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Improving cancer outcomes among culturally and linguistically diverse communities: a rapid review of the literature

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Improving cancer outcomes among culturally and linguistically diverse communities: a rapid review of the literature

Abstract

This Evidence Check review examined the knowledge, attitudes and beliefs of Chinese, Vietnamese and Arabic speaking communities in Australia in relation to cancer, its causes, screening, treatments, perceptions of susceptibility, and perceived outcomes. The review explores fear, stigma, taboos, and the role of family, as well as the evidence of effectiveness of cancer prevention, detection and treatment interventions. There are significant gaps in the evidence base.

Keywords

rapid, literature, communities, improving, diverse, linguistically, culturally, cancer, among, outcomes, review

Disciplines

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Improving cancer outcomes among culturally and linguistically diverse communities: a rapid review

Lyn Phillipson, Karen Larsen-Truong, Sandra Jones and Leissa Pitts



an **Evidence Check** review brokered by the Sax Institute for the Cancer Institute NSW

December 2012



This rapid review was brokered by the Sax Institute.

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December 2012

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Disclaimer

This **Evidence Check** Review was produced using the **Evidence Check** methodology in response to specific questions from the commissioning agency. It is not necessarily a comprehensive review of all literature relating to the topic area. It was current at the time of production (but not necessarily at the time of publication). It is reproduced for general information and third parties rely upon it at their own risk.



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Executive Summary

People from culturally and linguistically diverse (CALD) communities face unique challenges in regard to cancer screening and early diagnosis, as well as access to appropriate treatment. In line with the NSW Cancer Plan 2011-2015, the Cancer Institute NSW (CINSW) has prioritised programs that target people from CALD communities as a strategic direction in cancer care. A key component for planning and progressing this is a greater understanding of the current evidence base regarding cancer care for people from CALD communities.

To inform the development of CINSW strategies, programs, projects and its multicultural plan, this rapid review of the CALD cancer literature was commissioned. The first objective of the review was to identify and examine the knowledge, attitudes and beliefs of Chinese, Vietnamese and Arabic speaking communities in Australia in relation to cancer, its causes, treatments, perceptions of susceptibility, and the perceived likely short and long term outcomes for those diagnosed with cancer. Secondly, current available evidence regarding the effectiveness of cancer prevention, detection and treatment interventions in the three priority communities (Chinese, Vietnamese and Arabic speaking) and in other CALD communities in Australia and OECD countries with similar healthcare settings (i.e. New Zealand, Canada, and the United Kingdom (UK)) were also reviewed. This involved assessing the effectiveness of interventions in regards to the influence on the: knowledge, attitudes or beliefs of the target communities; their cancer-related behaviours (e.g. participation in screening, quitting smoking); and/or any improvements in delivery of services or cancer care outcomes.

A review of the academic and grey literature resulted in the identification 45 papers (including 34 journal articles and 11 reports from the grey literature). Of these, 26 explored the cancer knowledge, attitudes and beliefs of priority and other CALD communities; four evaluated programs targeting cancer prevention (all tobacco related); ten papers regarding programs designed to promote the uptake of cancer screening; two studies designed to improve the effectiveness, quality or delivery of cancer care services to people from CALD communities; and one study which reported results from formative research regarding a palliative care intervention.

Cancer knowledge, attitudes and beliefs of CALD priority communities

In regards to the knowledge, attitudes and beliefs of the priority communities, 19 of the 26 studies identified were conducted within Chinese speaking communities. Results underscored the presence of beliefs and faith in both Western and traditional medicine, with the latter particularly strong for the older generations. A sense of fatalism about cancer and illness and some shame and stigma associated with cancer was evident in those community members surveyed. This was to some degree informed by religious (Buddhist) concepts of karma, and also by Chinese beliefs concerning energy (ying/yang) and a cyclical view of life. Participation in screening was not a natural extension of views, also informed by fatalism and physical sensations. Similar views were evident within the Vietnamese community, though these conclusions rely on a smaller body of literature (three papers only). Only a single study (two papers) exclusively focused on cancer knowledge and attitudes within Arabic speaking communities. Within this, the presence of stigma, fear and shame surrounding a diagnosis of cancer was also identified, but also some knowledge in regards to personal and family health history as important in understanding cancer risk and susceptibility.

In both the Chinese and Vietnamese speaking communities, the role of the family was central to participation in and experience of cancer treatment. For some, issues concerning poor

communication lead to a preference for being treated by staff from a similar cultural background and to the family playing a central role in the treatment process. Taboos and beliefs around death and dying in the Chinese and Vietnamese communities also highlighted the importance of language (there are no words for palliative or hospice in Chinese) and models of care that incorporate cultural beliefs, understandings and preferences.

Overall, further research is required to gain further insight into the cancer-related knowledge, attitudes and beliefs of particularly the Vietnamese and Arabic speaking communities throughout the cancer care continuum. Whilst cancer beliefs and attitudes were described within the included studies, few measured the strength of any association between knowledge or beliefs and the use of cancer screening or treatment services. As such, the evidence of an association between knowledge, beliefs and actual help-seeking behaviours is relatively low.

Cancer prevention, screening, treatment and palliative care interventions in priority CALD communities

In regards to the second objective for the review, the evidence for the effectiveness of cancer-related interventions across the care continuum was very limited. All but one study was rated as low or very low quality using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) criteria, meaning that only limited confidence can be placed in the results in regards to any effects.

