



**Australian Government**  
**Cancer Australia**



Federation of Ethnic Communities' Councils of Australia

# Cancer and Culturally and Linguistically Diverse Communities

**October 2010**

This project received funding from the Australian Government through Cancer Australia, as part of the 2009 *Building Cancer Support Networks* initiative.

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# Table of Contents

<b>Acronyms .....</b>	<b>6</b>
<b>1. Summary and Recommendations .....</b>	<b>7</b>
1.1 Executive Summary.....	7
1.2 Recommendations .....	8
1.3 Introduction.....	9
1.4 Literature Review Methodology.....	9
1.5 Definitions.....	10
<b>2. Cancer and Australia’s Culturally and Linguistically Diverse Communities: General Findings .....</b>	<b>10</b>
2.1 Introduction.....	10
2.2 CALD Communities and Health.....	11
2.3 Commonly Held Attitudes and Beliefs Regarding Cancer .....	13
3. Cancer Prevention and Screening .....	14
3.1 CALD Communities and Screening .....	14
3.2 Barriers to Screening.....	15
3.3 Culturally Relevant Practices That May Encourage Screening: .....	17
<b>4. Risk Factors.....</b>	<b>17</b>
4.1 Generic Health Literacy .....	18
4.2 Medical Histories.....	18
4.3 Sedentary Lifestyles .....	18
4.4 Smoking (Lung Cancer).....	19
4.5 Hepatitis B Infection (Liver Cancer).....	20
4.6 Human Papilloma Virus (Cervical Cancer).....	20
4.7 Risk Factors and Refugees.....	21
<b>5. Knowledge and Attitudes to Health and Support Services by Cancer Patients and their Families.....</b>	<b>21</b>
5.1 Common Experiences and Responses Of CALD Families to Cancer Health and Support Services: .....	22
5.2 Common Barriers for CALD Communities when Accessing Health and Support Services Identified in The Literature:.....	23
5.3 Findings with respect to Palliative Care and End of Life Issues: .....	23
5.4 Common Findings with regard to the Provision of Culturally Sensitive Health and Support Service Provision.....	24

<b>6. Research Challenges and Gaps .....</b>	<b>25</b>
6.1 The challenges of researching CALD communities and cancer.....	25
6.2 Research Gaps.....	26
<b>7. CALD Engagement Strategies and Recommendations .....</b>	<b>27</b>
7.1 Strategic Planning for CALD Engagement.....	27
7.2 Recommendations.....	29
7.2.1. Assessment, research and information dissemination .....	29
7.2.2. Capacity Building .....	30
7.2.3. Service delivery.....	31
<b>8. Case Studies: Cancer and Australia’s Culturally and Linguistically Diverse Communities. Individual Community Findings .....</b>	<b>32</b>
8.1 The Chinese Community.....	33
Demographics.....	33
Incidence/Prevalence Data: .....	33
Attitudes/Understandings of Cancer .....	33
Prevention and Screening.....	34
Attitudes towards Prevention and Screening.....	34
Attitudes towards support Services .....	35
Systemic Barriers .....	36
Risk Factors .....	37
Addressing Cultural Barriers: Findings from the literature.....	38
8.2 The Greek Community.....	39
Demographics.....	39
Incidence/Prevalence Data.....	39
Attitudes/Understandings of Cancer .....	39
Prevention and Screening.....	40
Attitudes towards Prevention and Screening.....	41
Culturally relevant practices that may encourage screening: .....	41
Attitudes Towards Support Services .....	41
Systemic Barriers .....	42
Risk Behaviours.....	42
Addressing Cultural Barriers: Findings from the literature.....	43
8.3 The Italian Community .....	43
Demographics.....	43

Incidence/Prevalence Data.....	44
Attitudes/Understandings of Cancer .....	44
Prevention and Screening.....	44
Attitudes towards Prevention and Screening.....	44
Culturally Relevant Practices That May Encourage Screening: .....	45
Attitudes Towards Health and Support Services .....	46
Systemic Barriers .....	46
Risk Behaviours.....	46
<b>8.4 The Vietnamese Community.....</b>	<b>47</b>
Demographics.....	47
Incidence/Prevalence Data.....	47
Attitudes/Understandings of Cancer .....	48
Prevention and Screening.....	48
Attitudes towards Prevention and Screening.....	49
Culturally Relevant Practices that May Encourage Screening:.....	49
Attitudes Towards Health and Support Services .....	49
Systemic Barriers .....	50
Risk Behaviours.....	50
Addressing Cultural Barriers Findings from the literature .....	50
<b>8.5 Arabic Speaking Communities from the Middle East and North Africa.....</b>	<b>51</b>
Demographics.....	51
Incidence/Prevalence Data.....	52
Attitudes/Understandings of Cancer .....	53
Prevention and Screening.....	54
Attitudes towards Prevention and Screening.....	54
Culturally Relevant Practices That May Encourage Screening: .....	55
Attitudes Towards Support Services .....	55
Systemic Barriers .....	56
Risk Factors .....	56
Addressing Cultural Barriers Findings from the literature .....	57
<b>Appendix A: Resources to assist in Engagement with CALD Communities in Health Settings .....</b>	<b>58</b>
<b>Appendix B: Initiatives Targetting Specific Communities To Engage Them Effectively In Cancer Control. ....</b>	<b>59</b>
Victorian Non English Speaking Background Living With Cancer Education Programs (LWCEP) (Support Services).....	59

The Cancer Council of Victoria’s Cancer Helpline: Multilingual Line (Support Services).....	60
The Cancer Council of NSW Hepatitis B screening and Liver Cancer Surveillance Program (Screening and Education): The ‘B’ Positive Project.....	60
Macedonian Women in Whittlesea (Support Services During Diagnosis and Treatment) .....	61
Australia’s Biggest CALD Morning Tea (Education and Awareness Raising in New Arrivals) .....	61
Women Who Are Carers (Education and Support).....	62
An Evaluation of a Good Practice Initiative: Non English Speaking Background (NESB) Living with Cancer Education Program.....	63
<b>REFERENCES.....</b>	<b>66</b>

## **Acronyms**

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
CCNSW	Cancer Council of NSW
CCSA	Cancer Council of South Australia
CSDH	Commission on the Social Determinants of Health, World Health Organization
CALD	Culturally and Linguistically Diverse
DoHA	Australian Department of Health and Ageing
FECCA	Federation of Ethnic Communities' Councils of Australia
FOBT	Faecal Occult Blood Test
HPV	Human Papilloma Virus
LWCEP	Living with Cancer Education Program
MCWA	Macedonian Community Welfare Association
NESB	Non English Speaking Background
NHMRC	National Health and Medical Research Council
WHIN	Women's Health in the North
WHO	World Health Organization
PSA	Prostrate Specific Antigen

# **1. Summary and Recommendations**

## **1.1 Executive Summary**

In 2006, approximately 30% of Australia's population was born overseas. Research has shown that a number of these Culturally and Linguistically Diverse (CALD) communities are often under-served in the screening process, more vulnerable during the cancer treatment phase and less likely to utilize support services. The knowledge of cancer, its aetiology and prognosis also varies significantly across CALD communities. Different conceptions of cancer, its causes and prognosis may be traditionally held by various members of these communities. Commonly held beliefs include; that cancer is incurable, that it is pre-determined by past moral conduct, that it is contagious, that fear, worry and mental stressors (including interpersonal conflict) can cause the onset of cancer and that knowledge of a cancer can cause further illness or progress the spread of the cancer. These beliefs can and do impact on; participation in screening, engagement in risk behaviours, and, information seeking behaviour and decision making during the cancer treatment. As such, these attitudes and beliefs about cancer need to be explicitly factored into the development of appropriate health promotion, screening services, and culturally sensitive health and support services for CALD communities.

The research also highlights that, unsurprisingly, the experiences, knowledge and attitudes of Australia's diverse CALD communities to various stages of the cancer cycle from prevention through to health and support services and palliative care appear to share many of the barriers, concerns, and needs documented for other conditions. Issues regarding; communication, access, disempowerment, health literacy and inherited conditions and vulnerabilities from the originating country all impact on cancer outcomes for CALD communities. While the contemporary literature seems to support commonalities with other health issues pertaining to; access to, knowledge and understandings of the health system, and broader health literacy, there remains significant gaps in the literature on cancer and CALD communities in Australia. With regard to new and emerging communities, further research on cancer literacy, attitudes and experiences of cancer and cancer services in CALD communities nationally is required.

## 1.2 Recommendations

The following are the recommendations arising from the review of Cancer and CALD communities in Australia;

**Recommendation 1:** That initial work be undertaken/funded to examine the viability of creating uniformity in the collection of health statistics for CALD communities across States (i.e. collection of data on country of birth for all data collection processes).

**Recommendation 2:** That further research be undertaken/funded into attitudes, prevalence, screening, risk behaviours, risk factors and understandings of cancer in new and emerging communities and particularly refugee communities.

**Recommendation 3:** That further research into knowledge about and attitudes to cancer support services for individual CALD communities be undertaken/funded.

**Recommendation 4:** That research be undertaken/funded examining programs that support CALD communities at various stages of the cancer cycle, their efficacy and methods of evaluation.

**Recommendation 5:** That research be undertaken/funded focusing on CALD GPs' roles, engagement and attitudes in supporting cancer prevention in their communities.

**Recommendation 6:** That funding be provided to support, increase and refine current cancer education programs for individual CALD communities in all States and Territories.

**Recommendation 7:** That research be undertaken/funded to examine individual community cancer support groups in the various States, their activities, roles, reach, engagement with cancer councils and funding models, and, the potential to replicate their work in various under-served communities.

## **1.3 Introduction**

In 2010, the Federation of Ethnic Communities' Councils of Australia (FECCA) was commissioned by Cancer Australia as part of its 2009 Building Cancer Supports Initiative: Better Cancer Supports Through Consumers, to examine issues regarding CALD communities and cancer.

FECCA, as the national peak body representing Australians from culturally and linguistically diverse (CALD) backgrounds, provides advocacy, develops policy and promotes issues on behalf of its constituency to government and the broader community. Its membership comprises state, territory and regional multicultural and ethnic councils. Critical to its work is the development of comprehensive understandings of and respect for the health and well-being of Australians from CALD Backgrounds. This includes advocating and investigating appropriate and effective health care responses, and supporting the establishment of appropriate mechanisms for ensuring that CALD Australians have information to help them access health care and related services. Within this framework FECCA is committed to supporting the Federal Government's Chronic Disease Strategy and national health priority areas including cancer control.

This report therefore aims to provide an overview of the literature in Australia on CALD communities and cancer. It explores the published literature on attitudes, experiences, barriers and good practice in ensuring appropriate and responsive health services and health promotion for CALD communities with respect to cancer. The report covers all aspects of the cancer cycle including;

- Screening,
- Risk factors,
- Access, attitudes and experiences in health services,
- Access, attitudes and experiences with supports Services,
- Palliative care.

It should be noted that the literature is far from comprehensive. The significant gaps in the research evidenced throughout this report highlight the need for further investigation in a number of critical areas, for a number of communities, prior to the design of both long term and short term strategies to appropriately engage and support CALD communities through the cancer cycle.

## **1.4 Literature Review Methodology**

While the literature review is not exhaustive, it draws upon numerous publications produced outside traditional academic literature. Furthermore, the scope of the research was broadly defined and encapsulated multiple sites for cancer, a significant number of communities, as well as multiple stages for consumer engagement through the cancer cycle. Consequently, three methods were used to scope the research. In the first instance a limited word search utilizing various key medical databases (Web of Science, Scopus, OVID Medline) was

undertaken. Key words included; “cancer” and “Australia” and “migrant” or “culturally and linguistically diverse communities”, “culture,” “refugee” and where relevant, individual communities such as “Italian,” “Greek” and “Arabic”. Subsequently, research was ascertained through relevant references cited in articles sourced through the initial word search. Finally data and literature was sourced on advice provided by relevant organizations such as the State Based Cancer Councils.

## **1.5 Definitions**

Throughout the literature review Australia’s diverse communities were defined by a number of variables, most notably, language spoken at home (other than English), country of birth (outside of Australia) and religion. Consequently, to ensure consistency throughout this report, these diverse communities will be referred to as “Culturally and Linguistically Diverse” (CALD), that is; those from cultural backgrounds who speak a language other than English, or who have English as a second language<sup>1</sup>.

## **2. Cancer and Australia’s Culturally and Linguistically Diverse Communities: General Findings**

### **2.1 Introduction**

*Migrants diagnosed with cancer often have poorer cancer outcomes than comparable non-migrant groups, with lower screening and survival rates and higher rates of reported side effects (Butow et. al., 2009a, CCSA, 2008b).*

Ethnicity and Culture affect a person’s knowledge of cancer; their explanatory models and their psychological responses to diagnosis (Eisenbruch 1989). Cultural, psychological and socioeconomic factors all affect understandings of cancer and in turn, attitudes, behaviours and lifestyles, including susceptibility or resistance to risk factors. It is also clear from the emerging research that cancer and other health outcomes are impacted by health literacy (Keleher and Thomacos, 2009) and broader understandings of the health system, which in turn are likely to be impacted by; health practices and relationships to authority in the birth country and/or in the birth country of family members (Eisenbruch and Handelman, 1990; McKinley and Blackford, 2001) and the tenure and individual acculturation to the host country (Krupinski 1984).

Addressing the needs of CALD communities with respect to cancer requires an understanding of the importance of this work in ensuring equity in health outcomes for CALD communities. Many of the issues that pertain to CALD communities and cancer are applicable throughout the spectrum of health issues from disease prevention and risk behaviours, through to utilization and understandings of health care systems, health literacy

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<sup>1</sup> FECCA (2009) Report on Multicultural Youth Programs: A Possible National Model, FECCA, June, accessed at; [http://www.fecca.org.au/Submissions/2009/submissions\\_2009021.pdf](http://www.fecca.org.au/Submissions/2009/submissions_2009021.pdf).

and palliative care. While this paper will focus primarily on cancer, it should be recognized that both the issues and possible responses to addressing the needs of CALD communities with respect to cancer sit within the broader health framework for ensuring effective and appropriate health promotion, and health and support services for CALD communities. The following section will therefore briefly explore some of the key considerations for CALD communities within the health domain before explicitly exploring attitudes, behaviours and needs of CALD communities with respect to cancer.

## 2.2 CALD Communities and Health

*Avoidable health inequalities arise because of the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness. The conditions in which people live and die are, in turn, shaped by political, social, and economic forces (CSDH, 2008).*

The health status of the broader Australian population may significantly differ from that of individual CALD communities within Australia, and CALD communities as a whole. Similarly the health status within communities may vary. On some measures the health of immigrants may be better than that of their Australian born counterparts, as has been evidenced and attributed to the ‘healthy migrant effect’<sup>2</sup>. However, this advantage decreases with time spent living in Australia, and may not apply across all indicators of health or across all conditions for all communities. A number of factors inherited from originating countries and/or inherent in the migration and settlement process may contribute to health problems, or create, and/or sustain health inequalities between CALD communities and the broader Australian population. These factors include both systemic and cultural barriers to full and effective utilization of Australian health and support services, and, pre-existing conditions, vulnerabilities and attitudes brought from the originating country. Critical factors include:

- Poor access to services: including issues regarding knowledge of services, understandings of health systems, transport and financial barriers (FECCA, 2007).
- Communication barriers: that limits the efficacy and/or direct engagement with the health system, health promotion and health information (Butow et al., 2009a).

