Access to HIV Prevention Information among selected culturally and linguistically diverse (CALD) communities in Victoria

Stephen McNally
Sophie Dutertre
ACCESS TO HIV PREVENTION INFORMATION AMONG SELECTED CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) COMMUNITIES IN VICTORIA

STEPHEN McNALLY AND SOPHIE DUTERTRE

THE AUSTRALIAN RESEARCH CENTRE IN SEX, HEALTH AND SOCIETY, LA TROBE UNIVERSITY

Funded by the Victorian Department of Human Services

February 2006
Monograph Series Number 58
ISBN 1920948805
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Glossary

ACON: AIDS Council of New South Wales.

AIDS: Acquired Immuno-Deficiency Syndrome

ASHM: Australian Society for HIV Medicine

FARREP: Family and Reproductive Rights Education Program

FGM: Female Genital Mutilation

DHS: Department of Human Services

DIMA: Department of Immigration and Multicultural Affairs

HIV: Human Immunodeficiency Virus

MHSS: Multicultural Health and Support Service (Vic)

MHAHS: Multicultural HIV/AIDS and Hepatitis C Service (NSW)

VAC: Victorian AIDS Council
INVESTIGATORS

Chief Investigators

- Dr Stephen McNally, Australian Research Centre in Sex Health and Society, La Trobe University
- Professor Marian Pitts, Australian Research Centre in Sex Health and Society, La Trobe University
- Dr Jeffrey Grierson, Australian Research Centre in Sex Health and Society, La Trobe University

Research Officer

- Sophie Dutertre, Australian Research Centre in Sex Health and Society, La Trobe University

Associate Investigators

- Asvin Phorugngam at the Victorian AIDS Council/Gay Men’s Health Centre
- Country Aids Network
- Multicultural Health and Support Service (North Richmond)
ACKNOWLEDGEMENTS

The Investigators on this study are grateful to all the service providers and community representatives who agreed to be interviewed and generously shared their knowledge and insight.

We wish to thank all the Focus Group participants for their willingness to discuss HIV prevention information needs in their communities.

Thanks are due to the following individuals and organisations:

Advisory Group Members

- Frank Dawood (Victorian Arabic Social Services)
- Huu Tran (Vietnamese Community in Australia - Vic Chapter)
- Ass. Professor Pranee Liamputtong (La Trobe University)
- Samia Baho (FARREP)
- Jane Price & Naomi Ngo (North Richmond Community Health Centre)

Co-Workers

- Iman Allaf
- Tuong Nguyen
- Murdia Mahmoud
- Abraham Gebremariam

Focus Group Facilitators

- Ayman Allaf
- Adnan Al Ghazal (Shepparton)
- Linda Phan-Araya
- Hanh Tran
- Jago Adongjak
- Rachel Habtemariam
- Faduma Musse
The following people have provided valuable advice in the course of the project:

- Demos Krouskos, North Richmond Community Health Centre
- Leila Alloush, Victorian Arabic Social Services
- Cath Cosgrave, Women Health West
- Cheryl Teng, AIDSline
- Carmela Ieracitano, Working Women’s Health
- Tex McKenzie, Victorian AIDS Council/ Gay Men’s Health centre
- Roz Wollmering and Wemi Oyekanmi, Mercy Hospital
- Tadgh Mc Mahon, MHAHS
- Lynne Hillier and Kirk Peterson, Australian Research Centre in Sex Health and Society
- Adnan Al Ghazzal, Shepparton Iraqi Association
- Elleni Bereded-Samuel, Horn of Africa Communities Network
- Kin Hashi, African/Australian Welfare Council
- Julie Futol, RhED Project
- Nancy Atkin, Northern Division of General Practice
- Lew Hess, Victorian Foundation for Survivors of Torture
- Marion Cincotta, Asylum Seeker Resource Centre
- Hoang Nguyen, Open Family
- Oanh Nguyen, Burnet Institute

Special thanks to Bronwyn Kaaden from the Victorian Department of Human Services for her support and to the Department for funding this project.
EXECUTIVE SUMMARY

Victoria has seen significant increases in migration since the 1990’s from a range of countries that are currently experiencing high levels of HIV. The most notable increases in migration have been from the Horn of Africa (Sudan, Somalia, Ethiopia and Eritrea). Eight percent of new HIV diagnoses in Australia in 2004 were in people from Africa and the Middle-East.

With increased flows of people coming to Australia or undertaking return journeys to high prevalence countries, the provision of culturally appropriate information about HIV prevention has been necessary. This research project identified available support structures and materials relating to HIV/AIDS prevention, which have been developed specifically or translated for Horn of Africa, Arabic-speaking, Vietnamese and Thai communities in Victoria. Our selection of communities for this research was based on the priorities set by the Victorian Department of Human Services for the Multicultural HIV/AIDS Support Service (MHSS), established in 2003.

This 12-month Victorian based study reports on the availability of HIV prevention information for these communities, and specifically on how appropriate the information is to their cultural background and their needs. The study addresses issues such as what is the most appropriate language for young people and the challenges communities face when dealing with explicit material. Newly-formed communities often rely on informal channels of communication. Furthermore, their ability to absorb information is often compounded by a range of refugee and resettlement issues. The study outlines the channels of communication for HIV prevention considered the most appropriate for each of the communities, including communities with low literacy levels.

Over 25 key informant interviews were held with representatives and service providers, in addition to 10 focus groups from a wide range of people within the selected communities. Some of these sub-groupings addressed in this paper include:

- Iraqi men from Shepparton
- Lebanese & and Iraqi mothers of teenage children
- South Sudanese men from the Dandenong area
- Young people from the Horn of Africa
Aim/Background
This Research Project had the following objectives:

1. To provide a comprehensive audit of currently available materials (written and audio-visual) and support structures for each of the communities. This also reveals what gaps exist in each of the communities.

