed that it is unusual for people within their cultural community in Adelaide to discuss HIV and associated subjects, including sex. All were concerned about high levels of stigma and discrimination toward people living with HIV within their cultural communities. All recognised that this was, at least in part, driven by limited understanding of HIV and HIV transmission, which leads to irrational fears. As detailed above, many community members continue to believe that HIV can be transmitted by ordinary social contact or that HIV does not exist in Australia (AFAO 2014c:1). Similarly, stigma and discrimination were recognised as significant issues at forums conducted

over the past 5 years by the Australian Federation of AIDS Organisations (AFAO), with wide-ranging impacts on individuals, families and communities:

*There was agreement that HIV awareness and health promotion campaigns in African communities must continue to address stigma and discrimination. (AFAO 2014d:3)*

Women participants widely supported a mass education approach to improving the HIV-literacy of African and Asian communities in Australia. At least 2 participants in these consultations suggested that women in their cultural community might be more open to this information than men. Similarly, participants in the 2011 Women's Forum said:

*Women can be the trusted key players, mentors and leaders - women are often respected role models in the community.*

*Use our women's networks to share knowledge about HIV.*

(CALD HIV-positive women cited in Price 2012)

At the very least, separate education processes for women and men may increase the comfort of participants, encourage discussion and enable customised message delivery (AHRC 2009:18-23), including discussion of gender equity and female condoms. Asian participants in these consultations talked about the existing comfort with the use of (mainly male) condoms to protect against unwanted pregnancy: this might provide a building block for design of culturally-appropriate HIV education amongst Asian communities. Participants in the 2011 Women's Forum similarly advocated community education:

*The big issues in the community are low literacy in English. They don't have easy access to accurate information - they don't understand that I can live with HIV they assume that I am going to die!*

*Inform leaders in communities of the truth about HIV and educate all communities.*

*Use ethnic community radio more to educate.*

(HIV-positive women cited in Price 2012)

A proactive approach to this wider community education could play a valuable role in addressing commonly-held myths about HIV in Australia within Asian and African communities, and pre-empting the stigma and discrimination that continues to isolate HIV-positive women from their families and communities. A number of studies have focused on newly arrived Africans and others from high prevalence countries. These studies have argued the need for information programs on the Australian health care system provided in the language of the audience using *bicultural community trainers* (AHRC 2010:18) and *settlement programs which provide sexual health, education and support programs*, which include *a focus on de-stigmatisation of HIV* (Forbes & Godwin 2011:17). Community participants in the AHRC consultations also proposed *fostering connections with cultural, social and religious groups of their own ethnic background for newly arrived African migrants and refugees* (AHRC 2010:18).

Such an approach may also reduce the risk of a disproportionate reaction from the wider South Australian community. Whilst the number of HIV notifications amongst African and Asian born people continues to rise, the majority of these continue to be people who contracted HIV prior to coming to Australia (as evidenced through the high rate of late diagnosis and the frequency with which diagnosis occurs as part of the migration application process – see **Attachment 1**). There is no evidence of higher rates of HIV transmission within Asian and African communities in Australia, than in the Australian community more widely.

African and Asian women with HIV feel excluded from their cultural communities in Adelaide: all consultation participants felt that their community could, and should, be more supportive of its HIV-positive members. Most had heard and seen enough uninformed, judgmental attitudes about HIV in their communities to decide to keep their HIV status a secret – from family members, friends and/or their community more widely. Whilst none were confident that a significant change in community attitudes was imminent, most saw community education as the best way of moving toward (possibly multi-generational) change.

## Culturally-appropriate service delivery

Views on what constitutes *culturally appropriate practice* with African, Asian and wider migrant communities varies across the literature. Little data exists on HIV-positive people's service delivery preferences.

In 2011, the Australian Human Rights Commission (AHRC) consulted with African communities about their health needs. (The report did not discuss the needs of women living with HIV.) Some of the feedback from women participants resonated with the findings of this study, including the importance of having access to a female doctor, support to address family conflict and prevent family violence, and **the need for family-inclusive services and programs** – particularly in responding to mental health issues (AHRC 2011: 20-22). Körner (2007) also highlighted the importance of a family-focused service delivery. In light of many women's unwillingness to disclose their HIV status outside the health system, Körner argued the importance of *an ecological perspective of health in which decisions are not located in rational decision making alone but in the broader context of family and community*.