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<sup>2</sup> The Healthy Migrant Effect is argued to be a function of a number of health and social factors. Many immigrants originate from regions of the world where lifestyle-associated behaviours contributing to chronic diseases, particularly those associated with obesity, inactivity and diet, are less prevalent than those observed in the developed world. A further explanation is that the complex immigration selection processes often displays a bias for “healthier, better educated” candidates for migration programs. Finally, it has been suggested that immigration medical requirements and screening for chronic diseases may deny admission to individuals with existing illness or support self-selection of healthier individuals.

- Limited health literacy: possibly resulting from, broader literacy levels as well as the limited information available and the absence of appropriate health promotion in the originating country (Keleher and Thomacos, 2009).
- Behavioural and physiological risk factors: derived from the home country or acquired in Australia. There are numerous social and environmental determinants of human behaviour, which in turn, may also affect human physiology. These behavioural and physiological factors are commonly known as 'health risk factors'. These risk factors include smoking, excessive alcohol consumption, poor nutrition, physical inactivity, obesity, high blood pressure and high blood cholesterol. Individually or in combination, they are associated with increased levels of cardiovascular disease, cancer, injury and other diseases, and poorer mental health (AIHW, 2002).
- Traditional health beliefs that conflict with prevailing Western health paradigms.
- Resistance to usage of local health systems: due to perceptions or experiences of culturally insensitive health and support services, and/or attributed to attitudes or trust issues associated with institutions in originating country (Eisenbruch and Handelman, 1990; McKinley and Blackford, 2001).
- Social Determinants of Health: Differential exposures to disease-causing influences may be determined by the social and physical environments associated with social stratification. Depending on the nature of these influences, certain groups will have different experiences of material conditions, psychosocial support, and behavioural options, which make them more or less vulnerable to poor health (CSDH, 2008).
- Health profiles from originating and intermediate host countries: Migrants travel with their epidemiologic profiles, their level of exposure to infectious agents, their genetic risk factors, and their susceptibility to certain conditions. Also, they carry the vulnerability present in their original communities. If, for instance, immunization coverage is low in the country of origin or return, the original population risk will be carried to the destination country until (immunization) coverage of migrants reaches the same level as that for the host population. Similarly, if the prevalence of a given communicable disease or any neglected disease is higher in the country of origin or return, there is an increased likelihood among migrants of being affected by the condition and/or transporting it across borders (WHO, 2007).

The above factors all impact on the relative health of CALD communities in Australia and are as applicable in the context of cancer as they are for other illnesses, including both communicable and non-communicable diseases. Mitigating against these factors requires appropriate health care promotion, preventative practices and support services for culturally and linguistically diverse communities. This in turn requires understandings of attitudes, behaviours, community specific health profiles, vulnerabilities and decision making processes in these communities. This knowledge is critical in ensuring equal access to services, improved outcomes and decreased disparities throughout the cancer cycle from risky or preventative behaviours to

diagnosis and finally appropriate palliative care. It is these understandings that need to inform and encourage appropriate social marketing, health promotion and education programs, cultural competence in health care staff and health care systems that are tailored to address the needs of diverse communities.

A qualification to the above, however, should be added. When tailoring programs and creating health systems that can accommodate cultural diversity between cultures, it is necessary to acknowledge that diversity also exists within cultures. There can be significant differences in attitudes and beliefs between those within a particular culture according to gender, age, education, marital status, levels of acculturation, stages of settlement, cultural and religious affiliation and beliefs (Atmore and Naksook, 2007).

## **2.3 Commonly Held Attitudes and Beliefs Regarding Cancer**

An understanding of the issues surrounding cancer and CALD communities requires an exploration of attitudes towards cancer within these communities. The literature in Australia, though far from comprehensive, highlights the following commonly held attitudes to cancer including beliefs regarding the aetiology and prognosis for cancer. These beliefs are commonly held by a number of CALD communities and include:

- That cancer is incurable (Severino et. al, 2009; Miles et. al., 2004; Gifford, 1990; Kwok and Sullivan, 2007b; CCSA, 2008, Sharan, 1991).
- That cancer is contagious (CCSA, 2008, Goldstein, 2002; Sze, 2007; Lui, 2009).
- That knowledge of a cancer diagnosis can speed the progression of a tumor. Consequently, only relevant members of families rather than patients should be fully informed about the prognosis and should be able to act as intermediaries between health professionals and patients (Gifford, 1990; Eisenbruch and Handelman, 1990, Russell, 1996, Huang et al., 1999).
- That fear, worry and mental stressors (including interpersonal conflict) can cause the onset of cancer (Gifford, 1994; Gifford, 1990; MacKinnon, 1999, Kohli & Dallal, 1998, Kwok and Sullivan, 2007, Goldstein et. al., 2002; Russell, 1996).
- That cancer is predetermined (Yeo et. al., 2005; Eisenbruch and Handelman, 1990, DOHA, 2008).
- That cancer is a source of shame (this includes the belief that cancer is a consequence of previous behaviours in the present or past life) (Eisenbruch and Handelman, 1990; Goldstein et. al., 2002, CCSA, 2008).
- That cancer can be divided into two types according to Non Western, traditional beliefs, attributing them immediate benign or malignant status, irrespective of diagnosis (Gifford, 1994; Goldstein et. al., 2002; Gifford, 1990; Russell, 1996).

As is the case for all CALD communities, refugee communities will have specific attitudes to cancer determined by their beliefs and customs. Refugee communities are also likely to hold specific attitudes towards health services resulting from their refugee experience including;

distrustful relationships to authority (Eisenbruch and Handelman, 1990; McKinley and Blackford, 2001), the absence, possibly for long periods, of appropriate health care (Harris and Telfer, 2001; Lamb and Smith, 2002) and their experiences of trauma (Hollifield et. al., 2002). According to Hollifield (2002), refugees often have increased morbidity, decreased life expectancy, and a vulnerability to medical illness and poor health habits relative to the host population. Despite these particular vulnerabilities, there remains limited research in Australia and overseas around attitudes and experiences of cancer and cancer services for these communities. Further, data on the prevalence, presentations and mortality rates for cancer for refugee communities in Australia as a whole is undeveloped and under-researched. It should be emphasized that while the research is somewhat limited with respect to CALD communities and cancer in Australia, there is a far greater gap in the research on refugee communities and cancer.

### **3. Cancer Prevention and Screening**

#### **3.1 CALD Communities and Screening**

Consistent with misconceptions regarding the aetiology and prognosis for cancer and the broad barriers to accessing health services, it is unsurprising that some CALD communities are under-served in the screening process (FECCA, 2009). Detection of certain cancers amongst certain communities of CALD women may often be later than for the rest of the population. This is particularly pronounced for females in Arabic-speaking communities and to a lesser extent Chinese and Asian communities. Noticeably, refugee women have a particularly low uptake of preventative screening for diseases such as cervical cancer and breast cancer (FECCA, 2009). Below is the more recent information available on the participation of CALD communities in the three national screening programs.

##### **Breast Screening**

Data from a 2006, Australia wide, population based survey of those 50 years and older, identified that migrants from East Asia and North Africa/Middle East had significantly lower rates of mammographies (Weber, 2009). Other research has shown that women from non-English speaking backgrounds were more likely not to attend for second round screenings (O'Byrne et. al., 2000). Women who spoke South West Asian, North African and South East Asian languages had the highest risk of non-attendance for second round screening (O'Byrne et. al., 2000).

##### **Cervical Screening**

Data from the Australian Bureau of Statistics (ABS) National Health Survey in 2001 indicated that women who speak a language other than English at home are less likely to have regular Pap tests (42.8%) than women who speak English at home (56.9%) (Mullins, 2006).

## Colorectal Screening

Women from East Asia, South East Asia, Continental Western Europe, North Africa/Middle East had lower rates of bowel testing than Australian born women. Similarly, compared to those Australian born men, bowel cancer testing was significantly lower for men from all regions of Asia and Continental Europe, most particularly those men from East Asia (Weber et. al., 2009).

Though not part of any National screening program, it is worth noting that, with respect to prostate screening, only men from East Asia had significantly lower PSA (prostrate specific antigen) testing rates than Australian-born men (Weber et.al., 2009).

Finally, there is evidence that as the number of years lived in Australia increase, cancer testing among migrants for breast, bowel and prostate approach Australian born rates (Weber et. al., 2009). This is consistent with the 'transitional effect'<sup>3</sup> (NHMRC, 2005).

### 3.2 Barriers to Screening

There are a number of cultural attitudes and/or barriers identified in the literature that may impact negatively on screening behaviours, resulting in under-screening in various communities. These attitudes and barriers are often strongly related to cultural norms and experiences in their birth country, levels of health literacy, as well as experiences, attitudes and understandings of local health systems and other public institutions. These attitudes and/or barriers that impact negatively on screening behaviour include:

- A belief that the community is not at risk for particular cancers (Miles, et. al., 2004, Russell, 1996, DoHA, 2008)
- A lack of knowledge regarding screening. This is particularly the case for migrants from countries where there is an absence of strong preventative health strategies and population health programs (Webb, 2006; DoHA, 2004; Pennay, 2006, DoHA, 2008).
- A lack of knowledge of signs and symptoms of various cancers, and self screening tests (Bowel Cancer - DoHA, 2004; Severino et. al., 2009, Pennay, 2009, Markovic, 2006 – Gynaecological cancers).
- A belief that interpreters would not be available to undertake screening to explain both the process and the results (DoHA, 2008).
- General embarrassment and discomfort. Particularly for women, there may be a fear that female health professionals would not be available to undertake screening, thereby potentially compromising the modesty of the patient (Ward et. al. 2006, Miles et. al., 2004; Jirojwong et. al., 2001, Pennay, 2009, DoHA, 2008)

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<sup>3</sup> The transitional effect notes that the prevalence of particular illness in migrant communities tends towards that of the host country over time.

- A fear of a cancer diagnosis (Severino et al., 2009, Brushin, 1997, Jirojwong et.al., 2001).
- A fear that a cancer diagnosis can hasten the onset and spread of cancer (Gifford, 1990; Kwok and Sullivan, 2007a)
- A fear that attending a screening may cause illness (Kwok and Sullivan, 2007a, CCSA, 2008)
- A lack of transport (DoHA, 2008)
- Negative association of screening with other medical assessments undertaken prior to immigration (DoHA, 2008).
- Fatalistic attitudes/beliefs which undermine primary prevention (Miles et. al, 2004, Severino et. al., 2009, Gifford, 1990, Kwok and Sullivan, 2007b).

It should be noted that a range of factors may impact on screening behaviours and, according to Fiscella et al. (2000), the relationship between ethnicity, socioeconomic status, health prevention and accessing health services is complex. They note that health care choices and behaviours may be impacted by multiple variables including; geographic access, transportation, education, knowledge, literacy, health beliefs, racial concordance between physician and patient, patient attitudes and preferences, competing demands including work and child care and provider bias. The significance of any one of these factors is seen as varying by patient and physician. Hence, while any of the above may be impacting on participation in screening, multiple causal factors may exist and these factors may vary for each individual. Hence, it is important to understand which attributes are clearly identifiable for under-screened groups from CALD communities and what practices may encourage screening, recognizing that a singular approach may not definitively change screening behaviours and that further research is required on the barriers to screening examining both socio-economic factors as well as culturally determined factors.

The following are the attributes of members of CALD communities that are at risk of not receiving and having little or no knowledge of cancer screening identified in the literature:

- Those with lower level of education and those born in the Middle East or Asia are at greater risk of not receiving and having no knowledge of Pap tests (Siahpush and Singh, 2002)
- Women who speak a language other than English at home are less likely to have heard about screening mammography or to understand the purpose (Irwig et. al., 1991; DoHA, 2009).
- Data from the National Health Survey (ABS, 2001) indicates that women who speak a language other than English at home are less likely to have regular Pap tests (42.8%) than women who speak English at home (56.9%) (Mullins, 20006).
- Refugee women in particular have a low uptake of preventative screening for diseases such as cervical cancer and breast cancer (FECCA, 2009).

### **3.3 Culturally Relevant Practices That May Encourage Screening:**

In light of the barriers to screening identified for a number of CALD communities, the following are the culturally relevant practices identified in the literature that may encourage screening for under-served communities:

- Recognition of traditional notions of family lineage for genetic testing (Eisenbruch, et. al., 2004; 2006).
- Greater advocacy by GPs and more particularly GPs from CALD backgrounds, in promoting screening to CALD community members who are classified as high risk (Zorbas, 2003; Brushin, 1997; Gifford, 1990, DoHA, 2004, Cheek et al., 1999; Markovic, 2006, DoHA, 2008; Kelaher, 1999).
- Utilising existing non medical community and family networks to encourage screening (eg. Peer education programs) (Cheek, 1999, DoHA, 2008; 2004)
- Undertaking education campaigns that focus on providing basic information (including information addressing identified fears) tailored to specific communities (DoHA, 2004; Pennay, 2009).
- Promoting and ensuring the presence of interpreters and easy to read informational materials in multiple languages (Jirajwong et.a., 2001, DoHA, 2004) at screening locations. According to FECCA (2009) the production of health based multilingual material has simply not kept up with demand, especially in the context of changing population demographics. It is noted however, that translated brochures are more effective in conjunction with a health consultation and should not replace a personal interaction (Camit, 2009).
- Promoting and ensuring that female staff are available to undertake screenings of older CALD women and women from specific CALD communities (ie. particularly those of Muslim faith).

It should be noted that the efficacy of letter drops, radio and print media in increasing screen testing is difficult to ascertain, with conflicting and often indirect evidence of successful outcomes (Mullins, 2006; Page et. al., 2005; Del Mar, 1998; Turnbull and Irwig, 1991; 1992). Personal invitations to participate have had some successful outcomes in increasing participation in screening (Turnbull and Irwig, 1991; Page et. al., 2005).

## **4. Risk Factors**

The vulnerability of CALD communities to greater rates of certain cancers may be impacted by a number of behavioural and/or historical risk factors. As noted above, (see section 2.2) these risk factors are a function of both social and environmental factors that impact not only on behaviours, but also the knowledge base, susceptibility and epidemiologic profiles and exposures of these communities. The following outlines some of the key risk factors for cancer in CALD communities.

## **4.1 Generic Health Literacy**

Data suggests that health literacy in CALD communities, particularly within the aged sector, remains a barrier to appropriate screening and early intervention within the cancer cycle. According to FECCA (2009) only 3.4% of CALD individuals aged 65-74 have adequate health literacy levels compared to 17.4 per cent of 65-74 year olds in the broader population. More particularly women's health literacy often remains poorer than their male counterparts due to limited transport, childcare issues and competing family priorities which affects their ability to attend English and Education classes (FECCA, 2009). Health literacy can significantly impact on knowledge of risk behaviours and utilisation of appropriate screening and cancer health services.