2. To provide a comprehensive content analysis of all materials, which will explore how culturally and linguistically appropriate the products are.

3. To explore knowledge and understandings of HIV prevention that these communities develop from this material.

Methodology
Initial consultation with key organisations who provided recommendations on the selection of co-workers and were instrumental in the collection of existing prevention material about HIV in the selected languages.

An Advisory Committee consisting of the Associate Investigators, representatives from the selected communities and the principal researchers met at key points in the research to provide feedback on the findings from Key Informant Interviews and advice on the recruitment of focus groups; and findings from the focus groups.

The research involved 4 stages:

1. The collection of all publicly available materials about HIV for each of the communities in Victoria and the analysis of selected material.
2. 26 Semi-structured Key Informant Interviews with community representatives and service providers
3. Analysis and selection of material for focus group testing (with co-workers)
4. 10 Focus Group discussions

Four co-workers were recruited from the selected communities to provide cross-cultural advice for the duration of the project. Bilingual facilitators were recruited to organise and run the focus groups. Training was provided by ARCSHS staff.
Main findings
The main results we drew from this research are:

- Almost all participants were unaware of the existence of HIV prevention material produced in Australia in their language.

- Participants often held a false sense of security concerning HIV in Australia. Due to Australia’s practice of screening migrants for HIV; the different dominant modes of transmission from their home country; and much fewer highly visible public prevention campaigns, most participants believe that HIV is not a major issue for themselves or their community in Australia.

- Participants often rejected a format that used a personal sexual approach, preferring to see HIV as a general community health concern.

- The high level of sensitivity around HIV/AIDS and around how the content is presented means that at times, there is a risk of material being rejected.

- Most participants valued information delivered face-to-face. This allows for sensitivity to be addressed and helps place information within its cultural context.

- The language and literacy differences between and within communities means that no one method of communication will be appropriate for all.

- Bilingual information was identified by all communities as essential for addressing differences in language and literacy levels.

- The English template used in most material tested in the study often includes information that is not appropriate for some communities.
Recommendations/Actions for Implementation

1. A broad campaign is required to accompany the production of all material in languages other than English. Consultation about content and delivery needs to take place with each target community. Appropriate means of distribution of material should be discussed within the community consultation process.

2. In order to make HIV prevention relevant to these groups it is essential to raise awareness of incidence in Australia and in their own communities and to address concerns about stigma and support.

3. Information about HIV prevention will be more readily accepted if packaged within a community health framework and not within an individual sexual/relationship approach.

4. A particular effort must be made to investigate ways to negotiate the conflict between the sensitive nature of the material and the willingness to know about HIV. How to deliver sensitive information which does not alienate audiences will require community input.

5. The prime form of information delivery needs to shift away from the reliance on written information to face-to-face interactions (information sessions and one-on-one). In many cases this will include bi-cultural and bi-lingual community workers.

6. All information, including written material, should be delivered in community languages and in English. This will accommodate the range of language and literacy skills within each community and facilitate communication with English-speaking service providers.

7. Written material should be based on an English template that was developed specifically with CALD communities in mind. This will help to address concerns regarding appropriate terminology and presentation of material.
PART ONE

PROJECT OVERVIEW

&

CROSS-CUTTING ISSUES
PROJECT BACKGROUND

Victoria has seen significant increases in migration since the 1990’s from countries experiencing high levels of HIV. National Surveillance Data reveals that a significant number of new HIV diagnoses are in people from countries of high prevalence\(^1\) residing in Australia, temporarily or permanently. The HIV clinic at the Melbourne Sexual Health Centre noticed that in 2003, ‘a large proportion of those coming to grips with a new HIV diagnoses were from culturally and linguistically diverse (CALD) backgrounds’\(^2\) \(^3\)

The pattern of HIV exposure among people from CALD backgrounds is predominately heterosexual. Thirty three percent of HIV infections attributed to heterosexual contact in Australia from 2000-2004 were from people from a high prevalence country and a further 27% were from people with a partner from a high prevalence country. In 2004, 119 women were newly diagnosed with HIV and over half were from a high prevalence country.\(^4\)

The Annual Surveillance Report 2005 from the National Centre in HIV Epidemiology and Clinical Research reports that 7.2% of new HIV diagnoses in Australia in 2004 were from people from Sub Saharan African, 7.2% from Asia, and another 0.6% from the Middle East and North Africa. People born in Africa were also more likely to be late ‘HIV presenters’ to health and support services.\(^5\)

With an increased number of people coming to Australia or undertaking journeys to high prevalence countries, the most effective way to limit the spread of HIV is prevention, through education. The provision of culturally appropriate information is all the more necessary as these new communities experience many barriers to accessing health care, such as language, the refugee experience, or a lack of understanding of the Australian health system.\(^6\)

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2 Melbourne Sexual Health Centre (2004), Increased numbers of new HIV diagnoses in People from CALD backgrounds at MSHC, HIV Clinic Newsletter, July 2004
4 Twenty five percent of heterosexually acquired HIV cases in Australia from 2000 to 2004 were from people born in sub-Saharan Africa, a further 18% of cases were from people born in Asia.
5 Keynan M (2004), Late HIV Presentation among African Communities, Talkabout Feb-March 2004
1997 amongst communities of non-English Speaking Background (NESB),\textsuperscript{7} the Multicultural HIV/AIDS Service found that NESB communities had:

- Low level of knowledge of the difference between HIV and AIDS
- Poor knowledge of behaviours and practices to avoid HIV
- Low levels of knowledge and access to HIV/AIDS services
- Prejudicial attitudes towards People Living with HIV/AIDS
- A strong perception that HIV/AIDS is not present in their respective communities

In its 2002-2004 HIV/AIDS Strategy, the Victorian Department of Human Services identified people who have come from high prevalence countries, or who travel regularly to these countries as ‘people at particular risk’ of HIV infection and ‘[in need of] appropriate health promotion programs and initiatives’.\textsuperscript{8}

**Target communities**

The following communities: Horn of Africa, Arabic, Vietnamese and Thai were the target groups selected by the Victorian Department of Human Services for the Multicultural HIV/AIDS Support Service (MHSS), established in 2003. In 2005 it was decided that MHSS would no longer focus its attention on the Thai community and would direct its attention towards the remaining communities.