On the basis of the limited evidence available, in regards to cancer prevention interventions, there is some limited evidence that multi-component programs (media plus intervention and referral support) may have some effect on influencing smoking rates. In regards to cancer screening interventions the use of media alone and other passive educational strategies are likely to be ineffective. There is however some limited evidence for multi-component programs (media plus intervention and referral support) on influencing smoking rates. Multi-component interventions (incorporating both media and education); the use of personal and mail invitations; the delivery of face-to-face education with personal invitations; and the training of community cancer advocates/champions to improve engagement with cancer programs should be also further explored.

Overall, there is a need for interventions that incorporate and acknowledge both traditional and biomedical world views, targeting knowledge regarding lifestyle factors for high risk cancers and therefore challenging the associated fatalism.

In regards to programs to improve the quality and delivery of cancer care services to people from CALD communities, relationship based networks (providing practical, educational and social support) achieved high satisfaction and community support. Programs designed for mainstream non-CALD populations may also be satisfactorily adapted for use within CALD communities, but are likely to require support from bicultural workers and additional infrastructure to sustain. Overall, cancer care service providers should be seeking to develop models of care that view the patient within their family roles and structures. Equally, models of care which target the employment of bicultural health workers or seek to work in partnership with bicultural health practitioners (such as family general practitioners) should also be explored.

Recommendations

This review revealed that there are significant gaps in the evidence base required to inform programs and strategies to improve engagement by cancer services with CALD communities and ultimately their cancer outcomes. Overall, we recommend that what is required is a

systematic approach to applying the established principles of good multicultural health practice to the funding and support of research, program implementation and program evaluation with CALD communities across the cancer care continuum. The specific recommendations below have been made in order of priority to guide actions in response to the review.

- The establishment of expert consensus to guide current best practice in engaging with CALD communities – due to the limited published literature currently available to guide evidence-based cancer programs with CALD communities there may be value in the facilitation of a process to gain expert consensus in regards to current best practice principles and strategies
- The independent rigorous evaluation of current funded CALD focused programs and strategies – funding should be directed towards independent and rigorous evaluation of current large and small scale screening and treatment programs focused on CALD populations
- The establishment of new research paradigms inclusive of CALD communities this will require a commitment to the development of new research paradigms that engage communities via following established multicultural engagement principles to increase CALD participation in research itself
- Further research to establish the significance of cancer knowledge, attitudes and beliefs
 to cancer outcomes. Importantly, this research should be culturally and cancer specific.
 There is also a need for more rigorous research designs (e.g. randomised controlled trials,
 or well-designed observational studies that yield extremely large and consistent estimates
 of the magnitude of an intervention effect) to better determine the effectiveness of
 these interventions
- The development of models and approaches that apply community insights gained from research conducted with members of CALD groups should be utilised to inform the conduct of culturally appropriate interventions and programs.

1 Introduction

People from culturally and linguistically diverse (CALD) communities face unique challenges in regard to cancer screening and early diagnosis, as well as access to appropriate treatment. Among the most obvious challenges are language barriers and lack of familiarity with the Australian health system.^{1,2} In addition, many people from CALD communities hold attitudes and beliefs about cancer which may influence trust in health professionals and health systems [3]. Migrants have also reported that health professionals do not understand them, which may adversely affect their psychological and physical wellbeing.⁴

In line with the NSW Cancer Plan 2011–2015, the Cancer Institute NSW has prioritised programs that target improving cancer outcomes for people from CALD communities as a strategic direction in cancer care. A key component for planning and progressing this is a greater understanding of the current evidence base regarding cancer care for people from CALD communities.

The Present Review

The purpose of this rapid review is to review evidence that is currently available regarding cancer prevention, detection and treatment in CALD communities. This involves addressing five main questions:

Question 1: Knowledge, attitudes and beliefs

What are the knowledge, attitudes or beliefs of people living in CALD communities in Australia in relation to:

- The nature of cancer (what it is)
- The causes of cancer
- Their susceptibility to (or risk-factors for) cancer
- Cancer prevention and screening programs
- The likely short and long term outcomes for those diagnosed with cancer and
- The treatment of cancer.

Question 2: Cancer prevention models

What models, programs or interventions have been effective in reducing the risks associated with cancer in CALD communities – including tobacco use, alcohol use, fruit and vegetable consumption, physical activity, overweight and obesity, human papillomavirus infection and hepatitis B?

Question 3: Models of early detection and screening

What models or programs undertaken in CALD communities have been effective in promoting the benefits of early detection of cancer and increasing the uptake of cancer screening services

or practices? What factors are related to successfully implementing early cancer detection and cancer screening programs in CALD communities?

Question 4: Models of cancer servcies

What models or programs have been effective in improving the quality and delivery of cancer care services to people from CALD communities? How have these programs improved the experiences and health outcomes of cancer patients from CALD backgrounds?

Question 5: Models of palliative care services

What models or programs have been effective in improving the quality and delivery of palliative care services to cancer patients from CALD backgrounds? How has the experience of cancer patients from CALD backgrounds improved as a result of these programs?

2 Method

In order to address Question 1 we reviewed academic literature and grey literature to identify CALD specific formative research on knowledge, attitudes and beliefs in the Chinese, Vietnamese and Arabic speaking communities (the communities identified as the focus of the review in the proposal). The methodology utilised for the literature search is outlined below.

1. Academic Literature

A search of relevant academic literature published between 1990 and 2012 was conducted in the search engines Web of Knowledge (encompasses Web of Science and Medline), Cochrane, Scopus, and Psycinfo using the following key words:

- cancer
- AND
- aware* OR attitude* OR belief* or knowledge OR prevent* OR treatment* OR program*
- AND
- Chinese OR Vietnamese OR Arabic.