African women's feedback to the AHRC indicated that the attitudes of health professionals were the most crucial element of providing *culturally appropriate health services*. In particular, African women talked about the importance of *doctors (or other health practitioners) who listened to them, and health professionals who took the time to explain health issues and treatment options, explained how the health system worked, organised appropriate interpreters when needed and showed respect for traditional methods of healing* (AHRC 2011: 23). Service providers also highlighted the importance of having people on their staff who belong to the communities with which they work (AHRC 2011:23), however this was not emphasised by African women themselves. This suggests that the most important element is that service providers seek the advice of people who understand the cultural perspective of African women (including women themselves), and ensure that African Australians receive services untarnished by cultural assumptions, stereotyping or miscommunication:

*It is important that the doctor encourage questions as many of us in the community have had bad experiences with some health people, including doctors, and so some women are just too scared and will only speak or ask questions if they are made to feel safe.* (Comment at Community Consultations, AHRC 2010:22)

*A key area of discussion during all consultations was the need to support health professionals to better understand the background, experiences and perspectives of African Australians so they can deliver more appropriate and effective health services.* (AHRC 2010:18)

Women who participated in this consultation were clear that the personal approach of service providers (including being *warm, welcoming, thoughtful* and *considerate*), their willingness to listen to women's needs and their reliability in following up on agreed actions and/or service provision, were central to women's willingness to continue using a service. But, like many participants in the NSW study of HIV-positive Asians and Africans (Asante et al 2009), the single most important criteria was women's confidence that the service would understand and respect their need for confidentiality and privacy. This included understanding the cultural dimensions of their need for secrecy: indeed, many women were motivated to participate in this study by their desire for service providers and community members to understand their situation, experiences, preferences and needs. This includes recognising women's integral role within their family, and the multi-faceted consequences of any breach of privacy. This is the continuation of practices reinforced by the 2011 South Australian HIV-positive CALD Women's Forum:

*Living within a collective culture and the strong interdependence this brings has many implications for the HIV positive CALD woman and her family. Women talked about the impact of their communities' attitudes to HIV. In many communities being HIV-positive is also seen to bring shame on the extended family: parents, siblings, partners and children. Protecting their family from shame and social stigma is seen as vitally important for CALD women.* (Price 2012)

The limited available research reflects divergent views on the merits of employing health care workers from the same cultural community as women living with HIV. In the only study that expressly examined the

preferences of HIV-positive Asian and African people, between 42% and 50% of participants indicated that the cultural background of their doctor did not matter (Asante et al 2009:8). However, some participants (particularly Ethiopian participants who were more likely to prefer a non-Ethiopian doctor), had a preference:

*For those who preferred doctors from the same cultural or ethnic backgrounds, effective communication and ease of understanding were among the key reasons for their preference. By contrast, those who did not prefer doctors from the same cultural background raised the issue of confidentiality, indicating that such doctors could reveal their medical conditions to other members of the community.* (Asante et al 2009:8)

Forbes & Godwin looked at health care workers more widely than doctors, and recognised that HIV-positive Africans *may not trust service providers or interpreters from their community* (2011:16). They concluded that community health services should be enabled to provide *effective ethno-specific HIV counselling, treatment and education*, which is cognisant of the *complex treatment, interpersonal and disclosure issues for a person recently diagnosed with HIV settling in a new country* (2011:17) – that is, a service which could be delivered by culturally-informed health care workers from other cultural communities. Forbes & Godwin noted:

*the ... particular disclosure issues for women from high prevalence countries. Cultural norms of high-prevalence countries often require careful, ethno-specific case management due to the risk for many of ostracisation from family and community and/or domestic violence following disclosure to their partner and/or other family members. HIV education programs for migrant and refugee women from high prevalence communities who are planning children need to be better resourced.*

(Forbes & Godwin 2011:17)

On the other hand, AFAO concluded that for Africans with limited English language skills *programs providing one-to-one support by bilingual workers are usually more effective than those only providing printed materials* (AFAO 2014a:2).

Women participants in this consultation did not articulate any preference for health workers from their own cultural community: on the contrary, this would seem inconsistent with their oft-stated fear of having anyone from their region (even other HIV-positive women) aware of their HIV status. However, they did assert the value of peer support from other women living with HIV from outside their cultural community.

Participants in these consultations were very positive about women-only, highly confidential, family-focused services such as those provided by the HIV Women's Program. Women who had told no-one outside the health system about their HIV diagnosis particularly highlighted the value of non-medical support. In the absence of support from their cultural community and/or family, several women identified connection with HIV-positive women outside their community as their most important source of strength. Similarly, HIV-positive participants from a variety of cultural backgrounds who participated in the 2011 Women's Forum highlighted the value and importance of peer support:

*Peer support is vital to all positive women*

*When first diagnosed I said to the doctors - is there anyone else who is positive please show them to me? ... meeting other HIV-positive women from all cultures has been important to me.*

(CALD HIV-positive women cited in Price 2012)

## Conclusion

African and Asian HIV-positive women need access to a safe, women-only environment where they can meet other women living with HIV, and get *real life* reassurance that HIV is not a *death sentence* in Australia. As evidenced throughout this consultation, women need a service which walks *alongside* them – a service which engages with women *where they are at* (practically and culturally), allows them to gradually build a trusting relationship, maintains the highest level of confidentiality, and progressively introduces them to other HIV-positive women, programs and organisations, if and when they are ready and willing.