Our selection of communities for this research was based on the priorities set by the Victorian Department of Human Services for MHSS.

\textsuperscript{7} Multicultural HIV/AIDS Service (1997), *Inequity and Hope, a discussion of the current information needs of people living with HIV/AIDS from Non-English Speaking Background*, MHAHS, Sydney

\textsuperscript{8} Victorian Department of Human Services (2002), *Victorian HIV/AIDS Strategy*, Melbourne
### Characteristics of selected communities in Victoria

<table>
<thead>
<tr>
<th>Community</th>
<th>Size</th>
<th>Language</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vietnamese</td>
<td>56,664</td>
<td>Vietnamese</td>
<td>Buddhism, Catholicism</td>
</tr>
<tr>
<td>Thai</td>
<td>5,487</td>
<td>Thai</td>
<td>Buddhism</td>
</tr>
<tr>
<td>Arabic-speaking</td>
<td>47,147</td>
<td>Arabic</td>
<td>Islam, Christianity</td>
</tr>
<tr>
<td>Sudanese</td>
<td>Not available</td>
<td>Arabic</td>
<td>Islam</td>
</tr>
<tr>
<td>Somali</td>
<td>2,311</td>
<td>Somali</td>
<td>Islam</td>
</tr>
<tr>
<td>Ethiopian</td>
<td>1,970</td>
<td>Amharic</td>
<td>Coptic Christianity, Islam</td>
</tr>
<tr>
<td>Eritrean</td>
<td>996</td>
<td>Arabic</td>
<td>Islam (75%), Christianity</td>
</tr>
</tbody>
</table>

Source: ABS, 2001 Census of Population and Housing, VOMA

The most notable increases in migration flow to Australia in recent years have been from the Horn of Africa (Sudan, Somalia, Ethiopia and Eritrea). The number of humanitarian entrants coming to Australia from Sudan, for instance, has increased by 104.9% between the 1996 and 2001 census. Another Horn of Africa community who has experienced a significant growth since 1996 is Ethiopia, with an increase of 29.9% of the number of migrants. The 2001 Census reported 6,264 Victorians from Sudan, Somalia, Ethiopia and Eritrea, but this figure has now changed dramatically.

Between 2002 and 2004, 3,125 Humanitarian Entrants from Sudan, Eritrea and Ethiopia settled in Victoria. Informants from these communities estimate that there could be between 15,000 and 20,000 migrants from the Horn of Africa living in Victoria today.

The Horn of Africa continues to experience high rates of HIV infection. For instance, in 2003, it was estimated that 380,000 adults (2.3%) were infected in Sudan, 1.5 million people in Ethiopia (4.4%), and 60,000 in Eritrea (2.7%) – no figures were available for Somalia.

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9 Arabic-speaking communities come from 22 countries. Statistical information provided by the 2001 Census is organised by country of origin, not language spoken at home.

10 The Sudanese migration to Australia (including Victoria) is very recent and continuously increasing. There were no figures available from the 2001 census, however the census singled out Sudan-born migrants as the third fastest growing overseas birthplace group.


The number of migrants from the Horn of Africa in Victoria is small but their needs are vast, and they encounter many barriers to settling in their new country. For these newly arrived communities, particularly those from the Horn of Africa that have not come to join an existing, more established community, there is an acute need for information in their language about an array of topics, including HIV. Many have lived in refugee camps for years, their education has been disrupted or non-existent, and in some communities, such as the Ethiopian community, the majority are not literate in their own language.

Traditional channels of information, such as written material or the press, may not reach people from CALD backgrounds, particularly if the material is in English or translated from English without taking into account the cultural barriers that may interfere with the promotion of messages. This is compounded by the fact that these new communities are only starting to create structures and services for their members, and the channels of information and communication are therefore still unclear to most ‘mainstream’ Service Providers.

Other communities
Another refugee community that has experienced a significant increase in new arrivals is the Iraqi community with an increase of 77% between 1996 and 2001. In recent years there has also been an increase in the arrival of ‘stateless’ people, including ethnic Kuwaitis, Somali, Darood Somali, and Arabs.

In line with the Department of Human Services’ selection of communities for the MHSS, the Vietnamese and Thai communities were also identified as in need of HIV prevention information. Victoria has a Vietnamese population of almost 48,000 people. One of the groups of concern for HIV infection is Injecting Drug Users. It is well documented that Vietnamese who inject are at particular risk of HIV infection in Vietnam and in Australia. Another area of concern in regards to access to HIV information is the broader Vietnamese community, due to the low level of English language proficiency. Despite the fact that the Vietnamese community is not an emerging group, English language difficulties prevail and as a consequence barriers to accessing health care indicate that there is a need for information and services that address this group’s particular needs.

15 ABS 2001 Census, op cit
The Thai community is relatively small in Victoria (5,460 people). There is however a high number of Thai-speaking Sex Workers in the Victorian sex industry who constitute a group at high risk of HIV infection. It was decided that a focus on Thai Sex Workers was beyond the scope of the study. The focus within the Thai community for this study was on overseas students from Thailand. The combination of youth, freedom from parental discipline and cultural obligations, and a tendency to live in a close-knit group, preferring the comfort of speaking their native tongue and the safety of being cocooned by a shared culture\textsuperscript{16} makes Thai students studying in Australia particularly vulnerable to sexually transmissible diseases such as HIV.