Due to a paucity of available literature to answer Questions 2 to 5, the search was expanded to include other CALD groups but still restricted to studies conducted within Australia, the UK, Canada or New Zealand. The same databases were searched using the following key words:

- cancer
- AND
- aware* OR prevent* OR treatment* OR care*
- AND
- Migrant* or refugee OR 'non-English' or ethnic* or 'culturally diverse'.

The reference lists of identified articles were scanned for any additional relevant publications that were not identified through the review.

2. Grey Literature

The following websites from Australia, New Zealand, the UK, and Canada were searched for relevant literature:

- Australian Department of Health and Ageing
- Australian state government health departments (e.g. NSW Health, Health Victoria, SA Health, WA Health, NT Health, QLD Health)
- Cancer Institute NSW
- Cancer Council NSW
- National Health Service (NHS) UK
- Cancer Research UK
- Canada Health
- Canadian Cancer Society
- NZ Ministry of Health.

A Google search was also conducted using the same search terms as the academic literature search in an attempt to identify other relevant publications. We also searched the database of the library of the Centre for Culture, Ethnicity and Health

(http://www.ceh.org.au/resources/ceh library.asp) which holds a collection focused on health and health service delivery in relation to culturally diverse communities, including project reports.

Identified publications were reviewed to derive information on:

- The characteristics of the research/intervention (e.g. description of the intervention, formative research, target groups, communication strategy, theoretical framework)
- The evidence of the effectiveness of these interventions
- An assessment of the quality of evidence for these interventions
- Factors influencing the success of these interventions (e.g. barriers and enablers).

Methods for assessing the quality of evidence

One of the aims of this rapid review was to assess the quality of evidence regarding the effectiveness of cancer interventions and programs in CALD communities. In this review, the quality of data used to evaluate these interventions was determined using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) guidelines.⁵ This is a system for rating the quality of evidence for published articles that are included in systematic reviews.

More detail on this rating system is provided in Appendix A. However, in brief, this is a rating system that assesses the quality of evidence from observational studies and randomised controlled trials (RCTs) against a number of criteria (e.g. study design, imprecision, bias). Use of this rating system generates a quality of evidence score for a given study ranging from 'very low quality' to 'high quality'. The four quality levels are described briefly below:

- High quality: Very confident that the estimated effects are close to the true effects
- Moderate quality: Moderately confident that the estimated effects are close to the true effects
- Low quality: There is only limited confidence in the estimated effect.
- Very low quality: There is very little confidence in the estimated effect.

3 Results

The combined searches identified a total of 45 papers (including 34 journal articles and 11 reports from the grey literature). Overall, the literature was limited in scope, size and quality – consisting mainly of qualitative, observation or quasi experimental studies. The GRADE Quality Rating Criteria were utilised to evaluate the quality of intervention studies (Appendix B: Tables 2 to 5). Only one intervention received a moderate quality rating. The remaining were ranked as either low or very low quality, meaning that only limited confidence can be placed in the results in regards to any effects. In summary, the review included:

- Twenty- six studies which explored the cancer knowledge, attitudes and beliefs of CALD communities (23 journal articles, three reports)
- Four evaluated programs targeting cancer prevention all of which aimed to reduce tobacco use; two within Arabic speaking communities. And two evaluating programs targeting multiple CALD communities. Due to the limited literature on cancer prevention, three other reviews were included from the grey literature which described non-cancer specific prevention programs targeting CALD communities; two regarding physical activity and one regarding healthy eating. However, whilst all provide descriptions of programs, none provide adequate details to allow evaluation or grading or the interventions in regards to their effectiveness
- Ten papers regarding programs designed to promote the uptake of cancer screening five journal articles^{13–18} and five reports from the grey literature^{19–23}
- Two studies designed to improve the effectiveness, quality or delivery of cancer care services to people from CALD communities (both journal articles)^{24,25}
- One study which reported results from formative research regarding the potential utility of translated assessment tools to assist patient-practitioner communication during palliative care.

A summary of all articles and reports identified and included in the review can be found in Tables 1–5 in Appendix B.

Question 1: Knowledge, attitudes and beliefs

A total of 26 papers were reviewed (23 journal articles and three reports) that explored the cancer-related knowledge, attitudes or beliefs of people from the specified CALD communities, 22 from Australia and four from Canada. Details of these articles and reports can be found in Table 1 (Appendix B).

Chinese speaking communities

In relation to Chinese speaking communities in Australia, there were 11 papers which exclusively explored cancer knowledge and beliefs: two concerned hereditary cancers^{26,27}; four cancer in general (no type specified)²⁸⁻³¹; two specifically explored breast cancer and breast-screening^{32,33}; and one advanced or terminal cancer.³⁴ Two papers from Canada were also included which explored knowledge and beliefs about cervical cancer³⁵ and the other perspectives on palliative care³⁶ in Chinese speaking communities. While most studies included both Cantonese and Mandarin speaking participants born in various countries, no distinction was made between the results for these groups within the papers. As such, only general statements about Chinese communities as a whole can be made.

The nature of cancer (what it is)

The Chinese speaking community members surveyed in the literature viewed cancer as an illness or disease, associated with bad luck and characterised by some degree of fear and stigma. Fear could be fuelled by the belief that a cancer diagnosis is fatal 130,33; that talking about cancer can make it happen 26,27; and that social exclusion may result from a cancer diagnosis. For the Chinese a cancer diagnosis may also be accompanied by a sense of shame for both the patient and their family. In the studies reviewed there was an acknowledgement that traditional beliefs, which are particularly strongly held by senior members of the communities, influence cultural understandings of cancer, its causes and how it is best treated. These are outlined further in the following sections.