Women participants in this consultation consistently believed that the process of change within their cultural communities and families would take *generations*. That, until then, they could not be genuinely included in their communities as equals. Many, particularly newly diagnosed women and those isolated from their family and/or cultural community, need access to peer-based and/or intensive individual support on a short term, periodic or ongoing basis.

There is a significant knowledge gap – both in South Australia and nationally – about the gender-specific and culture-specific needs of Asian and African women living with HIV in Australia. In light of the growing numbers in this population group, further work in this area is urgently needed to ensure that the HIV sector has the capacity to provide culturally-responsive specialist HIV services. The sector must maintain the capacity to engage in sufficient depth with these women, to be able to learn about their cultural context, provide specialist HIV services in an appropriate manner, collect detailed feedback on women's preferences and needs, and advocate on their behalf.

This consultation should mark the beginning of efforts to learn more about Asian and African women living with HIV in South Australia. Given the congruence between the findings of these consultations and other studies, the South Australian HIV sector should look closely at these findings and ensure their use in ongoing planning and development.

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# Attachment 1

## Epidemiological Data

Conclusive data is not available on the number of African and Asian women are living with HIV in South Australia. However, state and national surveillance data and service provision agency data provide some useful indications.

### Australia

**As at 31 December 2012, approximately 480 Asian women and 535 African women were living with HIV in Australia.** Systematic collection of data about the country of birth of people diagnosed with HIV began in 2002. The Kirby Institute estimates that, of the estimated 2,671 women diagnosed with HIV as at the end of 2012 (Kirby Institute 2013:118) approximately 18% were born in North-East Asia, South-East Asia or in South/Central Asia and 20% were born in sub-Saharan Africa.<sup>7</sup>

Between 2008 and 2012, there were 1,364 new *heterosexual HIV diagnoses*<sup>8</sup> in Australia. Of these, 58% were people from high prevalence countries or their partners (Kirby Institute 2013:7). People born overseas accounted for 46% of new heterosexual diagnoses – an increase of 66% in the population rate of HIV diagnosis amongst both the sub-Saharan African-born and Asian-born populations compared with the preceding 5 years (Kirby Institute 2013:11). Amongst new heterosexual diagnoses, 28% reported their country of birth as Australia; 32%, as sub-Saharan Africa; and 22%, as Asia (Kirby Institute 2013:26). That is, nationally, approximately 436 of new heterosexual diagnoses were born in sub-Saharan Africa and approximately 300 were born in Asia. However, not all women with HIV acquired it through heterosexual sex. The source of transmission for a small number of women was categorised as *other/undetermined* (which includes transmissions related to medical settings or injecting drug use), and a few were infected through mother to child transmission (AFAO 2014b: 1).

This represents continuation of a trend which had already emerged between 2002 and 2009:

	% of total HIV notifications who were born overseas	% of total HIV notifications who were Asian-born	% of total HIV notifications who were African-born
<b>2002</b>	31%	8.5%	5.5%
<b>2009</b>	44%	13.8%	10.2%

**Table 13: Total HIV notification rates amongst people born overseas** (based on McMahon & Luisi 2011)

Not all HIV acquired in a high prevalence country is amongst people born in that country. For example, 34% of new heterosexual HIV diagnoses in 2003-7 and 30% in 2008-12 were amongst people with a partner from a high prevalence country (Kirby Institute 2013:25-26). Between 2008 and 2012, where the partner's country of birth was reported, 27% of new heterosexual diagnoses were partners of people born in sub-Saharan Africa, and 71% were partners of people born in Asia (Kirby Institute 2013:25). **Table 14** relates to all new heterosexual diagnoses where HIV transmission occurred in a high prevalence country – including people born both overseas and in Australia:

	% of total heterosexual diagnoses acquired in a high prevalence country	% of these acquired in sub-Saharan Africa	% of these acquired in South East Asia	% of these acquired in North Africa/Middle East	% notifications who were women
<b>2003 – 2007</b>	37.5%	58%	32%	8%	65%
<b>2008 - 2012</b>	40%	75%	22%	2%	60%

**Table 14: HIV notification rates for people who heterosexually acquired HIV in a high prevalence country** (based on Kirby Institute 2013:25)

<sup>7</sup> Unpublished data via email from Ann McDonald, editor of Annual Surveillance Reports, Kirby Institute, 4 August 2014.