This Project investigates these communities’ information needs in regards to HIV prevention. We have identified and analysed all materials available to these communities in Victoria relating to HIV/AIDS prevention, and conducted Interviews and Focus Groups to determine how appropriate these materials were to the communities' needs.

\textsuperscript{16} The Age newspaper (2005), \textit{Hello Stranger}, Melbourne, 19/09/2005
RESEARCH OBJECTIVES

The field work for this research project was conducted between February and September 2005. The research objectives were as follows:

1. To provide a comprehensive audit of currently available materials (written and audio-visual) and support structures for each of the communities. This also reveals what gaps exist in each of the communities.

2. To provide a content analysis of all materials, which will explore how culturally and linguistically appropriate the products are.

3. To explore knowledge and understandings of HIV prevention that these communities develop from this material.

This project does not aim to research the behaviour or personal experiences of people in the selected communities. It is solely concerned with their knowledge and understanding of HIV prevention in relation to the available material and structures.
INITIAL CONSULTATION

Information was gathered from Associate Investigators and key community organisations in the initial research. They provided recommendations on the selection of co-workers and were instrumental in the collection of all current prevention material about HIV in the selected languages.

An Advisory Committee consisting of the Associate Investigators, representatives from the selected communities and the principal researchers met at key points throughout the research. The committee guided the research and provided feedback on the findings from Key Informant Interviews, advice on the recruitment of Focus Groups, and findings from the Focus Groups.

Co-Workers

Four co-workers were recruited from the selected communities to provide cross-cultural advice for the duration of the project. Their support to the project included:

- Providing relevant community contacts
- Cultural understandings of HIV and Sexual Health
- Advice on suitable Key Informants
- Insight in content, appropriateness and relevance of material collected
- Identification of material to be presented to Focus Groups
- Recruitment of other facilitators and supervision of Focus Group process
- Insight in interpretation of preliminary findings

Choice of Focus Groups, line of enquiry, location, recruitment and composition were determined in consultation with co-workers. This research was informed at all times by the comments of co-workers, members of the Advisory Group and findings from the Key Informants.

Bilingual facilitators were recruited to recruit, organise and run the Focus Groups. Focus Group training was provided to all facilitators by ARCSHS staff.
RESEARCH STAGES

1. Collection of all publicly available materials about HIV for each of the communities in Victoria
   Analysis of selected material

2. Semi structured Key Informant Interviews with community representatives and Service Providers

3. Analysis and selection of material for Focus Group testing

4. Focus Group discussions

Stage I – Information Audit

An audit of currently available material in languages other than English for each of the selected communities was conducted within the first month of the project. Languages targeted were:

- Arabic
- Somali
- Tigrigna
- Oromo
- Amharic
- Vietnamese
- Thai

All relevant organisations that provide support to these communities were identified and contacted to obtain lists of materials used in their community education and information work. Research reports and articles published about HIV information and understandings in the selected communities were obtained. This was achieved
through an Internet search and through direct contact with the following organisations:

- Working Women’s Health (Information centre)
- Multicultural HIV/AIDS and Hepatitis Services (NSW)
- Multicultural Health Communication Services (NSW Health)
- Victorian Aids Council
- Melbourne Sexual Health Clinic
- Centre for Culture, Ethnicity and Health (North Richmond Community Health centre)
- Access Information Centre (Alfred Hospital)

Stage 2 – Key Informant Interviews

Twenty-six interviews were held with community leaders, community workers and other health Service Providers. A range of topics were discussed, including: the communities’ support structures, channels of communication and key issues for the community around HIV prevention. The interviews were also used to identify the most commonly used HIV prevention material. Key Informant Interviews helped to inform stage three of the research: the recruitment of Focus Groups.

Key Informants were identified in collaboration with Associate Investigators. Interviews lasted between 45 and 60 minutes. Topics covered in the interviews were:

- Perceptions and understandings of HIV prevention in the community
- Sensitive issues around sexual health and HIV/AIDS
- Issues related to sub-groups: young people, newly arrived, women, men
- Community channels of communication
- Input on Focus Group composition and recruitment approaches.

Interviews were conducted in Melbourne, Shepparton and Sydney.

Stage 3: Selection of materials

The most commonly-used documents for each community were identified, based on feedback from the project’s co-workers, Associate Investigators, organisations that
the material was obtained from and Information Officers in key organisations. The selection was refined through advice from community leaders and community workers obtained during Key Informant Interviews.

Materials (pamphlets, posters etc.) were analysed in collaboration with co-workers, with specific reference to cultural appropriateness and correctness of language. Particular attention was paid to the following questions:

- Is the information written in a way that is sensitive to the specific cultural context of the target communities?
- Is the imagery adapted to appeal to these communities?
- How much information is translated directly from English and how much is written specifically for these communities?
- Are the materials gender-disaggregated or is the same material used for men and women?

**Stage 4: Focus Group Discussions**

**Focus Group discussions** were held in each selected community to discuss:

- identified material’s cultural and linguistic appropriateness
- participants’ understanding of the material
- participants’ perception and understanding of HIV prevention
- preferred channels of communication for HIV information

A total of 10 Focus Groups were held:

1. Young people from the Horn of Africa
2. Women from the Horn of Africa
3. Iraqi and Lebanese women
4. Somali women
5. Men from Southern Sudan
6. Young people of Arabic background in the Dandenong area
7. Iraqi men in Shepparton
8. Vietnamese men
9. Vietnamese Injecting Drug Users
10. Thai students

A small Focus Group discussion was held with Family and Reproductive Rights Education Health Project (FARREP) workers at the end of the field work to obtain their feedback on the findings of the Horn of Africa (including Somali) women’s groups.

Discussions were semi-structured, to allow facilitators to adjust lines of enquiries to the cultural specificity of the groups.