## **4.2 Medical Histories**

The optimum health or early diagnosis of cancer in members of CALD communities may be significantly impacted by the absence or incomplete nature of family histories and/or regular health check-ups due to migration, lack of access to medical reports or the lack of available health services in the country of origin (Eisenbruch et. al., 2006; Eisenbruch et. al., 2004).

## **4.3 Sedentary Lifestyles**

The long term benefits of physical activity have been well documented and findings have shown that in the long term, physical activity can decrease the risk of a number of cancers (Guerin et. al., 2007). In Australia physical inactivity is responsible for 7% of the total burden of disease, second only to tobacco as a significant contributor to the disease burden (VICHEALTH, 2006). Anecdotal evidence suggests that physical activity is low in CALD communities (Velanoski and Karantzas, 2006). These findings are reinforced by those of the National Health Survey Summary in 2001 which identified that persons born in South and Eastern Europe, North Africa, the Middle East and Asia report lower levels of physical activity (ABS, 2001). It is important to recognise that women from different CALD groups, geographic areas and socio-economic backgrounds will experience different enablers and barriers to participation in physical activity. There are, however, some common prevailing themes, which include:

- Sport and leisure as a first world construct that is inconsistent with social norms in the originating country. For those who have lived in countries where sports are not the common culture it may seem unnecessary and artificial to undertake such activity in order to counteract a new, more sedentary lifestyle.
- Low prioritization of sport over academic activities for children
- Insecurity in public settings (particularly for Muslim women)
- Cultural constraints on freedoms and differing levels of comfort in certain social settings premised on gendered attitudes to sport, perceived appropriateness of sportswear and limited mobility outside the domestic domain

- Limited access due to a lack of information, skills, transport and limited resources (time and money); (VICHEALTH, 2006; Social Policy and Research Centre, 2006).

#### **4.4 Smoking (Lung Cancer)**

A study undertaken in 2001 showed that 15% of all deaths (approximately 19,000 deaths) were due to tobacco smoking. Cancer was responsible for 40% of these tobacco-related deaths, the majority of which were lung cancer. Most of these deaths (around 14,800) occurred at older ages, but a substantial number (around 4,200) occurred at ages under 65 years (Ridolfo & Stevenson, 2001). Several CALD communities have significantly higher rates of smoking than their Australian born/English speaking counterparts.

According to the literature;

- The highest rates of smoking occur among migrants from "Oceania (comprising New Zealand, Melanesia, Micronesia and Polynesia, but excluding Hawaii - excluding Australia) and North Africa and the Middle East (Scollo and Winstanley, 2006),
- Migrants who arrived in Australia after 1996 are less likely to be smokers than migrants who arrived prior to this date (Scollo and Winstanley, 2006),
- Migrants who arrived after 1996 are also less likely to smoke than the Australian population as a whole (Scollo and Winstanley, 2006),
- Vietnamese males and Lebanese males and females in NSW had much higher rates of smoking compared to the Australian born population (NSW Health, 2006),
- Females from all CALD groups except for Lebanon had significantly lower rates of smoking than Australian born females (NSW Health, 2006), and,
- Male smoking is significantly higher than female smoking in many CALD groups, reflecting trends in their country of origin. This is generally the case for all CALD populations from non-English speaking countries (CCSA, 2008a).

Commonly held attitudes towards smoking and/or barriers to quitting in CALD communities are:

- An unwillingness to recognize the negative health impacts of smoking unless health has significantly deteriorated (CCSA, 2008a).
- Lack of motivation to quit (Trotter, 1998, Quit Victoria, 2010a).
- Inherited health beliefs and cultural attitudes towards smoking (Scollo and Winstanley, 2008; Ramos et. al., 2009; Trotter, 1998, Quit Victoria, 2010b).
- A lack of awareness of the health consequences caused by smoking and second-hand smoke (Scollo and Winstanley, 2008; Trotter, 1998; Quit Victoria, 2010a).
- Difficulties accessing access health information due to low literacy in English (Scollo and Winstanley, 2008).
- Lack of community leadership to promote smoking cessation (Scollo and Winstanley, 2008).
- A belief that smoking relieves stress (Quit Victoria, 2010b).

Studies on the smoking attitudes of various communities noted that those who wanted to stop smoking said they would find it useful to have information on the health effects of smoking on themselves and their families and of the health benefits of quitting (Ramos, 2009, Quit Victoria, 2002). Nearly all of them were aware that smoking causes illnesses, citing cancer and heart diseases as the main illnesses:

Information was preferred in the following forms:

- Information leaflets (43%) – African Community (Quit Victoria, 2002).
- Information displays at community/religious events (34%) - African Community.
- Information on audio tape (30%) - African Community.
- Information posters (30%) - African Community.
- Television advertisements (Ramos, 2009).
- GP – Spanish Community (Ramos, 2009).
- Information stalls organised within the boundary of temples – Cambodian Community (Quit, 2010b).

#### **4.5 Hepatitis B Infection (Liver Cancer)**

According to the Cancer Council of South Australia (CCSA) (2008a) Hepatitis B Infection is a critical risk factor for liver cancer for members of CALD communities. Peoples from Asia, Central and Northern Africa, Pacific Islands, the Mediterranean and Middle East have high rates of Hepatitis B infection, many of which unknowingly carry the virus. Given the blood born nature of the virus, the possible absence of symptoms over long periods of time, and the health systems in origin and host countries (particularly for refugees – and people from countries where tests and vaccinations are not regularly undertaken) infected individuals are likely to be at increased risk of later development of liver cancer, or of passing the infection to children who are at a higher risk of developing the cancer in their early lives. The high incidence of primary liver cancer in East Asia and South-East Asia is largely attributable to the high prevalence of chronic HBV infection in these regions (CCSA, 2008b).

The Cancer Council of South Australia notes the critical importance of assessing the vaccination status of babies, children and adolescents from these ‘at risk’ communities, as well as offering vaccination, or treatment as appropriate, for adult community members (CCSA 2008a).

#### **4.6 Human Papilloma Virus (Cervical Cancer)**

A critical risk factor for cervical cancer in a number of CALD communities is the Human Papilloma Virus. Women from Germany and Eastern Europe have higher rates of cervical cancer than the Australian population. There is also a high incidence in African, Indian and South American born communities that is consistent with the prevalence of HPV in these countries (CCSA, 2008a).

The HPV immunisation of young girls may present culturally derived concerns as immunisation may be seen as a sanction for sexual activity within this group. The Cancer Council of South Australia (2008a) notes that it is critical that Pap smears are encouraged every two years for women aged 18-70 for women from these communities. Further, for communities where cultural concerns exist, referrals of patients to a female GP or women's health clinic are critical, as is the provision of culturally sensitive information. The status of HPV vaccination should also be determined for young women of these communities up to 26 years of age (CCSA, 2008a).

#### **4.7 Risk Factors and Refugees**

There are a number of cancer risk factors that may be particularly endemic to refugee communities. These factors may, at least in part, be attributed to the refugee experience, the health systems in refugees' birth places or health facilities in refugee camps in pre-immigration host countries. Refugees and those with refugee backgrounds are at risk of poor health both before and after arrival in Australia (Harris and Telfer, 2001; Lamb and Smith, 2002). For example, dental health needs for newly arrived refugees tend to be higher, with common problems including oral cancer (Davidson et. al, 2006). In addition, refugees often come from high risk areas for Hepatitis B and HPV. Given the high probability of instability in refugee home countries there is a greater likelihood that;

- immunisation and testing have not been undertaken,
- medical records are likely to be absent,
- there has been limited continuity and standards in health care systems both within originating and transit host countries (Harris and Telfer, 2001; Lamb and Smith, 2002, Eisenbruch et. al., 2006; Eisenbruch et. al., 2004).

As is the case for almost all areas of research on refugee communities and cancer in Australia, the research on cancer risk and refugees is significantly underdeveloped.

### **5. Knowledge and Attitudes to Health and Support Services by Cancer Patients and their Families**

The following section explores the experience and attitudes of both CALD cancer patients and survivors and their caregivers. As noted by Jefford (2009), with the shift in healthcare from hospital to more community-based care, increasing demands are placed on informal carers. In 2006, there were 400,000 overseas born carers, and of these, 277,400 spoke a language other than English at home (ABS, 2008). Studies have clearly identified significant stress, distress and unmet needs in this group (Girgis and Lambert, 2009). Further, as noted by Hagedoorn et. al., (2008) the psychological impacts on the caregiver are likely to be linked to that of the patient, hence the integral importance of considering both patients and caregivers in the context of any examination of attitudes and experiences of cancer health and support services.

The psychological distress of many cancer patients, survivors and their caregivers from CALD communities may be compounded by a number of factors including; difficulties within the dominant health system because of language barriers, ignorance of the health care system, differing beliefs and attitudes about illness and social isolation (Butow, et. al., 2008). Survivors and their families from Arabic, Chinese and Greek backgrounds have reported feelings of loss of power and control and consequent difficulties navigating the health system due to difficulties with both written and verbal language (Butow, et. al., 2008). Some of these difficulties may be accentuated in CALD patients/survivors and caregivers because of the stigma and taboos surrounding cancer and the associated reluctance to discuss this outside of the family, compounding their sense of isolation (Butow et. al., 2008).

Finally, it should be noted that research on the knowledge within family members of available support to family members and carers of a CALD person diagnosed with cancer in Australia appears to be incredibly limited. The findings from the literature only indicate that these types of services may be under-utilised by CALD communities (Tokatlian et. al., 2008).

### **5.1 Common Experiences and Responses Of CALD Families to Cancer Health and Support Services:**

The experiences and responses of CALD families to cancer health and support services identified in the literature are not unique to cancer but are common responses to illness and experiences of CALD communities in the usage, access and engagement with health services more broadly. These include;

- Greater reported stress and disruption to family life and more reported difficulty forming working relationships with the health care team (Tokatlian et. al., 2008).
- Greater dependence on medical staff for their information (Tokatlian et. al., 2008).
- A sense of powerlessness in the decision making process (Naksook, 2003).
- Lesser usage of support services (Tokatlian et. al., 2008).
- Greater usage of family support (Tokatlian et. al., 2008).

Despite these initial findings, there is a dearth of research on experiences of cancer services and supports for CALD communities. More particularly, there is limited information on the impact of the process on caregivers and families, including whether these experiences result in differences in psychosocial and medical outcomes between CALD communities and the broader Australian population (Tokatlian et. al., 2008, Jefford, 2009, Girgis and Lambert, 2009).

## **5.2 Common Barriers for CALD Communities when Accessing Health and Support Services Identified in The Literature:**

As was the case for the experiences and responses to cancer for CALD communities, the barriers to accessing health and support services are similar to those barriers experienced by CALD communities within the general health system. These barriers include:

- Language difficulties (Butow, et. al., 2008).
- Interpreter problems, which include: access to interpreters, uncertainty around roles of interpreters (ie issues around pastoral type responsibilities), lack of continuity of individual interpreters in supporting individual families, translatability of technical medical language, and, variability of disclosure by interpreters reflecting cultural beliefs (Butow, et. al., 2008; 2009b, Naksook, 2003).
- Cultural isolation, which includes: feeling misunderstood, being mistrustful of health professionals from another culture, lacking access to traditional medicines and receiving treatments contrary to their cultural practice (Butow, et. al., 2008).
- Communication barriers, which include: receiving more information and less reassurance than desired, (Butow, et. al., 2008), experiencing less access to information (Tokatlian et. al., 2008), or being unable to understand complex medical information in English. (Naksook, 2003).
- The lack of cultural models in some cultures for men as carers (CCSA, 2007).

## **5.3 Findings with respect to Palliative Care and End of Life Issues:**

Choices involving end of life medical treatment decisions and support services may be more related to ethnicity and culture than to age, education, socio-economic status or other variables. Culture profoundly affects the way people view and manage death, as well as their attitudes to and practices regarding advance care directives/advance care plans (HIC, 2007). Consequently, influencing, fostering and promoting the delivery of quality care for all at the end-of-life for cancer patients requires recognition of cultural diversity. Respecting and being sensitive to cultural needs, understandings and modes of communication are integral to providing appropriate palliative care (Aleksandric, 2009).

According to Aleksandric (2009) culture can determine experiences and choices with respect to end of life services including:

- Communications, including disclosure, consent and privacy.
- Patient autonomy and family roles in decision making.
- Ways of conceptualizing death, burial/cremation and grieving.
- Traditional rituals and their integration into palliative care.
- Acceptance and utilization of advanced care planning.

While a number of these issues have been discussed above, they have particular relevance for the delivery of appropriate and culturally sensitive palliative care. Recognition of the need for cultural sensitivity and understanding of traditional approaches to each of the above issues can better help support terminal CALD cancer patients. A caveat however, should be added, as there is significant variation both between and within cultures, including subcultures and demographics such as age, gender and sexual identity, which can shape both beliefs and practices concerning illness, death, and advanced care directives. Cultures and communities can also vary across space (e.g. urban compared to rural) and, over time. Health professionals should be wary, therefore, of stereotyping (Aleksandric, 2009; HIC, 2007).

As should be apparent from the above section, the evidence base to ensure more sensitive health, support services and palliative care for those with cancer in Australia is far from comprehensive. This area continues to be under researched despite the recent significant work in this area highlighted above. A number of good resources, however, are available in Australia, providing basic profiles of CALD communities and their understandings of health, attitudes to ageing and appropriate modes of communication. As identified in the introduction, the attitudes and needs of CALD communities within the broad health domain are often relevant considerations irrespective of the specifics of the underlying condition. A number of these profiles have therefore been included in Appendix A.

## **5.4 Common Findings with regard to the Provision of Culturally Sensitive Health and Support Service Provision**

The following are the common findings across CALD Communities within Australia, with respect to needs and means to ensure the provision of culturally sensitive health and support services:

- The need for personalised high quality written information to allow ownership over their health status (Butow et al., 2008, Kirk et al., 2004). Decision Aid booklets for CALD communities that increase knowledge regarding cancer and its treatment and are designed to account for sub-literate women. These can be used to facilitate treatment decision making potentially minimizing psychological distress in CALD communities (Lam et. al, 2009).
- Regardless of English ability, CALD survivors have described experiencing an additional level of comfort, support and familiarity when treated by people from their own culture and feelings of separation, isolation, and difficulty building relationships when this is absent (Naksook, 2003).
- The need for opportunities for CALD men to spend time with other male carers in a relaxed social environment. This is important as there may be limited recognition of the role of men in caregiving in some CALD communities and targeted programs for this group may be required (CCSA, 20007).