The causes of cancer

Amongst participants in the studies, beliefs about the causes of cancer often included a mix of both Western (biomedical) and culturally specific beliefs, myths and religious explanations. Older community members in particular appeared more likely to hold stronger traditional views about the causes of illness and cancer. In Chinese communities a belief articulated across studies was that ill-health and cancer were the result of an imbalance of the positive and negative life force (yin and yang) in the body.^{26,27} Other explanations in regards to ill-health (and cancer) among Chinese-Australians included^{27,31}:

- Karma
- Retribution
- Heaven's or God's will
- Fate or bad luck
- Geomancy (feng-shui)
- Touched evil
- Offending the gods or deities (requiring prayers and offerings)
- Kong-tau (spells invoked through human intervention).

There were some Chinese-Australians, particularly from the older generation, who believed that cancer could be contagious.^{26,27} There were also beliefs around the transmission of disease through the generations. This could be linked to the Buddhist view of karma – that misfortune or events in this life is connected to wrongdoing committed in this or a previous life.²⁶

Susceptibility to (or risk factors for) cancer

The dominant Western paradigm may not be as salient within Chinese communities.³³ For example, older Chinese women viewed the development of disease, such as cancer, as something associated with 'the unchanging cycle in the Chinese philosophy of birth, aging, sickness and death' rather than the result of behavioural or genetic risk factors.³³ The cycle is viewed as inevitable and, in terms of susceptibility to disease, every individual is expected to progress through these processes – with risk of contracting diseases (such as cancer) seen to increase with age.³³ For people from Chinese backgrounds the role of a higher power in predetermining illness and death was also important perhaps also leading to a sense that cancer is not preventable.³³

Another study also supports the proposition that behavioural/lifestyle risk factors are not highly salient, with Chinese speaking older women demonstrating low knowledge of the risk factors for cervical cancer.³⁵ However, higher knowledge was found in the younger generation²⁶, as well as those with a higher education, those who had a female general practitioner (GP) and those with a recent experience of screening.³⁵

In regards to genetic susceptibility, there was evidence of traditional beliefs that inheritance of genes was a 'retribution for ancestral misdeeds' and that natural and supernatural forces were still influential even in hereditary cancer.²⁷ Whilst some believed men and women contributed equally to genetic makeup (linked to yin-yang)²⁷, males, considered the authority in a Chinese family, were still perceived by others as a dominant force in passing down illnesses or 'shaping' of genes.^{26,27} The emphasis within these beliefs also appeared to differ between the generations, with older community members less likely to know or understand that some risk factors for cancer can be hereditary.²⁶

Awareness of/attitudes towards screening and prevention programs

Traditional Chinese beliefs were generally focused on preserving and promoting health and overall wellbeing, not detecting hidden disease by screening; thus unless one was symptomatic there was no reason to suspect disease and no reason to go looking for it.²⁹ There were also specific barriers identified in relation to breast screening including: fatalism; a low belief in efficacy of screening; and a sense that the cultural norms (outlined above) did not reinforce screening.³³ The only facilitator of cancer testing (rather than screening) identified was the recommendation of a doctor, with some suggesting they would consider genetic counselling and testing if recommended by a doctor.²⁶

Traditional approaches to prevention (apart from screening) were also identified, which included paying respects to the ancestors and making offerings to ensure good fortune and protection from ill-health for descendants.²⁷

The likely short and long term outcomes for those diagnosed with cancer

Some members of the Chinese speaking community experienced fear associated with a cancer diagnosis. As such, for some, the short term outcomes associated with a diagnosis were associated with shock, despair, uncertainty and, for some, an experience of stigma, shame and social exclusion. ^{26,30,32} In regards to longer term outcomes, community members commonly held fatalistic views about cancer, i.e. that cancer was not treatable and would eventually result in death. ^{30,33}

Knowledge of/approach to treatment

Within Chinese communities, approaches to treatment often included an integration of Western medicine and Chinese medicine, mythic and religious traditions.^{28,34} Traditional strategies employed to combat cancer included any combination of the following:

- Traditional Chinese medicine
- The consumption or avoidance of particular types of food
- Qi gong (a form of exercise)
- Fengshui (paying attention to spatial organisation)
- Worship of ancestors & gods and
- Philosophy of harmony and balance of yin and yang and qi.

Regardless of the mode of response adopted, living with cancer and negotiation of cancer treatment was usually kept within the immediate family.^{26,30} Families played a central role in liaison between patient and health professionals²⁸ and in the provision of day to day care, medical decisions, interpreting, providing transport and emotional support^[30]. Some families expressed a preference for non-disclosure of a poor prognosis to patients.²⁸ The stigma associated with cancer often meant that a cancer diagnosis was kept secret within the family in Chinese communities.^{26,30} Families also declined, or choose not to seek external help until the burden of care was no longer manageable.³⁰

Despite the incorporation of traditional beliefs, practices and family roles within their approach Chinese community members still considered the advice of doctors as very important when it came to cancer treatment.³⁴

Palliative care

In regards to 'end of life' or palliative care the Chinese do not have terms from 'palliative' or 'hospice'. More appropriate words that can be used to discuss these notions are those that convey 'care focused on comfort as one approached the end of life' and 'a place of comfort towards the end of life'. ³⁶ To speak of death and dying is often taboo. Linear models of palliative care are likely to be less understood than cyclical models focusing on harmony and balance. ³⁶

Vietnamese speaking communities

In relation to Vietnamese speaking communities three papers were identified for inclusion in the review. Two were from Australia; one explored cervical cancer screening beliefs in a survey with adult women³⁷, and the other terminal cancer and attitudes to palliative care with carers and health professionals.³⁸ A third, conducted with older Vietnamese speaking women (more than 70 years old) in Canada investigated breast and cervical cancer knowledge and beliefs.³⁹

The nature of cancer (what it is)

Similar to the Chinese communities studied, cancer was viewed in Vietnamese communities as an illness associated with an imbalance of energy and forces within the body and to some degree with bad luck.