Focus Groups were conducted in the preferred language of the participants. This could be their first language (e.g. Vietnamese), the common language from their country of origin (e.g. Arabic), or, for some groups, English, either because it was their common language or because it was the language they spoke best (e.g. young people of Arabic background). When several languages were spoken the group was run in these different languages and two facilitators were used.

Discussions were recorded, with the participants’ consent, in order to help report writing.

Bi-lingual facilitators from the target communities were trained in recruiting and facilitation of Focus Group prior to the Focus Group discussions. These training sessions included:

- Description of the project and its objectives
- Discussion of the Information Sheet and Information & Consent Form, their objectives and content
- Consultation with facilitators on best way to approach lines of enquiries in each community and sub-group
- Any foreseen issue
- Reporting (a pro-format was provided)

A Line of Enquiry was provided to all facilitators and explained during training (see Appendix 2).

Following each Focus Group discussion, facilitators prepared a report and then met with the project research officer for debriefing and discussion of findings. Reports
were then analysed thematically and collated. Cross-cutting issues were identified, as well as differences between groups. We have chosen to present findings for each Focus Group under these major themes, as this allows readers to select the findings that are most relevant to them.

**SELECTED MATERIALS**

Material was obtained, in person or online, from the following sources:

- Multicultural HIV/AIDS and Hepatitis Services (NSW)
- Victorian Department of Human Services (Victoria)
- Royal Women’s Hospital
- Working Women’s Health
- Multicultural HIV/AIDS Support Service
- Centre for Culture, Ethnicity and Health (North Richmond Community Health Centre)
- NSW Department of Health
- Family Planning Australia

The material collected was then analysed according to the following criteria:

- Availability in Victoria
- Internet-based/existence of hard copy
- Existence of an English version/written directly in language
- Inclusion of diagrams and illustration
- Proportion of text versus illustration
- Inclusion of contact details

Material was then selected to be presented to Focus Groups in consultation with co-workers and based on comments from Key Informants. For most groups, we included one piece of material produced by DHS (in language or/and in English), one ‘Getting it Right!’ booklet (widely available) and another piece of material with interesting characteristics for which we wished to obtain feedback (colours, bilingual, specific target audience).
A small number of materials selected were not directly related to HIV but were included in order to obtain feedback from the groups on presentation characteristics not offered by available HIV prevention materials: some were designed specifically for the target community, others were bilingual, well illustrated, etc.

The key materials selected were:

- **Getting it Right! (MHAHS)**: widely distributed, used by Service Providers, produced by a community consultation process, some pictures, basic information.

- **HIV/AIDS, Your Questions Answered, Sexually Transmitted Disease and Safe Sex (Victorian DHS)**: these A4 pages, which can be downloaded from the Internet, are the most up-to-date information produced by DHS. The booklets produced in 1998 were updated in 2003, but no hard copies were printed and they are only available through the Internet.

- **Going Home Safe (MHAHS)**: described by co-workers and Service Providers as ‘very good’, instantly recognisable presentation as South-East Asian, even in English, colourful, contains many illustrations.

- **Healthy African Women (Women Health West)**: this material was included due to its specifically African presentation (colours, pictures and general presentation). It was used in Focus Groups to obtain feedback on material that is immediately identifiable as addressing a specific group (along the same model as Indigenous Australians material).

- **Don’t Be Afraid to Ask (MHAHS)**: bilingual material that provides clear information and ethnically relevant pictures.
MAJOR FINDINGS

- Almost all participants were unaware of the existence of HIV prevention material produced in Australia in their language.

- Participants often held a false sense of security concerning HIV in Australia. Due to Australia’s practice of screening migrants for HIV; the different dominant modes of transmission from their home country; and much fewer highly visible public prevention campaigns, most participants believe that HIV is not a major issue for themselves or their community in Australia.

- Participants often rejected a format that used a personal sexual approach, preferring to see HIV as a general community health concern.

- The high level of sensitivity around HIV/AIDS and around how the content is presented means that at times, there is a risk of material being rejected.

- Most participants valued information delivered face-to-face. This allows for sensitivity to be addressed and helps place information within its cultural context.

- The language and literacy differences between and within communities means that no one method of communication will be appropriate for all.

- Bilingual information was identified by all communities as essential for addressing differences in language and literacy levels.

- The English template used in most material tested in the study often includes information that is not appropriate for some communities.
CROSS-CUTTING ISSUES

The following issues have emerged from this study as issues of relevance across all communities, although there were many variations in terms of their importance or the manner in which they affected HIV prevention.

Cultural appropriateness of material

As Health Educators, we need to find appropriate ways to deliver that information. It’s our challenge, not theirs. (Key Informant)

The level of sensitivity around HIV was high in all communities, although it was greater in the newly-arrived communities than in more established ones. All Focus Groups acknowledged that HIV was a sensitive topic for reasons of stigma, its association with homosexuality and drug use, or, in some communities, the fact that it is associated with ‘loose behaviour’ and casual sex.

Despite this, most Focus Group participants were very interested in gaining more information and in accessing material about HIV. Women in particular were keen to increase their knowledge to then share it with other women and with young people in their community. This thirst for information often led to a tension between wanting to know about the topic and feeling embarrassed by the nature of the information or the way it was presented. This in turn led to contradictory statements about the appropriateness of some of the available information.

In regards to the material currently available, sensitivity was mainly associated with:
  - Diagrams showing how to use a condom
  - Mention of sexual practices (oral and anal sex)

The perceived lack of appropriateness of some of the material limited its potential use:

  • by leading to outright rejection of material, as it was too shocking to handle – even though some of the less sensitive information included would have been of great interest to participants.
• by affecting how comfortable people were with taking brochures home, picking up written materials in public and sharing the information with community, family and friends.