<sup>8</sup> That is, cases for which exposure to HIV was attributed to heterosexual activity.

Between 2003 and 2012, people from sub-Saharan Africa and Asia had higher rates of late (CD4 count less than 350 cells/ $\mu$ l) and advanced (CD4 count less than 200 cells/ $\mu$ l) HIV diagnosis than people from other world regions. The highest recorded rate of advanced HIV infection was between 2008 and 2012 amongst HIV-positive people born in sub-Saharan Africa. (Kirby Institute 2013:29-30) During this period, approximately 50% of African-born people were diagnosed late or with advanced HIV infection compared to around 25% among people born in Australia (AFAO 2013:2). Rates of late and advanced diagnosis were similar for African-born women and men, mainly those with a heterosexual HIV diagnoses (AFAO 2014b:2).

## South Australia

**As at 30 June 2014, at least 30 African and 20 Asian women (a total of 50 women from these high prevalence countries) were living with HIV in South Australia:**

- 23 African and 16 Asian women were known to the Royal Adelaide Hospital (RAH) – the single agency in contact with the largest number of women in this population group, and,
- The HIV Women’s Program was in contact with 18 African and 13 Asian women – of whom 7 African women and 4 Asian women were known not to be patients of the RAH.

Whilst guaranteed not to involve any overlap, this is unlikely to represent the full number of African and Asian women living with HIV. Other agencies may be aware of additional women who are not engaged with either service, however further investigation was beyond the capacity of this project.

According to the Communicable Disease Control Branch (CDCB), since 2006, SA has experienced a change in the HIV epidemic demographics - with 50% of new notifications being heterosexual people and, amongst these, a predominance of overseas acquired HIV (CDCB n/d-b: 24). Between 2008 and 2012, approximately 42% to 51% of total annual HIV notifications in South Australia were people born overseas (CDCB n/d-b:24). The proportion of HIV notifications which are women has continued an upward trend from 11% (139/1114) of all notifications between 1985 and 2010 (CDCB 2011:31) to an average of 24% (44/180) of notifications between 2011 and 2013 (based on CDCB n/d-a:24).

Between 2007 and 2011, there were 272 notifications of HIV in SA. Of these, 128 (47%) were among people born outside Australia. 91 (33%) of all notifications were amongst heterosexuals – of these 53 (58%) were men; 38 (42%) were women. Country of origin was recorded for 88 of these 91 people. Of these 49 (56%) identified as African and 17 (19%) identified as Asian. Visa status was collected for 65 of the 91 people: 28 (43%) were humanitarian refugees, 15 (23%) were permanent residents, 10 (15%) were applying for permanent residency, 7 (11%) were on temporary visas and 4(6%) were on student visas. (CHIP 2012:11)

In 2012, a total of 43 people were diagnosed with HIV in South Australia. Of these 22 (51%) were born overseas including 12 Asian-born and 4 African-born people. Of the 10 (23%) women diagnosed, 8 were born overseas. All 8 overseas-born women acquired the infection overseas, with 4 reporting sexual mode of transmission. (Other possible modes of transmission were from mother to child, tattoos overseas and overseas medical or blood procedures in high prevalence countries.) 3 of the 10 women diagnosed in 2012 had advanced HIV infection and a further 2 were late diagnoses (CDCB n/d-b: 23-25).

The total number of Asian and African women living with HIV in SA remains unclear. Evidence on the number of African and Asian women diagnosed in SA prior to 2007 is not available. 38 women born outside Australia received heterosexual HIV diagnoses between 2007 and 2011 (CHIP 2012:11). A further total of 8 women born outside Australia were diagnosed in 2012 (CDCB n/d-b: 23-25).

# Attachment 2

## Interview Questions

### Your identity

1. How do you see yourself?
2. How much does being HIV-positive affect your life/choices/decision? How?
3. How much (%) of your identity is being HIV-positive?
4. How would your life be different if you didn't have HIV?

### Feeling comfortable using HIV and other services

5. What HIV services are you currently using?
6. What other services or support would you find useful?
7. What would make it easier for you to use these services?
8. What would encourage you to keep going back to a service?

### Reducing the risk of HIV transmission in your (cultural) community

9. What could your community do to reduce the risk of HIV transmission?
10. What would need to change in your community for women to feel more confident about negotiating safer sex?

### Feeling part of your (cultural) community

11. Have you experienced stigma or discrimination because of your HIV status? How has this experience affected your life?
12. What could your community do to be more supportive of its HIV-positive members?
13. What would it take for women to be able to be open about being HIV-positive within your community?