- The need to incorporate culture-specific treatments into care, particularly during the palliative care phase. The need for interpreters and psychological and spiritual support is also important (Huang et. al.,1999; Huang et. al., 2009, Eisenbruch, and Handelman, 1990).
- The need for recognition of the role of the family in liaising between health professionals and the patient (Kirk et. al., 2004; Huang, 2009; Eisenbruch and Handelman, 1990).
- The need for alternate accessible sources of information, treatment options and procedures, risks and side effects of treatment and discharge information (Kirk et. al., 2004).
- The need for recognition that the information and support needs of caregivers and patients may differ (Centre for Behavioural Research, 2010; Kirk et al., 2004)

The above review of the literature has highlighted some of the key attitudes, barriers and methods to strengthen prevention, support and health services for CALD communities. However, what is apparent is this remains an under-researched area. The following section will examine not only the gaps in the research but also the challenges presented in undertaking research in this area.

## **6. Research Challenges and Gaps**

### **6.1 The challenges of researching CALD communities and cancer.**

There are a number of challenges in undertaking research with cancer patients from culturally and linguistically diverse communities. Some of these challenges are specific to undertaking research on cancer in CALD communities and others are applicable to most survey based research on CALD communities. These latter challenges include:

- Sourcing bilingual and multilingual researchers with experience in qualitative research methods. These researchers are required to not only recruit participants, but also translate materials and conduct focus groups (Butow et. al., 2008).
- The cost of hiring staff (Butow et. al., 2008, NHMRC 2006).
- Ensuring culturally appropriate research methods. It is essential for research in this area to be conducted in a culturally sensitive manner. Establishing consumer advisory boards may be required to oversee the research and ensure that this aim is met (Butow et. al., 2008, NHMRC, 2006).
- Interviews and focus groups have to be transcribed and translated, ensuring the retention of unique cultural nuances. This may require careful and repeated review by the research team and significant cost (Butow et. al., 2008; NHMRC, 2006).

The above challenges highlight the need for appropriate funding for research on CALD communities and cancer and clear recognition of the incremental costs of undertaking this type of research. Additional challenges in undertaking cancer research in CALD communities are:

- A possible reluctance in a number of CALD communities to discuss cancer (for fear of accelerating the rate of growth of the tumour) (Butow et. al., 2008)
- Carers blocking discussion with the patient for fear of disclosure of the diagnosis (Butow et. al., 2008)

The above challenges for cancer research on CALD communities need to be addressed through relevant education campaigns (to address misconceptions), as well as appropriate research design that takes into account barriers to participation and incremental time and resource needs.

## **6.2 Research Gaps**

As has been evidenced throughout this paper there are significant gaps in the research on the experience of CALD communities and Cancer. The following were critical areas for future research identified throughout the literature review:

- Population based research on CALD communities' access and attitudes to and experiences of health and support services.
- GP knowledge of CALD communities' risk factors for cancer.
- GPs from CALD backgrounds and their attitudes to the promotion of screening to patients.
- Attitudinal research (cancer, screening) on refugee communities.
- Attitudinal research on new and emerging communities.
- Research on the knowledge base and informational needs of new and emerging communities with respect to various cancers.
- Incidence/prevalence/mortality rates of refugee communities as a group.
- Knowledge within CALD families of available support to family members and carers of a person diagnosed with cancer.
- Differences in psychosocial and medical outcomes of CALD cancer patients compared to Australian born cancer patients (Tokatlian, 2008).
- The specific needs of CALD cancer survivors and their families (Boyes, 2009).
- Large scale population studies conducted with representative samples of diverse cancer survivors on all aspects of cancer control. Projects like the CLEAR study of the Cancer Council of NSW examining lifestyle and genetic factors that influence cancer in the NSW community, require data sets from representative samples of various communities, including those that speak English not very well or not at all. These types of studies, by virtue of the challenges outlined above, have

traditionally excluded non English speakers thereby failing to account for these populations.

Having identified the challenges and gaps with respect to research on CALD communities and cancer, the following section highlights both long term and short term challenges and considerations in designing strategies for engagement of CALD communities in addressing their needs throughout the cancer cycle. The considerations and recommendations reflect CALD communities' needs within the broader health context as well as identified research gaps, both of which significantly impact on effective short and longer term engagement strategies.

## **7. CALD Engagement Strategies and Recommendations**

### **7.1 Strategic Planning for CALD Engagement**

In examining possible engagement strategies to address issues around CALD communities in all aspects of cancer control it should be stated that the breadth and scope of such a task is exceedingly difficult. Examining the State data on cancer prevalence and incidence highlights that there are multiple communities, multiple sites for cancer and various stages for interventions that may be prioritized with relevant communication strategies attached. Identifying priorities is therefore extremely difficult, and consequently designing strategies to engage these communities requires, in the first instance, further research and both short and long term planning with relevant strategies attached. An approach that singles out particular cancer sites, stages in the cancer cycle or specific communities has the following limitations:

- A. Focusing on the four most prevalent cancers in Australia (lung, prostate, cervical and bowel) which are also largely the most prevalent sites for cancer for CALD communities, would do little to refine future research and programming (as prioritizing communities, and points of intervention in the cancer cycle would remain an issue). Further, this would tend to ensure a short term view as presentations of other cancer sites increase (eg. liver).
- B. Focusing on communities with high prevalence data alone would tend to focus almost entirely on well established, ageing communities (e.g Greek and Italian communities) where the population of first generation migrants with low levels of English is declining. It is also worth noting that there is more (but still insufficient) research and programming focused on these communities in Australia than for newer communities.
- C. Focussing on disadvantage criteria alone would tend to focus largely on smaller, emerging communities, with a strong focus on refugee communities that, while

showing clear growth are, in part, contingent on immigration policies into the future. Further, research and programming would likely have lesser impacts and reach on cancer prevalence and targeting under-served communities merely due to smaller population sizes. It is, however, these communities that are severely under-researched and that have significant risk profiles that would likely see them approaching the health system at later and more intensive stages of cancer care (though research on mortality rates for these communities is still unavailable to provide clear evidence). Further, research into these communities may need to focus on less common but increasing cancers, such as liver cancer, in light of the high prevalence of Hepatitis B in these communities.

Therefore prior to any development of communication strategies, further research, better data systems and programs that reflect attitudes, behaviours and needs are required. As noted by the World Health Organisation in its report on the health of migrants (2007) Member States facing migration challenges have an increasing need to formulate and implement strategies to improve migrants' health. The following are the strategies recommended by the WHO for improving the health of migrants.

#### **Assessment, research and information dissemination**

Assessing the health of migrants and trends in migrants' health; identifying and filling gaps in service delivery to meet migrants' health needs; disaggregating health information by gender, age and origin and by socioeconomic and migratory status; encouraging health and migration knowledge production, including both quantitative and qualitative studies; documenting and disseminating best practices and lessons learnt in addressing migrants' health needs in countries of origin or return, transit and destination and disseminating good practices, such as migrant-friendly hospitals to other regions of the globe (WHO, 2007, p.4).

#### **Capacity building**

Sensitizing and training relevant policy-makers and health stakeholders involved with migrants' health in countries of origin or return, transit and destination; promoting increased cultural, religious, linguistic and gender sensitivity associated with migrants' health among health service providers and training health professionals in addressing the health aspects associated with population movements; creating a network of collaborating centres, academic institutions and other key partners for furthering research into migrants' health and for enhancing capacity for technical cooperation and training health professionals about diseases and pathologies that prevail in the country of origin or return (WHO, 2007, p.4).

#### **Service delivery**

Initiating or reinforcing migrant-friendly public health services and health care delivery methods for migrants with special needs; strengthening health promotion and disease prevention initiatives to reach out to migrants in the community; establishing minimum standards of health care for all vulnerable migrant groups (particularly women, children, undocumented or irregular migrants, asylum seekers, refugees and victims of human trafficking); and publicizing existing services (WHO, 2007, p.4).

## 7.2 Recommendations

In order to ensure that efforts in social marketing, education, health and support services reflect long term and short term need and relative disadvantage, further research in this underdeveloped area needs to be undertaken. In light of the gaps and issues raised in the literature, the priorities of the Federation of Ethnic Community Councils of Australia (FECCA 2009, 2007) and reflecting on some of the contemporary strategies of the State based Cancer Councils (CCSA 2008b), the following are the recommendations for improving and strengthening knowledge and practice in the delivery of appropriate cancer prevention and health and support services for CALD communities consistent with the WHO strategies outlined above.

### 7.2.1. Assessment, research and information dissemination

- **Greater coherence and consistency in data from cancer registries across States**

The data noted in the case studies in Section 8, highlights that it is not currently possible to compare prevalence data across States to determine the communities with the greatest numbers of presentations and the most common cancer sites for these communities. This is due to inconsistencies in the definition of CALD communities and the information collected by health providers and passed on to the cancer registries in each State. Hence, disaggregated, nation-wide, cancer prevalence and incidence rates for specific community groups (based on country of birth, language spoken at home) is currently unavailable, and National trends for these communities, currently impossible to examine.

**Recommendation 1:** That initial work be undertaken to examine the viability of creating uniformity in the collection of health statistics on CALD communities across States, (ie. collection of data on country of birth for all data collection processes). Streamlined data would serve not only efforts to understand CALD community issues with respect to cancer, but also increase knowledge of other areas of health, where data limitations can undermine National efforts to address critical health issues for these communities.

- **Improving knowledge of cancer issues in New and Emerging Communities**

As highlighted above, there is a significant dearth of information on New and Emerging communities. If research is not undertaken now to inform future programming, in the medium to long term, this will likely result in significant costs to both the community and to the health system itself.

**Recommendation 2:** That further research be undertaken/funded into attitudes, prevalence, screening, risk behaviours, risk factors and understandings of cancer in new and emerging communities and particularly refugee communities.

- **Determining CALD communities' knowledge of available support services for patients** diagnosed with cancer.

In light of the significant lack of research in this area, the following recommendation is made;

**Recommendation 3:** That further research into knowledge and attitudes to cancer support services for individual CALD communities be undertaken/funded.

- **Further research into programs that support CALD communities at various stages of the** cancer cycle, and evaluations of these initiatives.

Research into the range of initiatives to support CALD communities at various stages of the cancer cycle and the prevalence of, and approaches to, evaluation of these initiatives remains limited. This research is critical to the dissemination and determination of good practice and possibly to encourage greater knowledge exchange around programming.

**Recommendation 4:** That research be undertaken/funded examining programs that support CALD communities at various stages of the cancer cycle, their efficacy and methods of evaluation.

### 7.2.2. Capacity Building

- **Understanding roles, engagement and attitudes of CALD GPs in supporting cancer prevention:**

In light of the research clearly highlighting the critical role that GP's from CALD communities play in encouraging screening, further research into CALD GP's and their attitudes towards promotion of screening programs to CALD patients is recommended. This research is necessary to inform potential education programs or information guides (for example on under-screened communities or cancer risk factors of various communities) for GP's from CALD communities.

**Recommendation 5:** That research be undertaken/funded focusing on CALD GPs' roles, engagement and attitudes in supporting cancer prevention in their communities.

### 7.2.3. Service delivery

- **Support for Current Educational Programs**

To better support CALD cancer patients and their families it is critical that educational programs are, in turn, supported and refined. As highlighted in the Living With Cancer Education (LWCE) program outlined in Appendix B, this is an invaluable support service that can mitigate against isolation, address fears and provide greater understanding and empowerment to more actively engage in the decision making process. The evaluation of the LWCE program also contained in Appendix B identifies some of the challenges presented by these programs including the dependence on voluntary facilitators, and more generally, the absence of ongoing and appropriate funding for these programs. These programs are key support services and provide invaluable engagement between cancer councils and community groups. These programs provide both education and social support networks for cancer patients in their own communities, as well as developing champions within communities for raising awareness of these issues.

**Recommendation 6:** That funding be provided to support, increase and refine current cancer education programs for individual CALD communities in States and Territories.

- **Understanding and providing support for individual CALD community cancer support groups.**

The research clearly highlights the need for culturally appropriate support throughout the cancer cycle. While culturally competent health staff play a significant role, community support groups can provide culturally appropriate psychological, spiritual and social supports for CALD cancer patients and their families.

**Recommendation 7:** That research be undertaken/funded to examine individual community cancer support groups in the various States, their activities, roles, reach, engagement with cancer councils and funding models and the potential to replicate their work in various under-served communities.

## **8. Case Studies: Cancer and Australia's Culturally and Linguistically Diverse Communities. Individual Community Findings**

The following is a summary of research findings with respect to the demographics, prevalence, attitudes, barriers and recommendations for individual CALD communities with respect to all aspects of cancer control. It should be noted that there are significant issues around identifying and defining individual CALD communities in Australia. CALD communities may be defined on the basis of: language spoken at home, religion, place of birth and ancestry. As such, the individual communities and attitudes explored below are only loosely grouped, for example, the Greek community research includes those born in Greece and those who speak Greek, but may occasionally exclude non Greek speakers who were born in Greece. It presents a cogent argument for greater consistency in data collection and definitions across various cancer and research based agencies.

It should be noted that this section mostly considers Australian based data and literature reflecting the fact that the nature of communities, their attitudes and behaviours can and do vary according to host country. This reflects the differing waves of migration, conditions in the host country (including cultural attitudes) and the differing pre-migration experiences and geographical location of communities within their country of birth. However, where there was a dearth of research, some international research has been included for specific community groups.

Finally, it is worth reiterating that each community should not be assumed to be homogeneous and that the differences highlighted for migrant groups in different countries may also hold in migrant groupings within Australia. Hence, the findings highlighted in the literature summarized below may not be equally applicable to all members of the community, contingent on a number of factors including; English proficiency, sex, age, background, wave of migration, refugee status and level of acculturation. This qualification is reinforced by the nature of much of the qualitative research in this area - which tends to be undertaken using relatively small and not always representative sample populations, a reflection of the challenges in undertaking research with CALD communities highlighted in section 6.

## 8.1 The Chinese Community

### Demographics

According to the 2006 Census there were 206,600 people born in China living in Australia, representing 5% of our overseas population and 1% of the total population overall. Fifty five percent of this population live in NSW and 27% in Victoria. Fifty percent of the total population of the Chinese born arrived between 1981 and 2000. At the time of Census the unemployment rate for this group was 11.2% compared with the population unemployment rate which was 5.2%. The median age was 37 compared to the population median of 37.1. In 2008-9 there were 23, 692 Chinese born permanent additions to the Australian population. This makes China the fourth largest source of migrants to Australia behind the UK, New Zealand and India (DIAC, 2010). The 2006 Census also provides information on the numbers of women in the age range 50-69 with poor proficiency in spoken English living in Australia. Cantonese (12,102) and Mandarin (7,978) speaking women were the second and fourth largest language groups respectively with poor proficiency for this age. In total, 33.1% of the Chinese born population spoke English not well or not at all.

### Incidence/Prevalence Data:

In NSW, people born in China are the second largest population of those born outside of Australia. According to State Cancer registries' publicly available data, the Chinese born community in NSW had higher rates of cancer of the Cervix, Liver and Stomach than the Australian born population. Between 1991 and 2001, lung, colon and prostate cancers were the leading sites of new cancers for the males in this community, and breast, colon and lung cancers were the leading sites for women (Supramaniam, 2006).