When material was seen as inappropriate, this was sometimes interpreted as a sign that it had been written for others. Subsequently, the relevance of the topic and the material was then questioned.

Health Literacy

_People will come to the health system with a whole history … of living in outback Somalia and it’s a completely different experience. I don’t think you can ignore that._

(Key Informant)

Assumptions are often made that health terms and conditions are understood or if not, that this can be addressed by translating those terms into the preferred language. Findings show that these terms are often not understood in either English or in the preferred language. Typically, words such as ‘immune system’, ‘Chlamydia’, ‘intercourse’ or ‘lubricant’ were not understood.

Health literacy also includes knowledge of the Australian health system and of one’s rights as a consumer. Service Providers reported that such knowledge may be lacking and that materials needed to take this into account.

When terms were not explained, this resulted in either confusion or frustration with the material and in the impression that the people or organisations who wrote or published the material had little understanding of the community’s needs.

In order to help them better understand the material, participants requested that terminology be explained in their language, and that words be included in English (as well as translated). In many cases, they were more likely to have come across those terms in Australia than in their country of origin, and knowing the English terminology allowed them to discuss the issue with their health care provider.

Knowledge of HIV varied widely between participants, depending on their educational and professional background. It ranged from advanced (for community health workers, nurses and doctors in the groups) to very limited, to non-existent. Some
groups showed strong beliefs in 'conspiracy theories' to explain HIV infections and the development of the epidemic.

Most people had seen more information outside Australia than since they had lived in Australia: through media campaigns in Thailand and Vietnam, billboards, information sessions and awareness raising activities in refugee camps. This led to a sense that HIV was not an issue in Australia, as it was seldom discussed. Knowledge of HIV incidence in Australia was extremely low.

**Intergenerational communication**

*In an African context of living, they function completely differently, there’s an understanding of freedom, a respect for the elderly... but once they come here, I think it becomes looser, and parents actually lose their grip ...* (Key Informant)

Service Providers and Focus Group participants expressed a high level of concern about young people and the difficulty they have in reconciling their parents’ culture and the youth culture in Australia. Adults who are first generation migrants are concerned about the level of freedom enjoyed by their children in Australia, and the loss of the sense of community and respect for elders.

This ‘gap’ experienced by young people between their culture and that of their parents’ can lead to risk-taking behaviour, through a combination of freedom, peer pressure and lack of information. All groups conferred that HIV was a problem mainly for young unmarried people, who enjoyed more sexual freedom and many temptations in their new country. Adults sometimes felt ill-equipped to deal with these temptations. They felt that their children’s need for sexual health information was high – and rarely met by parents or other community members.

Women, as mothers, felt a responsibility to provide information to their children to ensure their welfare, including information about sexual health. They were often torn between their desire to inform their children and their own feelings towards the sensitive nature of the information.

For new communities, the first twelve months in Australia, when everything is new, presents a particular area of risk.
It shouldn’t be assumed that young people speak the language of their parents – or that they don’t. This depends on how long their community has been established, whether they have attended school in Australia, and how old they were when they arrived. In the group of young people of Arabic background, all bar one spoke English better than Arabic (several did not speak Arabic at all, while others spoke a ‘broken Arabic’). On the other hand, Thai students, even though they are attending university in English, used Thai in all their interactions. Young people from the Horn of Africa were fluent in English and their parents’ language, but expressed a preference for information in their parents’ language over English.

Language is not the only ‘tool’ to communicate effectively with young people. An acknowledgement of their cultural (including religious) background can also increase the relevance of the information provided. Without it, there is a risk that they will see the information as not targeting them, particularly if it is in English. One way of acknowledging their cultural difference and making information more adapted to their needs is to use a presenter from the same cultural background.

**Role of resettlement and the refugee experience in access to HIV prevention information**

*I tested these people for malaria last week, and (...) the little boy had the worst kind of malaria, and I had to send him to the hospital in an ambulance. They had been in the country five days, you know? HIV was the last thing on their minds.* (Key Informant)

For newly-arrived communities, resettlement and the many priorities that accompany it take precedence over other, more secondary, needs. Housing, income support, education and urgent health care are the highest priorities. Learning a new language and the many new structures and services are also important. In this context, there is little place and time for HIV prevention information.

On arrival in Australia, people accepted under the Commonwealth Government’s Humanitarian Entrants program are overwhelmed with written information relating to Medicare, Centrelink, opening a bank account, or enrolling children at school. It can be difficult, with few English skills, to differentiate between official forms and educational brochures. This and the enormous amount of information, means that
any written information that is not directly related to one of their priority needs is likely to be discarded.

The chaotic nature of this settlement period can also make it difficult for new arrivals to process information. Alternatively, this is also a time when people form a ‘captive audience’ that can be reached through English Language Schools or re-settlement programs, and can be given information in a more accessible and appropriate way.

For refugees, the fact that they had been screened for HIV before being accepted in Australia created a ‘false sense of security’ that HIV was a problem of the past, and was not present in their community (see more on this in the ‘Returning Home’ section). Some new arrivals who spent several years in refugee camps or as refugees in other countries felt that they have been already exposed to a lot of HIV prevention information before their arrival in Australia.

Service Providers suggested that including HIV information in a context of general health and with an emphasis on the well-being of the community, and particularly of young people, would be an effective way to reach new-arrivals as these are issues of high importance for them.

Returning home

   The fluidity between the two countries is a big thing in certain groups.

   (Key Informant)

The risks associated with trips to the country of origin or the country of temporary residence was often mentioned by Service Providers and participants alike. The links between the communities settled in Australia and their relatives and friends in the country of origin remain strong and visits are frequent. This is an issue for HIV prevention when the country of origin is a country of high HIV prevalence. This issue was brought up by some participants in relation to their concern about HIV rates in their community in Australia. Because of the screening process when applying for permanent residency, they identified these trips as opportunities for infection – as there is no HIV testing on re-entry.