The causes of cancer

In Vietnamese communities ill-health was perceived as being caused by an imbalance of the positive and negative life force (yin and yang). The role of a higher power in predetermining illness and death was also important.³⁹ Similar to the Chinese, Vietnamese conceptualisations of health and illness were focused on preserving and promoting health, guided by their physical sensations.³⁹ Beliefs about the causes of breast and cervical cancer also appeared to be influenced by Buddhist views of karma for wrongdoing committed in this or a previous life.³⁸ Disease and illness were also seen as possibly being caused by bacterial invasion or predetermined by a higher power.³⁹

Susceptibility to (or risk factors for) cancer

The studies provided little information in regards to perceived susceptibility to cancer.

Awareness of/attitudes towards screening and prevention programs

Cheek et al³⁷ conducted a survey to establish the factors that influenced the participation of Vietnamese speaking women in cervical or breast screening. Within this report a number of cultural factors are highlighted that acted as barriers to women attending screening. Firstly, health-seeking for women from Vietnamese cultural backgrounds, as for the Chinese, was often guided by physical sensations i.e. they would not think they had a health problem unless they experienced unusual physical discomfort. Actual screening tests were also perceived negatively and were inconsistent with cultural knowledge and values with regard to women's bodies as private; and as such breast or cervical examination may a cause of great embarrassment. Finally Cheek and colleagues^[37] also highlighted that beliefs and values concerning the doctor-patient relationship as hierarchical may leave women feeling intimidated or unwilling to ask for information or request screening, unless it is suggested or offered by the doctor. Overcoming these barriers is likely to require the active promotion of screening by GPs. Within Vietnamese communities doctors are especially held in high regard and members suggested that they would attend cancer screening on recommendation from their doctor.^{37,39}

The likely short and long term outcomes for those diagnosed with cancer

The perceived short and long term outcomes for those diagnosed with cancer from the perspective of the Vietnamese speaking community was not explored in the literature identified.

Knowledge of/approach to treatment

As for the Chinese it was common that family members act as the liaison between the patient and health professionals.^{38,40} Some families from Vietnamese communities also preferred that information regarding the patient's diagnosis and prognosis was not communicated directly with the patient.^{38,40} As with their approach to screening and cancer prevention, Vietnamese community members considered the advice of doctors as very important when it came to cancer treatment.^{34,41}

Arabic Speaking Communities

In relation to the Arabic speaking communities, only two papers from a single study were identified for inclusion in the review both concerning cancer beliefs in general.^{42,43}

The nature of cancer (what it is)

The Arabic speaking community surveyed in this report viewed cancer as an illness or disease, associated with bad luck and characterised by some degree of fear and stigma. It was perceived by many as a fatal illness (though this was less common in cancer patients than the general Arabic speaking community).^{42,43} This was evident in views expressed in regards to a desire for social avoidance of people with cancer – because it may bring bad luck. Some community members were even hesitant to talk about or use the word 'cancer'.⁴³ Having a family history of cancer may also have had an adverse impact on marriageability.⁴²

The causes of cancer

Despite the stigma, participants believed that cancer could be caused by a range of factors including genetics, lifestyle factors, stress or the influence of a higher power.⁴³

Susceptibility to (or risk factors for) cancer

Some community members reported an outdated belief was present within the community – that patrilineal inheritance (the father's genes) were stronger than the mother's in causing illness.⁴² That said all noted the importance of understanding one's family and personal health history in understanding the risk of cancer for future generations.⁴². As already mentioned the role of a higher power in predetermining illness and death was also important.⁴³

Awareness of/attitudes towards screening and prevention programs

There was not sufficient information in the papers reviewed to comment on attitudes to cancer prevention and screening programs.

The likely short and long term outcomes for those diagnosed with cancer

There was not sufficient information in the papers reviewed to comment on the likely short and long term outcomes for those diagnosed with cancer.

Knowledge of/approach to treatment

In regards to knowledge and approach to treatment of cancer, community members felt that stigma, fear and secrecy were barriers to accessing health services and some families expressed a desire for non-disclosure of diagnosis to patients.⁴³

Palliative care

There was not sufficient information in the papers reviewed to comment on knowledge and attitudes regarding palliative care.

CALD communities in general

There were eight papers included that explored the cancer knowledge and attitudes of community members from a number of CALD communities within a single study. Five of these studies concerned cancer beliefs in general: two from Australia with the Chinese Arabic and Greek communities^{4,44}; two from Canada with Chinese/South Asian⁴⁵ and Chinese, Persian, Jamaican, Dutch, Indonesian, Filipino and First nations⁴⁶; and one which reviewed the international literature.⁴⁷ Two Australian studies addressed colorectal cancer: one explored attitudes of adult men and women to bowel cancer screening⁴⁸; and one colorectal cancer beliefs among older men and women from the Greek, Iranian, Vietnamese, Indigenous and Anglo-Australian communities.⁴⁹ One study examined breast cancer screening beliefs and attitudes with Arabic, Chinese, Croatian, Greek, Italian, Macedonian, Maltese, Mandarin, Polish, Portuguese, Serbian, Spanish, Turkish and Vietnamese speaking community members in Australia.²²

While most papers explored multiple CALD communities as a whole, some defined the specific knowledge, attitudes and beliefs of the key cultural groups (Vietnamese, Chinese and Arabic). These have been reported separately below where available. Also, Javanparast et al.⁴⁹ was inclusive of some members of Indigenous Australian communities (not the focus of this review), and as such where their beliefs and attitudes were distinguished they were not reported in the results.