In Victoria, lung, bowel, breast and prostate cancer are currently the leading sites of new cancers in the Chinese born community. In total there were 827 cancer cases diagnosed in the last five years, the 8<sup>th</sup> highest incidence of cancer in the non Australian born community.

### Attitudes/Understandings of Cancer

- Chinese born Australians may perceive cancer as a death sentence (CCSA, 2007, Kwok and Sullivan 2007b).
- Chinese born Australians may be reluctant to undergo testing or be provided with test results due to a belief that the consequent distress from a positive result may be a possible catalyst for further decline (Eisenbruch, 2004; 2006).

- Cancer may be seen as a stigma for the individual and the family not to be discussed outside the family (Eisenbruch 2006; 2004; Kwok and Sullivan, 2007a; 2007b).
- There is evidence that, to a degree, Chinese beliefs may match Western biomedical explanations for cancer, however, traditional Chinese beliefs are often concurrently maintained, irrespective of high degrees of acculturation (Eisenbruch, 2006;2004).
- The level of acculturation, however, may not correlate with holding beliefs about Western biomedical or traditional concepts of inheritance, kinship and causes of hereditary cancer (Eisenbruch, 2004; 2006).
- Explanations of illness (including cancer) may be culturally understood within the following concepts: (i) karma (yeh), (ii) retribution (bao ying), (iii) fate (ming yun) or Heaven's or God's will, (iv) geomancy (feng-shui), (v) touched evil (zhong chia), (vi) misfortune or bad luck (shui wan, dong hark); (vii) offending the gods or deities requiring prayers or offerings for appeasement; and (viii) kong-tau (spells invoked through human intervention) (Eisenbruch, 2004; 2006; Kwok and Sullivan 2007a; 2007b).
- Cancer may be seen as contagious (Lui and Chui 2009)
- Chinese born persons may believe that blood cannot be replaced (Eisenbruch et., al 2004, DoHA, 2008) with implications for cancer surgery and blood testing.

## **Prevention and Screening**

A number of studies have highlighted that Chinese women have relatively low participation rates in mammographic and cervical cancer screening (Kwok and Sullivan, 2007a, Lam et.al, 2009). However, this finding is qualified by other evidence from a sample of 16,000 women screened for breast cancer in South Australia of higher than average participation rates by Chinese speakers (Mandarin and Cantonese) (CCSA, 2008).

## **Attitudes towards Prevention and Screening**

The following are cultural attitudes and/or barriers identified in the literature that may reduce the participation of Chinese born Australians in screening:

- Health and illness may be taken-for granted experiences of everyday life. When they are asymptomatic, they may be unlikely to suspect that they may have diseases (Kwok and Sullivan, 2007a).

- If women are unaware of any sign of illness in themselves, they may not attempt to discover disease through screening for fear of making themselves feel ill (Kwok and Sullivan, 2007b).
- Women may focus on preserving and promoting health and overall well-being in everyday life rather than attempting to detect hidden disease by screening (Kwok and Sullivan, 2007b).
- Fatalism is likely to be a significant barrier to Chinese born women's participation in cancer screening services (Kwok and Sullivan, 2007a, Cancer Council of Australia, 2007).
- Family history taking that underpins the surveillance, management, and referral to genetic counseling can be undermined unless recognition is made of the patrilineal concept of kinship prevalent in the Chinese-Australian community (Eisenbruch et. al., 2006; 2004).

**Culturally relevant practices that may encourage screening:**

- Recommendations by GPs: Chinese women who participate in screening, predominantly follow the recommendations of their GP (DoHA, 2008).
- Chinese women are more likely to participate in screenings if they have knowledge that the service is free (Kwok and Sullivan, 2007a).
- Chinese women are more likely to participate in screenings if there is encouragement or pressure from a female family member. (Kwok and Sullivan, 2007a).
- In the case of older Chinese-Australian women, breast cancer screening promotion programs may overcome fatalistic beliefs if risk is emphasized following immigration (Kwok et.al, 2007b).
- Government endorsement of screening programs may be seen by Chinese Australian women as legitimizing the service. The promotion of this endorsement may therefore serve to encourage Chinese Australian women to trust that the service and staff are professional (DoHA, 2008).

**Attitudes towards support Services**

- Non-disclosure of a poor prognosis may be favoured, with a clear preference for the family to liaise between health professionals and the patient (Sze, et. al., 2007).
- Patients may desire a confident and clear diagnosis and treatment recommendation (Sze et. al., 2007).
- Patients may desire incorporation of Chinese culture-specific treatments and supports into their care including relevant psychological and spiritual support (Huang, et. al., 1999).
- Diet and nutrition education programs for Chinese born cancer patients may be confusing if the recommendations provided refer exclusively to a Western Style diet rather than a Chinese style diet (Lui and Chiu, 2009).
- Chinese born patients have indicated that information on new and developing treatments and clinical trials of new cancer therapies need to be provided in education programs (Centre for Behavioural Research, 2010).

### **Systemic Barriers**

CALD communities may experience difficulties within the dominant health system because of language barriers, ignorance of the health care system, differing beliefs and attitudes about illness, religious and spiritual difference, social suffering and isolation.

Research highlights the following issues and barriers for cancer survivors from the Chinese born population:

- Language difficulties: Survivors and their families have reported feelings of loss of power and control, and consequent difficulties navigating the health system due to difficulties with both written and verbal language (Butow et. al.,2009a)
- Lack of recognition of the levels of health literacy and more specifically cancer literacy in the community by health professionals (Butow et. al., 2009a; Eisenbruch, 2006; 2004)
- Cultural isolation: including; feeling misunderstood, being mistrustful of health professionals from another culture, lacking access to traditional medicines and receiving treatments contrary to their cultural practice (Butow et. al.,2009a)
- Communication barriers: receiving more information and less reassurance than desired (Butow et. al.,2009a).
- Interpreter problems: these problems include; access to interpreters, uncertainty around roles of interpreters (ie issues around pastoral type responsibilities), lack of

continuity of individual interpreters in supporting individual families, translatability of technical medical language and variability of disclosure by interpreters reflecting cultural beliefs (Butow, et. al., 2008; 2009b, Harris and Telfer, 2001).

- Failure of the multicultural media to report on genetics issues (Eisenbruch 2006; 2004)
- Lack of referral to genetic clinics by GPs and specialists (Eisenbruch, 2006; 2004)
- Incomplete family histories due to migration or lack of access to medical reports (Eisenbruch, 2006; 2004).

### **Risk Factors**

As noted in Section 4, Asian born Australians are at risk of liver cancer due to high rates of Hepatitis B (CCSA 2008a).

One of the critical behavioural cancer risk factors for Chinese born men is smoking. A Sydney study of 1084 Chinese patients attending a Chinese GP found that 25% of Chinese men and 4% of Chinese women self reported smoking (Lin and Ward, 2000). A study of cardiovascular risks in adult Chinese (in Melbourne) found a smoking prevalence rate of 27% for Chinese men. This compares to a figure of 23% in the entire Australian population in 2003-2004 (ABS, 2006)

Surveys undertaken in 1997 and 1998, suggested a lack of knowledge among Chinese smokers about the dangers of smoking (Trotter, 1998).

A Victorian survey of 718 people in the Chinese community showed only small differences between Chinese smokers' knowledge, beliefs and behaviours compared to the Victorian population. However, the data highlighted a lack of knowledge among Chinese smokers about the dangers of smoking. This study noted that although this was a cause for concern, this may reflect the views of committed smokers rather than any cultural differences.

The study found:

- 18% of Chinese smokers said they thought cigarettes are safe and 13% said they did not believe cigarettes contain cancer-causing substances.
- 38% of Chinese smokers, 23% of ex-smokers and 16% of non-smokers said they perceived smoking as a traditional social activity.
- 48% of Chinese smokers accepted smoking as a part of life and 33% thought that most heroes or celebrities of their ethnic group smoke.
- 62% of the Chinese smokers reported having attempted to quit at least once compared to 78% of Victorian smokers (QUIT Victoria 1998).

Other more anecdotal evidence reinforces the idea that the Chinese community may be sceptical about the health risks of smoking and that the risks of smoking are viewed as not serious enough to cause them to stop smoking. Many also feel that the health warnings on cigarette packets are 'meaningless' and do not relate to their lives. Chinese people will often cite long-lived relatives or friends they know who were/are smokers, as evidence that smoking is not damaging. They often cite Deng Xiaoping's longevity and his smoking habit (QUIT Victoria, 2010).

### **Addressing Cultural Barriers: Findings from the literature**

- Decision Aid booklets that increase women's knowledge of breast cancer and its treatment and are designed for sub-literate women can be used to facilitate treatment decision making potentially minimizing psychological distress amongst Chinese women (Lamb et.al., 2009).
- There is a need to avoid assumption of beliefs and to incorporate clients' beliefs systems into the explanations and communications with target populations for screening as well as cancer patients and their families (Eisenbruch, 2006; 2004; Lui and Chui, 2009).

## **8.2 The Greek Community**

### **Demographics**

According to the 2006 Census there were 109,988 Greece-born people living in Australia, this represented 1.9% of our overseas born population and 0.55% of the total population overall. Thirty one percent of this population live in NSW and nearly fifty percent live in Victoria. The Greek born population in Australia increased significantly between 1961 and 1971, however, this is now a declining and ageing population with a median age of 63.4 at the last Census date compared to the overall population median age of 37.1.

Greece is the ninth largest source of migrants to Australia. According to the Census 32.1% of this population did not speak English very well or not at all. At the time of the 2006 Census, the participation rate in the labour force was only 33.6%, with unemployment lower than the Australian average at 4.7%. However, the median individual weekly income for the Greek born in Australia aged 15 years and over was \$246, compared with \$431 for all overseas born and \$466 for the total Australian population.

### **Incidence/Prevalence Data**

According to State Cancer registries' publically available data, the Greek born community in NSW had higher rates of cancer of the Stomach and thyroid Cancers than the Australian born population. Between 1991 and 2001, prostate, lung, colon cancers were the leading sites of new cancers for the males in this community and breast, colon and cervical cancers for the females in the community (Supramaniam, 2006).

In Victoria, bowel, prostate, lung and breast cancers were the most prevalent forms of new cancers diagnosed in the Greece born community in the last five years. In total there were 2179 cases diagnosed for this population, the 2<sup>nd</sup> highest incidence of cancer in the non Australian born community.

Similarly, in South Australia colorectal, breast, lung and prostate cancers were the most prevalent cancers in all CALD communities irrespective of country of birth.

### **Attitudes/Understandings of Cancer**

- Having a cancer may be regarded as a source of shame (Goldstein et. al. 2002, Pennay, 2009)
- Cancer may be viewed as potentially contagious ( Goldstein et. al 2002, Sze et. al. 2007)
- A fear may exist that a cancer diagnosis could result in a more rapid progression of the cancer and ultimately death (Gifford, 1990). Hence disclosure of diagnosis, but

less so prognosis, was favoured, and only to immediate family members (Goldstein et. al. 2002).

- This fear of patient decline following prognosis may result in family members who are translating for the doctor, altering or 'softening' the doctor's message without the patient's knowledge in order to protect the patient. (Goldstein et. al. 2002). Such beliefs may need to be discussed, especially if they lead to guilt or conflict within the family (Goldstein et. al. 2002).
- Cancer may be seen to be 'good' or 'bad' according to a masculine/feminine dichotomy. 'Male' cancers (external) may be seen to have a better prognosis, whereas 'female' (internal) cancers are likely to be considered incurable. (Goldstein et. al. 2002, Gifford 2004, Pennay, 2009)
- Although in many respects this dichotomy accords with the conventional distinction between primary and metastatic disease, special care may be needed when it does not. For example, Greek patients with melanoma may have an unrealistically optimistic view of their condition, while those with an early colon cancer may be overly pessimistic. (Goldstein et. al. 2002)
- Similarly, cancer causation may be attributed by some to microbes within the body, interpersonal conflict ('nagging') and fatigue. (Goldstein et. al. 2002, Gifford 2004)
- There may be some perception that cancer surgery worsens prognosis by disturbing infected blood within the tumour and that internal medicines are dangerous. (Goldstein et. al. 2002, Gifford 2004, 1990)

## **Prevention and Screening**

- Research has identified an under-representation of women who speak Greek participating in cervical screening in NSW (Lesjak, et.,al., 1998).
- In South Australia, during a 2004 pilot program for colorectal/bowel cancer screening, data indicated that participation rates were significantly lower for Greek speakers (20.9%) than for speakers of other non English languages and English Speakers (42.2%)(Cancer Council of Australia, 2008).
- A study of 224 women from Greek, Italian, Vietnamese and Arabic Speakers in Queensland indicated a high, but irregular and infrequent rate of pap smear testing (Sharan, 1991).
- Research exploring intention to participate in FOBT (Faecal Occult Blood Testing) screening in Victoria highlighted that screening was lower in respondents speaking

Greek or Italian at home (48% likely to participate versus 77% of all those aged 50 years or more).(Pennay,2009)

### **Attitudes towards Prevention and Screening**

The following are cultural attitudes and/or barriers identified in the literature that may reduce the participation of Greek born/Greek Speaking Australians in screening:

- A Queensland study concluded that within the Greek born community there is a lack of knowledge of the benefits of cervical cancer screening using the pap smear method (Sharan, 1991).
- Studies including Greek speaking participants also found a lack of understanding of bowel cancer-related issues and of the benefits of preventative measures and early detection. The latter causing some anxiety and confusion among participants, often leading to a passive rejection of the faecal occult blood test (FBT) rather than active consideration (DoHA, 2004, Pennay, 2009).
- Fear, religion and community attitudes may all play a role in how breast cancer is perceived (DoHA, 2004).
- The Pennay study (2009) noted that Greek speakers were more likely to feel embarrassed about seeking help or information on bowel cancer (16% versus 9% of the total sample) and less comfortable with self-administration of a FOBT (59% 'comfortable' versus 81% of all those aged 50 years or more).
- In some members of the community regular breast screening is not viewed as relevant because individuals' destinies are predetermined by God (DoHA, 2008)

### **Culturally relevant practices that may encourage screening:**

- Encouragement or pressure from a female family member may motivate greater participation in breast screening (DoHA, 2008)
- The GP may play a key role in influencing whether Greek born women go for a mammogram (DoHA, 2004).

### **Attitudes Towards Support Services**

The data in this area is limited. However, one study that included Greek Australian Colorectal cancer surgery patients (Naksook, 2003) identified the following concerns:

- That medical information was too difficult to understand.
- That there was limited access to interpreters.
- That there was a lack of alternate sources of information, treatment options and procedures, risks and side effects of treatment and discharge information (Naksook, 2003).
- That they were overly reliant on their health practitioner and did not feel consulted regarding options and decision making (Naksook, 2003).
- That they were not satisfied with what happened post discharge, identifying that they did not feel well enough to leave or that they weren't given enough information to manage their condition when they left (Naksook, 2003).