Women in the Vietnamese community were concerned about the risks taken by men when visiting friends and relatives in Vietnam. They blamed men for infecting their
wives upon their return. With more recently arrived communities (such as Horn of Africa), such trips are beginning to occur, and this also caused concern to women in these communities.

In other instances risk behaviours takes place in Australia, as a result of estrangement from one’s family. For some men, their wife and children may have remained in the country of origin. Overseas students, away from parental influence, enjoy more freedom in Australia than in their home country.

**FINDINGS ABOUT INFORMATION PROVISION**

*If a community was consistently telling you that was offensive ... I don’t think the information should be there. The difficulty is how do you reach the people within that community who are engaging in those practices?* (Key Informant)

**Language and literacy**

Our study has highlighted the differences between, but more importantly within, communities: differences based on gender, age, time of arrival, resettlement experience, social and educational background. HIV Prevention is a sensitive topic, and is intimately linked to cultural norms, which vary between communities and sub-groups. Within the Arabic community for instance, there are vast differences between the way young people feel and talk about sexual relationships and the way their parents do. There are also differences between Lebanese, Egyptian and Iraqi’s levels of comfort (or discomfort) with the topic, and within these communities: Muslims or Christians, established groups or recently arrived refugees, may address these issues differently.

No conclusions can be drawn that apply to all communities in regards to the best ways of providing information about HIV prevention. Even the most basic elements of information provision (language and literacy) differ widely between groups. The preferred language of participants cannot be assumed from their nationality. Their ethnic background (as opposed to nationality) and their migration history often determine their preferred spoken and written language/s. In Focus Groups of women from the Horn of Africa, no two participants showed the same 'equation' of language spoken at home/preferred written/preferred spoken languages.
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It also became clear through the Focus Group process that the participants’ literacy in English or in their preferred language varied from one person to the next: here too, history of migration, time spent in refugee camps and educational opportunities determine peoples’ literacy levels. It was not uncommon for women who spoke a language other than English at home (for instance Somali) to only be literate in English, as they had had no opportunity for education before migration to Australia.

Different approaches for different communities

‘The utilisation of strategies that take account of the cultural shaping and sensitivities relating to sexual health’ are a challenge for service providers.17 Given the diversity outlined above, there is not one approach that meets the needs of all communities. Whatever material (written or audio-visual) is produced, it needs to be flexible enough to be adapted to the different needs – or to be produced specifically for one community, after a consultation process.

A limited number of themes emerged with consistency across all groups:

- The preference for face-to-face interaction.
- The lack of awareness that material was available about HIV in their language. Participants, whatever their cultural or socio-economic background, profession or age, had never seen material about HIV in their language in Australia and were not aware that such material existed or of websites offering translated health information. In many cases, they were adamant that such material was not available.
- The need for privacy when accessing material about HIV.

While most participants raised these issues, there was little common ground in the way they were approached.

In regards to channels of communications, Focus Group findings highlighted the vast differences between communities and sub-groups on how they obtain information of this nature:

17 Gifford S and Temple-Smith M (2005), Diversity and difference: the cultural shaping of sexual health, in Sexual Health, an Australian perspective, IP Communications, Melbourne
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- Internet use and confidence in the medium. The internet was surprisingly popular and its use was high, in great respect because of the privacy it allowed. Most participants were not aware that material published in Australia in their language was available on the Internet.
- Language ‘pull factor’: for some groups, such as women from the Horn of Africa or Iraqi men in Shepparton, the availability of materials in their language is vital. For other groups, such as young people of Arabic background, material in English is preferred. Many participants across all groups recommended the inclusion of English terminology to describe symptoms and diseases as this allows them to discuss their concern with their GP, and as they may be more familiar with the terminology in English than in their preferred language.
- Preferred Service Providers ranged from GP, community workers, friends and family, the internet, to community leaders and books.
- How much the material’s design and general appearance influenced readers’ uptake and perception of material also varied between participants.

This diversity presents a challenge for the writers and publishers of such information, as they can rarely afford to design information or materials specifically for each subgroup.
THE ROLE OF GPs

The role of General Practitioners as information providers was discussed by Key Informants and by Focus Group participants alike. One Service Provider felt that GPs are in an ideal position to do that kind of brief intervention. However, for Focus Group participants, asking their GP for information about sexual health was often the result of a perceived lack of alternatives.

For many participants in this research, visits to the GP were their only contact with health services, the ‘first port of call’ and the only source of health information they knew of. People often turned to their GP for information because they did not know where else to go, and held little hope of receiving detailed information. A frequent comment was that General Practitioners have little time, and will only provide information if specifically requested. A GP working with refugees confirmed that consultation time was limited and that HIV prevention would only be addressed if there was a certain context in the consultation.18

While some participants were nervous about confidentiality and privacy issues when discussing sexual health, this was mainly the case in small communities where the risk of inadvertently meeting a GP outside the consultation setting was higher. Service Providers working in the sexual health field reported that people of CALD background were often reluctant to consult with GPs for sexual-health related issues, but this was not reflected in the Focus Groups. Young people were more comfortable than adults discussing sexual health issues with their GPs.

When people are reluctant to consult a GP from their community background, they can lack alternatives if their English-language skills are poor.

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18 In November 2005, the Commonwealth Government announced that from May 2006, refugees would be given a new Medicare item that covers them for a full medical check up, particularly targeting diseases such as HIV/AIDS, cholera, malaria and TB.
The perceived level of confidence in GP’s knowledge and competence was high – apart from Thai students who found the health system in Australia less satisfactory than in Thailand.

Other sources of health information mentioned were community workers: while some participants suspected that they may not be as knowledgeable as GPs, they were likely to be more aware of the community’s needs and cultural context.