The nature of cancer (what it is)

In research regarding colorectal cancer, the CALD groups surveyed (Greek, Vietnamese, Iranian) appeared to hold fatalistic views about cancer that generated fears and anxiety regarding cancer diagnosis.⁴⁹

The causes of cancer

According to one study some community members in Australia (Greek, Vietnamese, Iranian and Indigenous) tended to see cancer as unpreventable.⁴⁹ For Greek and Vietnamese Australians, in particular, health and disease, life and death were seen to be in God's hands.

Susceptibility to (or risk factors for) cancer

While CALD groups tended to have a fatalistic view about cancer⁴⁹ it is unclear from this limited literature how this view translated into their sense of susceptibility to the disease.

Attitudes to cancer prevention and screening programs

From the three studies that explored this topic^{22,48,49} it appears CALD groups were less familiar with cancer screening and tended to relate more barriers to participation in prevention and screening programs than the general population.

In regards to self-administered faecal occult blood testing (FOBT) [a screening test for colorectal cancer], CALD groups (Greek, Vietnamese, Iranian and Indigenous Australians) faced barriers to participation including: a fatalistic view of cancer (won't make any difference); language barriers; low self-efficacy to perform FOBT; tests viewed as undesirable; and the importance of privacy. Another study looking at Cantonese, Vietnamese, Greek and Italian communities' opinions, attitudes and behaviours regarding FOBT found that CALD groups tended to rely heavily on their GP to conduct screening and/or advise them whether screening was necessary. Some even experienced alarm at receiving an FOBT kit in the mail and seeing the word 'cancer' without any personal explanation as to why they had received it.

Women of non-English speaking backgrounds surveyed as part of an evaluation of the 2000/2001 phase of the BreastScreen Australia Campaign were less likely than English speakers to: cite breast cancer as a health problem; rate screening as a very good idea; suggest biennial screening; perceive screening mammograms and breast self-examination, and GP examination as effective; and have been screened in the last two years. They also indicated significant barriers to mammography including: being lazy/not getting around to it; discomfort; not thought about it; not at risk; and no symptoms. However these barriers were not different to those cited by Australian or overseas born English speakers.

Motivations for those members of CALD communities who did participate in screening relied on a number of beliefs including: the belief that prevention was better than cure; moral obligation and responsibility to care for own health; and, for those few who attributed cancer to lifestyle – the belief that cancer could be prevented by lifestyle choices. Personal life experience and the social environment may also have provided motivation for some CALD community members to participate in prevention and screening programs. These included factors such as: social acceptance and encouragement to take part; desire for quality of life in old age(motivated by involvement with grandchildren and the community); family history of colorectal cancer; and perceived ease of use of screening kit, particularly when compared to colonoscopy. Reserved

Recommendations from the study conducted by the Department of Health and Ageing suggest there is a need for knowledge and awareness raising for bowel cancer and for FOBT testing prior to the kits being distributed; translation of promotional and kit materials and components; support from GPs and health workers to encourage and conduct FOBT screening; use of ethnic media to create awareness of program in language and broadly in the community; and utilising community organisations for discussion and awareness raising.⁴⁸

Knowledge of and approach to treatment of cancer

Whilst there was some respect for Western medicine, knowledge, attitudes and beliefs within CALD groups regarding cancer treatment, their approach to treatment was also strongly informed by culturally specific beliefs and behaviours. These included⁴⁷:

- Family function
- Sex roles
- Language
- Disclosure of information
- Pain
- Attitudes towards illness and health practices
- Immigration
- Religion
- Autonomy/dependency
- Death
- Bereavement.

For many CALD groups it was common that family members acted as the liaison between the patient and health professionals. Chinese (Mandarin and Cantonese) and South Asian (Hindi, Punjabi, Urdu) parents were sometimes uncomfortable with healthcare providers communicating

sensitive health-related information directly with their child^[50]. This was also true of Chinese, Arabic and Greek adult patients where families often choose to meet with health professionals separately from the patient in order to direct what information was shared with the patient and how this would occur.⁴⁴ This resulted in some patients assuming a passive sick role, especially within Chinese communities.⁴¹ However, despite this common practice some studies with cancer patients from CALD communities suggested that non-disclosure of diagnosis or prognosis was not always the wish of the patient themselves.^{44,46}

Participation by CALD communities in cancer treatment delivered by health services was often marred by language and communication difficulties. Research with Chinese, Arabic and Greek Australians, highlighted some of the most significant implications of these difficulties for cancer treatment.⁴ They included:

- Difficulties understanding verbal and written information; the implications of which included missed appointments, non-adherence to treatment or clinic procedures and poor self-care
- A sense of cultural isolation and the distress of being misunderstood, which often lead to wanting to be treated by 'one of their own' and travelling long distances to accomplish this
- Being treated differently (whether actual or perceived); some patients from CALD backgrounds felt they had received inferior care and less information
- Lack of skill with English language which resulted in being unable to advocate on their own behalf, difficulty forming a relationship with care providers and building trust.