### **Systemic Barriers**

Issues identified in the literature:

- A lack of pro-activity amongst a number of GPs particularly from the Greek community in informing or referring women from some backgrounds to attend breast screening (DOHA, 2008).
- Lack of transport and interpreting services were perceived to restrict access among women from non-English speaking backgrounds to Breast Screen Australia services. Transport was reportedly a problem for Iraqi, Greek, Chinese and Vietnamese women, who tended to be dependent on family members as they did not have driving licences or their own vehicle (DOHA, 2008).
- Loss of power and control and consequent difficulties navigating the health system due to lack of accommodation of limited English language skills. (Butow, et. al, 2008).
- Problems with access to, consistency and medical literacy of interpreters in addition to poorly defined roles for interpreters (Butow et.al, 2009b, 2009a).
- Communication barriers – receiving more information and less reassurance than desired, and receiving treatments contrary to their cultural practices (Butow et.al, 2009a).

### **Risk Behaviours**

One of the critical cancer risk factors for the Greek community is smoking. According to Trotter (1998) there were a high number of Greek smokers who were reluctant to quit until health issues arose. Trotter (1998) proffered that among Greek smokers this reluctance to quit may be due to the retention of cultural norms that supported smoking in Greece, which remain unchanged due to limited access to public health messages as a consequence of language barriers in Australia.

### **Addressing Cultural Barriers: Findings from the literature**

- With respect to Bowel and other cancers, research suggests that awareness-raising activities need to start with basic information about bowel cancer itself, ie that it is something that can affect everybody. Once this is understood the community is in a better position to receive and understand information about management or prevention through early detection and regular screening (Pennay, 2009).
- The Pennay (2009) study showed that while, when taken as a group, Greek and Italian speakers had relatively low awareness of bowel cancer and some concerning attitudes towards bowel cancer screening, the same was not necessarily true of those Greek and Italian speakers who resided in a pilot program area, where promotional activities and advertising had been undertaken. The positive impact of exposure to the Pilot Program was evident as Greek and Italian speakers who lived in the Pilot Program Area had a much higher incidence of having ever been tested for bowel cancer (61%) compared to those who did not (39%), were much more likely to have used FOBT (25% compared to 7%) and were much more aware of the National Bowel Cancer Screening Program (49% compared to 21%).

## **8.3 The Italian Community**

### **Demographics**

The Italian community is the fourth largest community born outside of Australia, comprising 1% of the total Australian population and 3.44% of the total population of those born outside Australia. Over 41% of the Italian born community live in Victoria and 27% in NSW. In South Australia, the Italian born community is the second largest community born overseas outside of the UK.

The Italian community is an ageing community with 76% over the age of 55 at the last Census. The median age for this population was 65.7 years old, close to thirty years older than the median for the Australian population. Over 21% of this population spoke English not well or not at all, close to 43,000 people. The first Italian migrants arrived in the late 1800's, increasing significantly after Federation in 1901. In 1947 the population of Australia's Italy born was 33, 600 and by 1971, this figured had grown by close to nine fold (289,476). In 2001, this figure had started to decline. In 2006, Italian born migrants numbered only 199,120.

## **Incidence/Prevalence Data**

In NSW the Italian born population had prevalence rates higher than the Australian average for liver, stomach and thyroid cancer. The NSW community also had the highest presentations of cancer of people born outside of Australia. The 4 most common sites for cancers for this community were; (from highest to lowest) breast, colon, rectal and prostate cancers.

Similarly, in Victoria, the Italian community had the highest number of cancer presentations of those born outside Australia. In total 5156 cases were diagnosed in the five year period from 2003-2007, the four most common cancer presentations for this community were bowel, prostate, lung and breast cancers respectively.

## **Attitudes/Understandings of Cancer**

- In studies with Italian born participants, descriptions of cancer centred upon metaphors of infection and growth. Participants noted a belief that even if a person received treatment they would not be assured of being completely cured, because, the 'roots' of the cancer or infection may travel throughout the body to other sites (Severino et.al, 2009, Gifford, 1990).
- Community members may perceive certain cancer sites as being either 'benign' or 'evil' /'malignant' (Severino et.al, 2009). This is in keeping with ideas present in the Greek and Macedonian community as noted by Gifford, (1994) and Goldstein et. al., (2002).
- Strong negative emotions including those resulting from diagnosis and prognosis may be perceived as increasing the onset and risk of cancer and other illnesses. These included feelings such as stress, sorrow, anxiety and anger (Gifford, 1994; MacKinnon, 1999).

## **Prevention and Screening**

Lesjak (1998) identified women speaking Italian as under-served and consequently a recruitment priority, for cervical screening in New South Wales. Sharan (1991), however, found that pap smear testing for Italian speaking Queenslanders was not uncommon but was irregular. According to the Cancer Council of South Australia (2008) findings from a 2004 pilot program for colorectal/bowel cancer screening indicated that participation rates were significantly lower for Italian speakers (38.1%) than rates for speakers of other non English languages.

## **Attitudes towards Prevention and Screening**

The following are cultural attitudes and/or barriers identified in the literature that may reduce the participation of Italian born Australians in screening:

- According to DoHA (2004), one of the major barriers to participation was a lack of awareness. The study showed a lack of understanding of bowel cancer-related issues and of the benefits of preventative measures and early detection. Similar findings regarding Bowel Cancer knowledge were found in a survey that included a significant number of Greek and Italian (n=166) speakers undertaken by Pennay (2009).
- Pennay (2009) found that a lack of confidence and a sense of embarrassment with regard to seeking help or information on bowel cancer (16% versus 9% of the total sample) and being less comfortable with self-administration of a FOBT (59% 'comfortable' versus 81% of all those aged 50 years or more) were critical barriers to participation. Gifford (1989) similarly found that embarrassment was a primary cultural barrier for participation in breast and cervical cancer screening by older Italian women.
- Fear of cancer and the desire to avoid knowing whether or not one had cancer, was found to be one of the primary reasons for avoiding cancer screening generally (Severino et.al., 2009, Brushin et.al., 1997, Gifford, 1990, Gifford, 1989).
- Fatalism toward primary prevention may be a significant barrier to participation in screening for the Italian born community (Severino et. al., 2009, Pennay 2009).
- Low perceived risk may be a further barrier to participation in screening for older Italian born Australians (Severino et.al., 2009).

#### **Culturally Relevant Practices That May Encourage Screening:**

- According to DoHA (2004), in undertaking a FOBT, non English speakers required support, encouragement or endorsement from GPs and health workers because they lacked confidence in their ability to self-screen and complete the test correctly.
- Older Italian speaking women may prefer a doctor as opposed to a nurse or other health care provider, but not a young male (Gifford, 1990).
- Older Italian speaking women may prefer hospital based clinics than local community health centres, not only because they are more familiar, but also because interpreter services are more likely to be guaranteed (Gifford, 1990).
- Italian born Australians noted the following preferred sources for information on cancer screening:
  - Television programs (English or Italian),

- Italian speaking GP and/or Health Provider (Brushin et.al., 1997,Gifford, 1990 ).
- social clubs, and,
- family members.(Severino, et.al., 2009)

Findings from research indicate that participants were less enthusiastic about the role of Italian newspapers in communicating information or motivating interest in health issues. (Severino, et.al., 2009). According to Page et. al., (2005), both radio and Italian-specific newspaper advertisements, did not significantly increase breast screening attendance but required a combination of an intervention campaign to have an impact. The most effective prompt to encourage screening may be an invitation from a National or State screening service, followed by information or recommendations from a GP (Page, et.a al, 2005).

### **Attitudes Towards Health and Support Services**

There is little data available on Italian born Australians' attitudes towards cancer based health and support services

### **Systemic Barriers**

The systemic barriers identified were:

- Language and communication (Gifford 1989, Naksook, 2003)
- Perceived lack of participation of patients in decision making (Naksook, 2003)
- Lack of a guarantee that clients would have access to female health service providers (Gifford, 1990)

### **Risk Behaviours**

The Italian community is an ageing population. Some issues of concern are:

- Low exercise patterns
- Higher levels of smoking and obesity than the Australian population (particularly in males), but lower levels of heart and respiratory disease (IAA, 2010).

In Greek, Italian, Vietnamese, Chinese, Middle Eastern and Eastern European communities there are a high number of male smokers with decades of exposure. A reluctance to quit until an immediate health issue arises may also be evident (CCSA, 2008a).

## **8.4 The Vietnamese Community**

### **Demographics**

There have been three waves of Vietnamese migration to Australia. The first wave occurred around 1975 and was comprised of mostly urban, educated Vietnamese. The second wave arrived escaping the communist regime after 1975. It is during this wave that the number of Vietnamese born persons more than doubled. The third wave occurred from around 1992 and are mostly relatives of previous migrants entering the country under the family reunion program (74% between 1996-2004) (Jupp, 2001).

According to the 2006 Census there were 159,849 Vietnamese born people living in Australia, this represented approximately 2.75% of our overseas population and 0.81% of the population overall. Approximately 40% percent of this population live in NSW, 37% in Victoria and 8% and 6.6% respectively in Queensland and South Australia.

At the time of Census the unemployment rate for this group was 11.4% compared with the population unemployment rate which was 5.2%. The median age for this community was 41 years compared to 37.1 for the total Australian population and 46.8 years for all overseas born Australians. Seventy eight percent of Vietnamese born people arrived before 1996. In 2006, 41.6% of the Vietnamese born spoke English not well or not at all. It is worth noting that 96% of Vietnamese born spoke a language other than English at home. The 2001 Census identified that 77.9% of the Vietnamese born spoke Vietnamese, 17.4% spoke Cantonese, and 0.6% spoke Mandarin.

### **Incidence/Prevalence Data**

According to the State Cancer registries', publicly available data, the Vietnamese born community in NSW had higher rates of cancer of the cervix, liver, stomach and thyroid than the Australian born population. Between 1991 and 2001, the lungs, liver and head/neck were the leading sites of new cancers for the males in this community, and breast, cervix and thyroid were the leading sites for women (Supramaniam, 2006).

In Victoria, bowel, breast, liver and lung were the leading sites of new cancers in the Vietnamese born in the last five years. In total there were 668 cases diagnosed in the last five years for this population, the 9<sup>th</sup> highest incidence of cancer in the non Australian born community.

## **Attitudes/Understandings of Cancer**

- Misconceptions of the illness, ie. that the cancer is contagious, untreatable (Del Mar, et.al., 1998).
- A preference towards traditional treatments and self medication in the first instance (Del Mar, et.al., 1998, MICEAST, 2004) but this may be coupled with a reluctance to disclose this to the health care provider (QLD Health, 2010).
- Paternalistic approach to disclosure and a preference for disclosure to relevant family member rather than to patient, where the patient is not a patriarch (Le and Le, 2005).
- Discomfort in disclosure of health information to health practitioner, perception that health information is private (Le and Le, 2005).

Reinforcing the findings above, a US study regarding knowledge attitudes and practices of breast and cervical cancer screening among Vietnamese born women found that participants believed (Pham and Phee, 1992):

- that there was little one could do to prevent cancer (52%).
- that breast or cervical cancer could be caused by poor hygiene (39%).
- that these cancers could be contagious (29%).

In terms of beliefs regarding cancer, though not undertaken within the Australian context, the findings of Pham and Phee (1992) seem to indicate that beliefs about cancer as contagious and untreatable may also be found within the Vietnamese born Australian community.

## **Prevention and Screening**

- A Queensland study found that Vietnamese women in a sample of 224 non English speakers had the lowest percentage of pap tests (Sharan, 1991). Consistent with this finding, Taylor et. al., (2003) determined that estimated biennial cervical screening rates in a Vietnamese nominal cohort of women aged 20-69 years were significantly lower than those for NSW overall, by 10-12 percentage points.
- Vietnamese born women had a significantly higher incidence of cervical cancer than the Australian population (Jelfs, 1995).
- Data from January 2004 to December 2005 of over 16,000 CALD women screened for breast cancer in South Australia showed that the Vietnamese speaking community had higher than average participation rates (CCSA, 2008b).
- Compared to Australian born men, bowel cancer testing was significantly lower among men from all regions of Asia (Weber et. al., 2009)
- In a survey of 199 Vietnamese born women over the age of 18 years and resident in Adelaide, 87% of the women had heard of a Pap and 75% had had a test at some time (Cheek et. al., 1999).

## **Attitudes towards Prevention and Screening**

The following are cultural attitudes and/or barriers identified in the literature that may reduce the participation of members of the Vietnamese community in screening:

- Vietnamese born may perceive that they are not at risk of bowel cancer (DoHA, 2004).
- Discomfort in disclosure of health information to health practitioner, resulting from a possible perception that health information is private.(Le and Le, 2005).
- Misconceptions that cancer is untreatable (Del Mar, et.al., 1998).

## **Culturally Relevant Practices that May Encourage Screening:**

- According to Cheek et. al, (1999), the importance of the family doctor to the Vietnamese community cannot be over emphasised. The study showed that GPs were the major source of health information on Pap smears for Vietnamese women. The majority of the women included in the survey also reported that they would have a Pap smear if it were recommended in a consultation with their doctor.
- Existing nonmedical community networks are likely to be a primary source of health information and attitudes for Vietnamese women and may be effectively utilised to encourage screening. The use of written materials for education may be of less value, particularly with women who have recently arrived in Australia and whose literacy levels may be low (Cheek et. al., 1999).
- Vietnamese and Chinese born women interviewed for BreastScreen Australia, indicated that government endorsement of the program gave it greater legitimacy and encouraged women to trust that the service and staff would be professional (DoHA, 2008). Increasing awareness of Government endorsement may increase participating numbers.
- Personalised letters may not increase the number of appropriate (ie regular) screens within the Vietnamese community (Del Mar, 1998). However, where personal letters to members include an offer of a personal screening appointment, there is some evidence that this may be more successful in increasing regular participation (Turnbull and Irwig 1992).

## **Attitudes Towards Health and Support Services**

There is little data available on Vietnamese born Australians' attitudes towards cancer based health and support services

## **Systemic Barriers**

- **Accessibility to Health and Screening Services.** Transport may be a significant problem for Vietnamese women, who may be dependent on family members as they may not have driving licenses or their own vehicle (DoHA, 2008).

## **Risk Behaviours**

As noted in Section 4 above, Asian born Australians are at risk of liver cancer due to high rates of Hepatitis B (CCSA 2008a).

One of the critical behavioural cancer risk factors for Vietnamese born men is smoking. In Vietnamese communities there are a high number of male smokers with decades of exposure (CCSA, 2008a). A reluctance to quit until an immediate health issue arises may also be evident. In 2006, a New South Wales (NSW) study found that Vietnamese males (30%) had higher rates of smoking compared to that of all Australians (23.8%). Vietnamese women however, had the lowest smoking rates at only 2.5% (NSW Health, 2006).

Further, results from focus groups with Vietnamese speaking caregivers of children aged between 0 – 6 years old revealed concerning levels of knowledge, attitudes and behaviours regarding children's exposure to Environmental Tobacco Smoke (ETS). A poor understanding existed regarding what constituted passive smoking and the severity and extent of harm that ETS has on children. Smoking attitudes and behaviours described were not always consistent with the concern expressed about children's vulnerability to smoke. Initial changes in smoking patterns at home since the arrival of children were not always sustained.