**Dealing with sensitivity**

A great deal of sensitivity was raised concerning the inclusion of sexual practices such as oral and anal sex in information material. It was frequently claimed that such practices were not relevant to the community and were in fact very offensive. As a consequence, it was often resolutely stated that such material would not be read.

Whether or not we give credence to the claims that oral sex does not occur in these communities, it is important that we listen to the reaction to the inclusion in HIV prevention material of this sexual act as a risk practice. If a document is rejected as a whole because it includes description of oral or anal sex, or a diagram of how to use a condom, then the whole effort put into producing this document amounts to nothing, and information that would be useful and would respond to the expressed need for education, does not reach its target audience. As stated by a service provider: *If it’s not culturally appropriate, well, then it’s just not going to work.* This leaves health professionals and service providers with the challenge of responding to cultural sensitivities without omitting useful information.

Most material is currently translated into languages from a common English template, written for an English-speaking audience, no doubt in the belief that ‘the process of translation will ensure understanding of the content in the destination language’. As a result, it keeps with the ‘Anglo-northern communicative preference for ambiguity avoidance’ and ‘precisely defines sexual acts’. According to Fletcher, this English-language blueprint ‘directly affects the ability of non-English speakers to internalise and act on messages which could save their lives’.

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19 Fletcher G (2002), *Mind your language? Deconstructing an HIV/Aids information leaflet in English and in translation*, unpublished, La Trobe University, Melbourne

20 Ibid
The difficulty of producing material for such diverse needs is made even more complex by the sensitivity of issues related to HIV. As discussed above what is seen as acceptable in a community may be perceived as highly offensive by another, and result in the rejection of the material as a whole.

We asked Key Informants and Focus Group participants to make suggestions on the best way to provide information that meet their needs and respect their sensitivity. They offered the following suggestions:

- placing the description of sexual practices further in the documents – not on the first page
- placing sensitive information on a separate, detachable leaflet
- announcing the presence of such information as a ‘disclaimer’, admitting that it may shock some readers.

Ultimately, these suggestions are about choice and respect: giving readers a choice instead of imposing the information, and respecting their sensitivity by acknowledging that this information, however useful, may seem offensive.

**The role of written information**

For most, written information was not the preferred way to receive information about HIV prevention. Face-to-face communication, through information sessions or one-on-one discussions with a health or community worker, was preferred. Written information was seen as a support or an extension of this direct and personal interaction.

Participants highlighted many positive aspects of written information, such as:

- It is easily accessible
- It offers the advantage of presenting all the necessary information at once, in one document
- It is generally clear
- It can be read in one’s own time.
Negative aspects that were also mentioned included:

- The terminology used can be difficult to understand
- The inclusion of insensitive diagrams
- It cannot be accessed by the illiterate members of a community
- There is a risk of being ‘found’ with it.

If written information was to be used, Focus Group participants offered suggestions that would encourage members of their communities to pick up the material and read it. For example: a Q&A format, simple and clear content with no ‘jargon’, pictures and diagrams representing people and families, a clear indication of the language of the brochure on the front page (as this can be the reason for picking up the material), and a culturally-specific presentation that makes the material instantly recognisable as being addressed to one community.

**Face-to-face communication as a way to address diversity**

Written materials in themselves are not sufficient to get the message of HIV prevention across: while it is an important part of the jigsaw, the key to making it specific to its audience resides in when and how it is used. If it is presented by someone who understands the group’s cultural context and where discussion of sexual health sits in this context, and who acknowledges the sensitivities, then this opens a space where boundaries can be pushed and sensitive information can be introduced.

This need for material to be accompanied by face-to-face interaction is one of the few findings common to all the communities researched. Information sessions were seen as the most effective way to pass on prevention information about HIV. While there was some acknowledgement, particularly from men, that these may be difficult to organise, information sessions were seen as a way to address the heterogeneity of communities, cultural and language differences, differences in literacy levels, and to place information in a context that makes it acceptable to audiences. Information on HIV transmission, for instance, is better received if it is presented in a context that audiences can relate to, such as in relation to religious background, to migration, to the refugee experience, etc.
At the same time, our Focus Groups with men also showed the reluctance men may have in exposing and acknowledging gaps in their knowledge in front of other men, or in admitting to sensitivity around certain issues when they realise this may be interpreted as conservatism or lack of sophistication. This has to be taken into account when organising information provision as it may limit the value of group sessions.

Information sessions require informed multilingual and multicultural community educators, supported through regular training and professional development. Based on their experiences as advocates in their community, they can provide input when material is written and designed. They are an essential link between institutions and communities, an ‘ear to the ground’ that can inform the way the public health sector works with the CALD members of our communities and develop a stronger awareness of HIV prevention.
RECOMMENDATIONS

1. A broad campaign is required to accompany the production of all material in languages other than English. Consultation about content and delivery needs to take place with each target community. Appropriate means of distribution of material should be discussed within the community consultation process.

2. In order to make HIV prevention relevant to these groups it is essential to raise awareness of incidence in Australia and in their own communities and to address concerns about stigma and support.

3. Information about HIV prevention will be more readily accepted if packaged within a community health framework and not within an individual sexual/relationship approach.

4. A particular effort must be made to investigate ways to negotiate the conflict between the sensitive nature of the material and the willingness to know about HIV. How to deliver sensitive information which does not alienate audiences will require community input.

5. The prime form of information delivery needs to shift away from the reliance on written information to face-to-face interactions (information sessions and one-on-one). In many cases this will include bi-cultural and bi-lingual community workers.

6. All information, including written material, should be delivered in community languages and in English. This will accommodate the range of language and literacy skills within each community and facilitate communication with English-speaking service providers.

7. Written material should be based on an English template that was developed specifically with CALD communities in mind. This will help to address concerns regarding appropriate terminology and presentation of material.