Chinese and South Asian parents of a child with cancer in Canada reported similar challenges which serves to heighten systemic and socio-cultural barriers to accessing health information and resources. 45,50 More specifically language barriers influenced parents' role in caring for their child such that they did not always see themselves as a member of the healthcare team or able to participate in discussions. Some parents reported that they had missed out on services and resources because they weren't able to communicate effectively with the healthcare team. Language barriers also made it difficult to learn complex medical terminology, a source of significant confusion and frustration.

Palliative care

Attitudes to palliative care were explored in a report by the Migrant Information Centre (Eastern Melbourne)^[41]. The report profiles a range of different groups including Chinese and Vietnamese attitudes.

In general the Chinese had negative emotions towards hospitalisation, residential and hospice care and older generations were uncomfortable with health professionals in the home, thus reinforcing the importance of family in end of life care.⁴¹

In Vietnamese communities whilst the doctor's authority was never questioned, the role of the family was always central to the delivery of palliative care. The family played a strong role in communication and decision making, and most often requested that information be given to them rather than directly to the patient. While hospitalisation was acceptable it was considered to cause bad luck for the family if the patient did not die at home. For this reason and others Vietnamese Australians' appeared more open than the Chinese to health professionals in the home, particularly if they were sent by their doctor.⁴¹

Question 2: Cancer prevention models

What models, programs or interventions have been effective in reducing the risks associated with cancer in CALD communities – including tobacco use, alcohol use, fruit and vegetable consumption, physical activity, overweight and obesity, human papillomavirus infection and hepatitis B?

In regards to cancer prevention programs or interventions the searches conducted identified only four relevant programs - all aimed at reducing tobacco use in CALD communities.⁶⁻⁹ There were no identified 'cancer prevention' programs targeting fruit and vegetable consumption, physical activity, overweight and obesity, human papillomavirus infection or hepatitis B. Due to the lack of cancer specific programs, three relevant reports were also analysed from the grey literature: two reviews of Australian physical activity programs which were inclusive of CALD programs^{10,11}; and one review of generic healthy eating programs targeting vulnerable communities in Australia, also inclusive of CALD programs ^[e.g.12]. Details of these articles and reports can be found in Table 2 (Appendix B).

Tobacco use

Two of the programs targeting tobacco use were conducted within Arabic speaking communities in NSW.^{6,7} Strategies utilised in these interventions included: smoking cessation sessions (x6) facilitated via the telephone with trained bilingual counsellors⁶; and a multi-component social marketing campaign incorporating mass media, brief intervention and referral services and training of bilingual community educators.⁷ Despite high acceptance of the service there were no significant differences in smoking abstinence or intentions to quit for the telephone counselling intervention.⁶ However, the multi-component social marketing campaign demonstrated high exposure and recall of campaign messages and a significant decline in self-reported smoking rates.⁷

The National Tobacco Campaign⁸ also targeted a range of CALD communities with known high prevalence of tobacco smoking – including Arabic, Cantonese, Korean, Mandarin, Pacific Islanders, Spanish and Vietnamese – utilising mass media. Self-report evaluation suggested that exposure to the campaign messages contributed to quitting behaviour in 28% of recent quitters and encouragement of friends and family to quit (20%). Finally the multiple component QUIT program in Victoria also sought to encourage smoking cessation in various migrant and refugee communities.⁹ Strategies in this program included: e-newsletters; ethnic media campaigns; development of ethno-specific resources; scholarships for bilingual QUIT educators; targeted recruitment of bilingual staff; CALD information sessions; and CALD Community Support Grants. However, there was insufficient published evaluation data regarding the impact of these strategies to judge their effectiveness of the program in relation to smoking cessation or preventing cancer.

Physical activity

The search identified no interventions targeting CALD groups and physical activity as cancer prevention interventions. In the absence of any 'anti-cancer' interventions, two reviews inclusive of CALD physical activity programs were included in the review. 10,11 These identified four Australian health promotion programs aimed at increasing physical activity in CALD communities: (1) intervention for Italo-Australians; (2) a project with migrants from Croatia – 'Get up, have a go, and be active'; (3) a collaboration with TAFE to train bilingual, bicultural fitness leaders to run classes for older, non-English speaking people conducted in South Eastern Sydney; and (4) a 12-week quasi-experimental physical activity and nutrition intervention in the Hunter region (NSW) with women from Polish, Dutch, Greek and Macedonian backgrounds. Whilst the fourth program was evaluated – and reported a decreases in body mass index and blood pressure, as well as

improved fitness in the intervention group^{51,52} – none of the individual reports for the other interventions are publically available. Overall, the report's authors^{10,11} conclude that the limited studies available are all relatively small, with short intervention and follow-up periods, and thus insufficient to draw conclusions form in regards to effectiveness. That said, the reviewers conclude that adherence and maintenance seemed best in those programs that were conducted by bilingual community educators in culturally appropriate and accessible venues, such as local church halls, and where there was strong community support for the initiative.