Despite awareness of the harm caused by smoking in the presence of their children, some caregivers continued to smoke in closed environments. Others felt it was sufficient protection to smoke in another room, with doors and/or windows open or by ensuring that visible smoke did not reach the child directly, whilst some smoked in the home or car only when children were not present. Smoking attitudes and behaviours in the presence of children were influenced by cultural and social norms associated with smoking. The desire to be sociable and hospitable often superseded concerns for children's health (Jochelson, et. al.,2003).

## **Addressing Cultural Barriers Findings from the literature**

Literature on addressing cultural barriers for Vietnamese speaking or Vietnamese born peoples not directly pertaining to screening was limited.

## 8.5 Arabic Speaking Communities from the Middle East and North Africa.

Due to the dearth of literature in Australia, and the common inclusion of countries like Egypt in studies of peoples from Middle Eastern countries, the following examines demographics, cancer prevalence and attitudes of Arabic speakers from Middle Eastern and North African Communities to cancer and cancer services.

### Demographics

According to the ABS, **the Middle Eastern countries with populations in Australia** include: Bahrain, Gaza Strip, the West Bank, Iran, Iraq, Israel, Turkey, Jordan, Kuwait, Lebanon, Oman, Qatar, Saudi Arabia, Syria, United Arab Emirates and Yemen. In total these communities comprised 193,668 persons on the 2006 Census date, 0.98% of the Australian population. According to the Census, the Lebanese, Iraqi, Turkish and Iranian born communities respectively were the largest Middle Eastern communities in Australia. Close to 60% of this community lives in NSW, and approximately 27.5% in Victoria, 4% in Queensland and 4% in Western Australia.

**Lebanese born:** There have been three waves of Lebanese immigration and Settlement in Australia, from around 1880 – 1947, from 1947-1975 and post 1975. The population tripled between 1966 and 1976 and more than doubled between 1976 and 2006 as a consequence of the instability arising from the civil war in 1975. The current population of Lebanon born in Australia is 74,850, 74.5% in NSW, and 20% in Victoria. The median age of the Lebanese born is 45 years, significantly older than the median Australian age of 37.1. The main language spoken by those born in Lebanon was Arabic accounting for 89.4% of the Lebanon born. Of those who spoke a language other than English at home (92.6%), 22.8% spoke English not well or not at all. The unemployment rate for this community was 12.1%.

**Iraqi born** – The Census first identified people born in Iraq as a separate grouping in 1976. From 1986 to 2006 the population moved from 4516 to 32,520, 74.5% reside in NSW, and 20% in Victoria. The median age of the Iraqi born is 35.7 years. The main languages spoken by those born in Iraq are Arabic (48.6%) and Assyrian (38.9%). Of those who spoke a language other than English at home (96%), 27.7% spoke English not well or not at all. The unemployment rate for this community was 22.3%.

The Northern African countries include Algeria, Egypt, Morocco, Sudan, Tunisia, and Western Sahara. In total these communities comprised 56,874 persons on the 2006 Census date, 0.29 % of the Australian population. Egyptian (58.8%) and Sudanese (33%) born communities made up 92.% of these populations. Of this population 47% were in NSW, 37% in Victoria, 9% in Queensland and 5% in South Australia.

**The Sudanese born:** This community is one of the fastest growing over the past few years. During 2007-08, 1,159 Sudanese born people arrived in Australia. More than 98% of Sudanese born arrivals come to Australia through the humanitarian channels. The Sudanese in Australia are frequently from the south, especially the Nuer and the Dinka, many of whom are Christians.

According to the 2006 census, there were 19,050 Sudanese born people in Australia (287.7% increase from 2001) and 32.6% resided in VIC, followed by 31.4% in NSW and 12.6% in QLD. The median-age of the Sudanese born was 24.6 years old (compared to 37.1 for the total Australian population). Seventy nine percent of Sudanese born entrants describe their ability to speak English as not very well or not at all. Fifty percent of the population spoke Arabic, 17% Dinka, and 11% described their language as “African”.

**The Egyptian born:** In the Census of 1901 there were 108 Egyptian born persons in Australia. Post World War II and Egypt’s independence in 1953 a number of Coptic Christians and other minorities arrived in Australia as a result of the pan Arab policies, further the 1967 war with Israel led to further migration. Following independence there was a shortage of skilled employment and consequently many migrants who came to Australia were highly educated. In 1971, Egyptian migrants numbered 28,230. In 2006 this number was 33,497, 51.3% reside in NSW, and 34.6% in Victoria and 5.3% in Queensland. The median age of the Egyptian born was significantly higher than that of all Australians at 55.4 years. The main languages spoken by those born in Egypt were Arabic (49.5%) English (22.2%) and Greek (11.7% ). Of those who spoke a language other than English at home, 12% spoke English not well or not at all. The unemployment rate for this community was 6.2%.

### **Incidence/Prevalence Data**

The incidence of cancer in migrants to New South Wales (NSW) from, Egypt, Iran, Iraq, Israel, Lebanon, Syria, and Cyprus and Turkey was compared with that in the Australian-born population using data from the NSW Central Cancer Registry for 1972–91. Age-standardized incidence rates showed overall cancer incidence to be less common in migrants from each Middle Eastern country than in the Australian-born. There was a clear pattern of generally low rates for cancers of the mouth and pharynx, esophagus, colon and rectum, lung (men only), ovary, prostate and testis, and melanoma. Cancers which tended to be more common in these migrants were nasopharynx, stomach (women only), liver (men only), gallbladder (chiefly in women), bladder (men only), and thyroid. Breast cancer did not show a uniform pattern among migrant groups, rates being high in the Egyptian-born but low in Lebanese-born women (McCredie et. al., 1994).

According to more recent State Cancer registries’ publically available data, in NSW the Egyptian born had a higher incidence than the broad population of liver cancer

and the Lebanese born had a higher incidence of thyroid cancer. For Arabic speakers in general, breast, prostate and lung cancers were most prevalent.

In Victoria, for peoples born in countries in the Middle East as a whole there was a total of 966 cancer diagnoses in the five year period (2003-2007). The leading cancer sites for this group were breast, lung, bowel and prostate respectively. For peoples born in North Africa, there was a total of 576 new cancer diagnoses in the five year period (2003-2007). The leading sites were breast, prostate, bowel and lung respectively. Included in these were a total of 461 new cancer diagnoses for Egyptian born peoples (2003-2007), the 12th largest presentations of cancers for those born outside of Victoria. Unsurprisingly, the leading sites for the Egyptian born were prostate, breast, bowel and lung respectively.

### **Attitudes/Understandings of Cancer**

- According to Russell (1996) Arabic speaking women made judgements about whether they thought cancer was curable or not using either the traditional paradigm of male and female-type cancers, or the western medical paradigm of early detection and treatment.
- Arabic speaking women may believe that cancer is incurable (Russell, 1996; Sze et. al., 2007). Similar attitudes were found in an Israeli study for Arab Muslim and Druze women (Azaiza and Cohen, 2006).
- However, in the Russell study (1996) some Arabic speaking women believed cancer was curable if; the cancer was detected early, or was a male cancer, or because they knew someone who had been cured (Russell, 1996).
- Arabic speaking women may associate a range of risk factors with increased susceptibility to breast cancer including:
  - infection and germs,
  - emotional distress (potentially caused by knowledge of diagnosis),
  - being predestined to get the disease,
  - classic health risk factors such as smoking and alcohol, and "having the disease run in the family," and,
  - Milk retention in the breast due to either breastfeeding or not breastfeeding was associated with increased risk (Russell, 1996).
- Being single, having breastfed and not having cancer in the family may be associated with a reduced sense of susceptibility amongst some women. (Russell,1996).
- Arabic speaking women may believe that fear and worry may kill a cancer patient or make them worse (Russell, 1996).

- The psychological suffering which results from knowing you have cancer may be perceived by Arabic speaking women as reducing the quality of the patient's life (Russell, 1996).
- The Russell study (1996) clearly highlighted two disparate views on disclosure:
  - Women with negative attitudes to a cancer diagnosis believed that fear and worry would kill the patient or make them worse, or that the psychological suffering which results from knowing you have cancer would reduce the quality of the patient's life. These women advocated that you should tell the patient that she has another disease, while telling the family she has cancer and seeking their cooperation in giving the woman treatment.
  - Women with positive attitudes to a cancer diagnosis thought that you had to be aware in order to receive treatment and look after yourself. Women also valued awareness as important in itself. These women did not think a woman could be treated without knowing that she had the disease, thought treatment as essential and viewed the patient's role in her treatment as active rather than passive.

### **Prevention and Screening**

A study of 224 women from Greek, Italian, Vietnamese and Arabic Speakers in Queensland indicated a high rate of pap smear testing amongst these communities, however, testing was not undertaken at regular intervals (Sharan, 1991).

In a study of Arabic speaking women attending 20 Arabic speaking general practitioners, only 73% of women at risk had been screened in the last two years. Nine percent had never been screened. Findings showed that Muslim women and older women were more likely to be underscreened (Russell, 1996).

Research examining recruitment priorities for cervical screening in NSW highlighted that Arabic-speaking women should be a priority for public campaigns for cervical screening, particularly Muslim and older women (Lesjak, 1997)

### **Attitudes towards Prevention and Screening**

Findings from Russell (1996) indicated that negative attitudes to a cancer diagnosis may not deter Arabic speaking women from screening (Russell 1996).

The following are cultural attitudes and/or barriers identified in the literature that may reduce the participation of members of the Arab speaking and Middle Eastern community in screening:

- The belief that if there was no history of breast cancer in the family, regular screening is not relevant (DoHA, 2008)

- Embarrassment may be a significant barrier to overcome in relation to screening mammography for some women from non-English speaking backgrounds. Research identified that Iraqi and Lebanese born women interviewed regarding breast cancer associated mammograms with discomfort, humiliation and invasive handling of their breasts (DoHA, 2008). Similar attitudes were found in Arab Muslim women in Israel (Azaiza and Cohen, 2006).
- On limited evidence, there may be a belief that mammograms are against the Muslim religion as they require a woman to reveal her breasts to a stranger (DoHA, 2008).
- Breast screening may not be available or common in the home country and therefore knowledge about breast screening may be limited (DoHA, 2008).
- A concern regarding access to female health workers for Breast Screening may discourage participation in breast screening for some Arabic speaking women (DoHA, 2008).

### **Culturally Relevant Practices That May Encourage Screening:**

- Although the detection of female cancers may be viewed as futile by Arabic speaking women, the curability of male cancers is associated with Western medical treatment. These beliefs are therefore not expected to undermine recruitment efforts for mammographic screening which is perceived as a male cancer (Russell, 1996).
- Having access to either an interpreter or bilingual health worker may increase comfort levels and encourage Arabic speaking women to screen regularly. Assistance of this kind may be seen as particularly important during a first visit to help explain unknown factors and procedures, particularly for recent arrivals to Australia (DoHA, 2008).

### **Attitudes Towards Support Services**

While not directly related to cancer, but consistent with much of the cancer literature for a number of other CALD communities, it was found that shame and stigma in the Arabic speaking community appeared to be the overwhelming hindrance to accessing services and particularly mental health and support services. This is due to strong cultural prohibitions on exposing any personal or family matters to outsiders. The findings emphasized the perceived negative effect of mental illness on important cultural institutions, such as marriage. The results revealed strong concerns about confidentiality and lack of trust in service providers (Youssef and Dean 2006).

## **Systemic Barriers**

The following are systemic barriers and difficulties encountered by Arabic speaking cancer patients identified in the literature:

- The absence of personalised high quality written information to allow ownership over their health status (Butow et. al., 2009a).
- A lack of access to acceptable services that take into account the cultural background of the women as an explanation for the irregularity of pap smear testing for Arab and other non English speaking women (Sharan, 1991).
- Cultural isolation – including feeling misunderstood, mistrustful of health professionals from another culture, lacking access to traditional medicines and receiving treatments contrary to their cultural practices (Butow et. al.,2009a)
- Communication barriers – receiving more information and less reassurance than desired and feeling a loss of control over the process (Butow et. al., 2009a)
- Limited access to interpreters (DoHA, 2008).
- A lack of reassurance that provision of health and service information would be available in patients' first language and that they would have access to interpreters. This may be particularly salient according to the research of Butow et. al., (2009a), which found that this dearth of language support was the expectation held for Arabic speaking people with respect to interactions with health professionals and government organisations. This was particularly the case for Iraqi women who had very low English language proficiency as noted in the DoHA, study (2008).

## **Risk Factors**

As noted in Section 4, men from the Middle East are at risk of liver cancer due to high rates of Hepatitis B (CCSA 2008a).

One of the critical behavioural cancer risk factors for Arabic speaking men is smoking. In 2006, a New South Wales (NSW) study found that Lebanese males and females had much higher rates of smoking compared to the Australian born population (NSW Health, 2008). A more recent study in NSW with twenty-nine (53.7%) Arabic speaking GPs in southwest Sydney noted that of 1371 patients seen, 29.7% were smokers. Smokers were more likely to report poorer health. Of those surveyed, 35.7% reported high nicotine dependence. Dependence was higher in men and those who reported poorer health. Of those smoking, 35.9% had attempted to quit in the previous year; 17% were in preparation stage of change; 42.7% recalled quit advice. From this sample it can be seen that the proportion of self reported current smokers among the Arabic speaking community is likely higher than for the Anglo-European majority (Girgis et. al., 2009).

## **Addressing Cultural Barriers Findings from the literature**

- From the DoHA (2008) study, feedback from Lebanese participants suggested that women from Lebanese cultural backgrounds would be more likely to undertake breast screening regularly if they could access a 'walk in' service where they did not need to make an appointment.
- The same study noted that given low literacy levels, particularly within the 50-69 age group, it would be helpful if all written materials used large fonts to make reading as easy as possible. They also recommended that information should be presented in a format that is brief and clear and uses images to emphasise key messages where possible.
- Women from CALD backgrounds may often miss breast screening appointments due to overseas travel and may not know how to reschedule. Women from this sub-population may, therefore, benefit from additional information about how to organise or reschedule breast screening appointments under these circumstances (DoHA, 2008).

## **Appendix A: Resources to assist in Engagement with CALD Communities in Health Settings**

There are a number of useful resources which can support engagement with CALD consumers within health settings. These resources provide information on individual communities, their cultural practices and history, as well as other relevant general health information, including attitudes to health and epidemiological profiles. These should be considered in conjunction with the specific findings regarding the individual CALD communities and their attitudes, risk behaviours and experiences with respect to cancer and cancer health and support services outlined in the case study section above.

### **Broad Overview of Communities**

Department of Immigration and Citizenship (2010) Country Profiles, accessed at [http://www.immi.gov.au/media/statistics/country-profiles/\\_pdf/china.pdf](http://www.immi.gov.au/media/statistics/country-profiles/_pdf/china.pdf)

### **Health Issues**

Italian Assistance Association, Community Health Profile – Italian, accessed 4/2010 at; <http://www.vtpu.org.au/resources/communityprofiles.html>

Le, Q., and Le, T., (2005) Cultural Attitudes of Vietnamese Migrants on Health Issues, Australian Association for Research in Education, No. LEO5645, accessed at <http://www.aare.edu.au/o5pap/le05645.pdf>

Migrant Information Centre Eastern Melbourne (2004) Cultural and Religious Profiles to Assist in providing Culturally Sensitive Care and Effective Communication, accessed at <http://www.miceastmelb.com.au/documents/mep/H&PCarekit.pdf>

Queensland Health, Vietnamese: A Guide for Health Professionals, accessed 7/4/2010 at [http://www.health.qld.gov.au/multicultural/health\\_workers/viet.pdf](http://www.health.qld.gov.au/multicultural/health_workers/viet.pdf)

Victorian Transcultural Psychiatry Unit (2010) Community Profiles: Immigrant and Refugee Community Profiles in Australia, accessed at <http://www.vtpu.org.au/Default.aspx?PageID=1389264&A=SearchResult&SearchID=522560&ObjectID=1389264&ObjectType=1>

National Health and Medical Research Council (2006) Cultural Competency in Health: A Guide for Policy, Partnerships and Participation, accessed at <http://www.nhmrc.gov.au/publications/synopses/hp25syn.htm>

## **Appendix B: Initiatives Targeting Specific Communities To Engage Them Effectively In Cancer Control.**

The following are some examples of initiatives targeting specific communities to engage them in various aspects of cancer control. While methods to encourage CALD communities in preventative screening have largely been considered in section 3.3 the following will outline specific programs targeting CALD communities and engaging them in various aspects of cancer control. The programs highlighted include education programs, support programs and screening programs. The selection of programs was primarily based on access to program information. Given the disparity in methods of evaluation and often, the absence of evaluation, it is very difficult to identify good practice. A handful of programs are considered below. This small sample attempts to include programs delivered by a range of providers on differing scales to get a better understanding of the breadth and reach of the programming being undertaken. The summaries are outlined below.

### **Victorian Non English Speaking Background Living With Cancer Education Programs (LWCEP) (Support Services)**

This is a free program designed and supported by the Cancer Council of Victoria and run by trained health professionals to give people with cancer and their friends and family, the chance to learn about cancer, its treatment and their emotional reactions to it. The program is for small groups and usually runs for 2 hours a week for 4 to 8 weeks. The program is designed to help inform:

- What cancer is and how treatment decisions are made,
- The various symptoms, cancer treatments and side effects,
- The doctor-patient relationship,
- How to access the cancer services available,
- Information on important factors like diet and exercise,
- Myths about cancer,
- Unproven methods,
- Relationships, self-esteem and body image,
- How to meet with others dealing with cancer in a comfortable and relaxed environment,
- Coping with grief and loss.

This program had been running in Victoria for a number of decades for English speakers. The first of the LWCEP undertaken for a community whose language of origin was not English, and whose cultural attitudes towards cancer was not necessarily identical to the group for which the program was originally designed, was undertaken in 1992 for the Hispanic community. This program and the subsequent programs with other communities were designed and undertaken in conjunction with key community based organizations (Todd and Epifanio, 2000). For an evaluation of the program see below.

## **The Cancer Council of Victoria's Cancer Helpline: Multilingual Line (Support Services)**

The helpline switchboard is staffed by enquiries officers and registered cancer nurses with oncology qualifications and experience. While individual medical advice is not provided, effects of specific types of cancer as well as processes like chemotherapy can be discussed as well as information on radiotherapy or other cancer treatments. The service also provides information on support groups and other community resources. The multilingual line provides callers with cancer information recorded in their own language as well as providing an option to connect to a cancer nurse, assisted by an interpreter. In 2008 there were 373 calls relating to the multilingual line.

## **The Cancer Council of NSW Hepatitis B screening and Liver Cancer Surveillance Program (Screening and Education): The 'B' Positive Project**

The 'B Positive' Project is a NSW Cancer Council-led collaboration between hospital clinicians, general practitioners, researchers and community organisations representing the affected communities. In addition to detecting and treating chronic hepatitis B infection, the program will screen people at risk for liver cancer, aiming to increase the number of early cancer diagnoses, which may be curable by clinical intervention. A component of this pilot study included modelling the cost effectiveness of a targeted program of hepatitis B and liver cancer screening. It was found that a comprehensive screening and treatment program of high-risk populations (this includes Asian-born males over the age of 40, Asian-born females over the age of 50, African-born people over the age of 20) across NSW is both feasible and cost-effective. If the program was expanded to the Greater Sydney area with an estimated 8,000 people enrolled, (approximately 13% of the infected population in NSW), this program could save 8,700 life-years at a cost of \$18,000 per life year (the Cancer Council of NSW 2007).

This pilot program targets the Fairfield and Liverpool Local Government Areas of South Western Sydney where the incidence of Liver Cancer and Chronic hepatitis B is significantly higher than the rest of NSW and Australia. The program is particularly targeting Vietnamese and Chinese born persons given that they are 6-12 times more likely to be diagnosed with liver cancer than an Australian born individual due to the high incidence of chronic hepatitis B infection in these communities.

A protocol to support individualised treatment planning has been developed, with treatment decisions based on liver function and viral load. This includes a key 'B Positive' Project decision-support resource), with a matching GP process flowchart for patient enrolment and follow-up. Resources in Chinese and Vietnamese are a further component of the program and are being produced in partnership with relevant community organisations.

The Cancer Council NSW has also developed and delivered a series of educational workshops (November 2007 - November 2008) in the Fairfield - Liverpool area for GPs participating in the 'B Positive' Project. All 329 GPs in the local divisions were invited to participate, with 57

in 2008 attending at least one evening seminar (Tipper and Penman, 2009). This project has also worked with community organizations to provide educational sessions on Hepatitis B and to distribute educational materials. Evaluations of these sessions have shown that 76% and 87% of Vietnamese and Chinese participants respectively were more likely to see their doctor about Hepatitis B after the event. Close to 60% and 68% were considering being a part of the B positive screening program.

### **Macedonian Women in Whittlesea (Support Services During Diagnosis and Treatment)**

The Women's Health in the North (WHIN) (Victoria) undertook activities to develop a model of psychosocial support for CALD women from Macedonian backgrounds. This community was targeted in light of the fact that over half of these women were over 45 years old and therefore at risk for breast cancer. Consultations with primary care providers (such as breast care nurses) expressed concerns regarding women's access to existing psychosocial supports at the time of diagnosis and during treatment.

In developing a model that could potentially meet the needs of Macedonian-born women in the north living with breast cancer, the WHIN Worker undertook a comprehensive literature review. Particular attention was given to the barriers that women from CALD backgrounds experience in accessing mainstream services and the cultural meanings of illness, healing and death given by those from the Macedonian community. A model was then drafted that addressed the barriers and supported women and their families in exploring the complexities of their cultural understandings.

The model consisted of four key intervention areas:

- Building networks for women.
- Providing cross-cultural awareness for service providers.
- Creating supportive environments for health.
- Exploring cultural meanings of health.

The WHIN Worker then consulted with key informants on whether the model would 'make a difference' to the lives of Macedonian-born women. Informants included representatives from the Macedonian Community Welfare Association (MCWA) and the Transcultural Psychiatry Unit at St Vincent's Hospital. Feedback was overwhelmingly positive from these consultations (WHIN, 2004a). Further evaluations of the program could not be accessed, or may not have been undertaken.

### **Australia's Biggest CALD Morning Tea (Education and Awareness Raising in New Arrivals)**

This event was planned at the same time of year as the Cancer Councils' annual fundraising event, "Australia's Biggest Morning Tea." It was designed to raise awareness about the different programs and services of The Cancer Council of South Australia and related agencies among the students in the New Arrivals Program at Thebarton Senior College. The

planning group consisted of staff from different units and programs at The Cancer Council South Australia, the Coordinator New Arrivals Program at Thebarton Senior College, Staff from Quit SA and the Palliative Care Council, representatives from West Torrens Council and members from various CALD communities. In total there were 96 participating students from the New Arrivals Program. These students came from a variety of cultural backgrounds, and most were between the ages of 18 to 30. The event was incorporated into Life Skills program. The presentations to the students included: Volunteering at The Cancer Council (Filipino), My Cancer Experience (Kurdish), Working as a CALD Cancer Educator at The Cancer Council South Australia (Chinese). Students were issued with passports before visiting tea stalls, each stall represented a program or service and were hosted by culturally diverse community members and staff from TCCSA and related agencies.

The stalls were decorated with culturally specific artefacts. Community members provided culturally specific tea, coffee and food. Staff provided written health promotional resources relating to services and programs. Students circulated around the tea stalls in groups of 12 with their teachers. The staff members at each stall gave 5 minute presentations with key messages. Students filled in relevant pages in their passports. Evaluations were undertaken and a very strong, positive response, particularly to the speaker on their experience of cancer was found. Suggestions were made that in future more information could be provided on skin cancer, what causes cancer, smoking, alcohol and cancer experiences (Tait, 2008).

### **Women Who Are Carers (Education and Support)**

This project was a combined initiative of the Cervical Cancer Program and the Breast Cancer Program of the Women's Health in the North (Victoria). A steering committee comprising representatives from WHIN, Panch Health Service, CarerLinks North, North West BreastScreen and St. Vincent's BreastScreen was established to plan, deliver and evaluate a 'Pamper Day' for carers largely from culturally and linguistically diverse backgrounds. Activities for carers would be free of charge.

The steering committee met on five occasions to discuss, plan, implement and evaluate the Pamper Day. The 'Pamper Day' was entitled 'Looking after Yourself: A Pampering Morning for Women Carers of All Cultures', and was held in May 2004 at Panch Health Services. The Pamper Day was organised in order to give carers an opportunity to focus on their own health and wellbeing, while enjoying a morning of socialising, pampering and relaxation.

The 'Pamper Day' was considered a success by all partners, with 21 carers participating. A high proportion of women attending were from CALD backgrounds (86%), including those from Arabic, Chinese, Greek and Italian backgrounds. The women were all aged 40 and over.

The pamper day enabled the women to take some 'time out', while becoming acquainted with local health services, in a relaxed and non-threatening environment. The day began with short presentations from members of the steering committee about agency programs and services. Women then participated in neck and hand massages, manicures, and enjoyed live music and refreshments. They were also able to access information including resources on

breast health, Pap tests, continence, menopause, diabetes, blood pressure, respite care, transport assistance and interpreting services. Women were encouraged to make appointments with services participating in the day. The feedback from carers was that they enjoyed the chance to meet and chat with other carers and were delighted with the live music, massages, manicures, food and information available.

WHIN noted a number of significant impacts from the 'Pamper Day'. The day was a success insofar as it managed to 'target' the women it was designed for. A number of carers approached the WHIN Worker on the day to discuss their particular health concerns and to find out how WHIN can support them. One woman was very interested in the translated information provided by WHIN and was appreciative of being able to access and understand the information in her own language. Two women became members of WHIN and have subsequently participated in other programs and services including a health education session for members on managing stress. For all carers attending the day, a very important aspect was that they were given the opportunity to talk about their own health and how they felt. At the same time they were able to access information about services that could support them, for example, access to respite care. Many of the carers who attended on the day were not aware of CarerLinks and found their information to be useful and worthwhile. Further, a strong working relationship between agencies represented on the steering committee was established. In a final evaluation meeting members of the steering committee all agreed that the carers took on board the importance to take 'time out' to attend to their own health and wellbeing, particularly regarding breast health and Pap tests (WHIN, 2004b).

### **An Evaluation of a Good Practice Initiative: Non English Speaking Background (NESB) Living with Cancer Education Program**

This program was evaluated through a series of interviews held with staff who coordinate the resourcing for the Living With Cancer Education Program, program facilitators and key contributors from community organisations. These interviews examined the problems around sustainability from the point of view of the Cancer Council of Victoria. They sought to identify impediments and contributors to sustainability and to identify achievements of the program (Todd and Epifanio, 2000).

#### **Identification of common impediments to sustainability:**

- a) the Greek, Spanish and Polish programs were reliant on one or two trained facilitators. Should circumstance arise where they are unable to run more courses, continuity would be interrupted and their expertise would be lost. At best, courses can only be run when the facilitator has time.
- b) All programs were inhibited by lack of money. In some areas this can be mitigated through appropriate substitution such as free venues, reliance on donations of tea, coffee and biscuits, volunteer translations etc. Because some expenses were unavoidable, funds had to be requested from the Cancer Council of Victoria in the absence of any alternative.
- c) The Spanish, Greek, Chinese and Italian programs did not have well-developed relationships with their community organisations. In most cases this was due to lack of

contact and lack of resources in the community which placed a limit on involvement. In some instances there had been good liaisons created which had not been sustained when a person has left the position. However this lack of contact reduced opportunities for reciprocal arrangements or pooling of resources.

- d) While there had been attempts in most of the communities to establish support groups, at the time of review the only viable one was the Chinese Cancer Support Group.
- e) All facilitators ran the programs in their spare time and were paid on a casual basis by Cancer Council of Victoria. The only notable exception was the Chinese Living With Cancer Education Program at the Box Hill Hospital. Spare-time work meant planning was difficult. It also adversely affected promotion and recruitment of participants. Additionally, it meant that the programs did not benefit from ongoing input and evaluations were done “on the run”. This may result in programs becoming staid and not reflecting their community’s changing needs.
- f) Each program relied on guest speakers volunteering their time. This works in a hospital and community health centre where staff give their time to the program during working hours. However, the Non English Speaking Background programs require that guest speakers come after work. In some cases, health professionals had to absent themselves from their private practices and consequently lose income. Within each community setting, the availability of health professionals was variable. For example, there were no Polish or Spanish speaking oncologists available, while Greek speaking dietitians were hard to find. It may be necessary to pay for interpreters if English-speaking guest speakers are to be used in the future.
- g) All programs suffered from a lack of resources in the relevant language, in comparison to the amount of material available in English.

### **Common contributors to Sustainability**

1. All the facilitators contributed both their enthusiasm and commitment to the programs. They considered that they were providing a service to family, friends and their community in providing support to deal with this difficult condition.
2. All the programs contributed to the common aim of providing access to Non English Speaking Background people to the Living With Cancer Education Programs.
3. The programs went beyond this aim in that they provided access to cancer information, welfare services and counselling for Non English Speaking Background people that they had missed out on from other services.
4. Some of the programs were developing innovative forms of cross-cultural evaluation. This included evaluation by third parties as well as by the participants using diaries.
5. The programs were sufficiently flexible such that changes can be made if content was not culturally suitable and/or something which is more culturally suitable needed to be added.
6. The level of knowledge of psycho-social needs of people from other cultures has been extended.
7. Facilitators, guest speakers and staff were making substantial contributions to the resources available in other languages.

8. The programs promote cancer services and cancer information in CALD communities. In turn the programs promoted the needs of CALD people with cancer to health professionals.
9. The CALD programs promoted collaborative work between organisations and health professionals.
10. The programs addressed the stigma of having cancer that still exists in some communities (Todd and Epifanio, 2000).

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