Fruit and vegetable consumption

The search identified no interventions targeting CALD groups and fruit and vegetable consumption as 'cancer prevention' programs. In the absence of any relevant literature meeting the inclusion criteria, a review of generic healthy eating programs targeting CALD communities in Australia was identified in the grey literature¹² and was included to provide some examples of current practice. Programs identified in this review included:

- Ethnic meals delivered to elderly migrant groups (My Mother Cooked this for Me, Preston)
 which operated within mainstream meal services, but experienced challenges in relation to cost, authenticity, and delivery
- The Recreation and Nutrition Program physical activity sessions, health information and a support group three times per week for 12 months for elderly women from an Eastern European background which achieved the participation of a total of 29 women with an average of 12 women at each session
- Healthy Eating Activity/Story Books which promoted healthy eating messages to preschoolchildren of parents of Arabic, Chinese, Vietnamese, Croatian and Serbian background. These were popular with services and community members but were not evaluated in any other way
- A diabetes prevention program developed on the basis of a needs assessment about cultural issues related to diabetes (Culturally Appropriate Diabetes Prevention and Management for the Vietnamese Community Footscray)
- Healthy Food for a Healthy Family, New South Wales which targeted Arabic families in central Sydney to improve their cardiovascular disease risk profile – included media, point of sale promotions in shopping centres, recipe distribution, supermarket tours, a telephone info line and education for GPs. This program achieved some improvements in knowledge and attitudes in line with campaign messages. Recipes and taste testing were the most popular strategies with community members
- Food and Nutrition Project for Recent Arrivals from Refugee Backgrounds targeted Australia's newest arrivals during their settlement phase by promoting the role of diet of lifestyle in health, including the importance of maintaining traditional diets.

Overall, these reports provided only a description of programs and strategies (or at best very limited qualitative evaluation of programs). As such they cannot be utilised to draw any conclusions regarding their effectiveness in changing diet or eating habits, or reducing the risks associated with cancer in CALD communities.

Question 3: Models of early detection and screening

What models or programs undertaken in CALD communities have been effective in promoting the benefits of early detection of cancer and increasing the uptake of cancer screening services or practices? What factors are related to successfully implementing early cancer detection and cancer screening programs in CALD communities?

The literature search identified five studies (academic journal articles)¹³⁻¹⁸ and four reports from the grey literature^{19-21,23} describing evaluated interventions designed to promote the uptake of cancer screening in CALD communities. Details of these articles and reports can be found in Table 3 (Appendix B).

Six of the interventions promoted and evaluated uptake of cervical screening. These included: two in Vietnamese communities^{16,19}; one in Macedonian and Spanish communities¹⁹; one targeting Arabic, Cantonese, Mandarin, Greek, and Italian²³; one in 'Asian' communities^[13]; and one targeting Arabic, Chinese, Croatian, Greek, Italian, Macedonian, Serbian, Polish, Spanish, Turkish, and Vietnamese.¹⁵ Only one study utilised a randomised control design^[16], and two utilised quasi-experimental designs.^{13,15}

McAvoy and Raza¹³ compared the effectiveness of three methods of providing health education to promote cervical testing in communities in the UK (including people from Commonwealth countries, Pakistan, Bangladesh and East Africa). Intervention groups received either: written materials by post; written materials by personal visit; video material by personal visit; compared to a no intervention (control) group. Only descriptive analyses were conducted; however, it appeared that information delivered by personal visit (written or video) was the most effective in promoting uptake of screening (by 26% and 30% respectively) in the target communities.

Mitchell¹⁵ found that a media campaign (including radio, newspaper and quizzes with prizes on radio) was effective at increasing screening rates in neighbourhoods with high non-English speaking background (NESB) populations in Victoria. However, a multi-component social marketing campaign which included media (TV, radio, print) and community and peer education activities delivered by PapScreen Victoria achieved an increase in awareness of Pap tests but no change in screening rates in the Vietnamese²⁰, Macedonian or Spanish communities.²⁰ In 2005, PapScreen Victoria implemented another multicultural radio and print media campaign, with Vietnamese and Chinese among the target audiences, which also had little success in achieving significant increases in Pap test rates.²³

DelMar and colleagues¹⁶ evaluated the success of a media campaign and personalised letters to increase cervical screening rates in Vietnamese women, aged between 18 and 67 years in Brisbane. While all were potentially exposed to the media campaign delivered in Vietnamese through Vietnamese newspapers and radio, 689 women were randomised from the electoral roll to a group who received a personalised letter about cervical screening in Vietnamese or a control group. Assessment of screening records showed that there was no significant difference between the intervention and control groups.

Three interventions were identified that promoted breast screening. One of these interventions was conducted within the Chinese (Cantonese speaking) community in Sydney. ^{17,18} The program trained 'breast health advocates' or champions from within the community in breast awareness and communication skills, with the aim of encouraging these women to promote discussion about breast health and screening within their communities. Whilst the strategy showed high satisfaction with those who trained to be advocates and an ability to improve knowledge and attitudes in the advocates, the evaluation was not adequate to draw any conclusions about the effectiveness of the intervention in increasing screening rates.

Two breast screening interventions were also reviewed that targeted people from a broad range of NESB. 14,22 Turnbull et al. 14 conducted a RCT examining the effectiveness of mailed invitations to promote screening at a mobile Breast X-ray Program run by a local Area Health Service in NSW. Results suggest that a mailed invitation from the health service was more effective at promoting screening attendance for women than no invitation (control group) (p<0.0001) and that the intervention was as effective in promoting screening in women from NESB backgrounds as from English speaking backgrounds in the neighbourhood (X²=0.16, df=1, p=0.7). Finally, the NESB component of the BreastScreen Australia Campaign which included media (ethnic radio) and passive distribution of translated educational materials via libraries was ineffective at influencing knowledge, attitudes, intentions to screen in NESB women 50-69 years. 22

Question 4: Models of cancer care services

What models or programs have been effective in improving the quality and delivery of cancer care services to people from CALD communities? How have these programs improved the experiences and health outcomes of cancer patients from CALD backgrounds?

Only two journal articles were identified that met the inclusion criteria and reviewed interventions designed to improve the effectiveness, quality or delivery of cancer care services to people from CALD communities. These were both case studies, one which described the development of the Chinese Cancer Society in Victoria (Australia)²⁴ and the other the development and adaption of the 'Living with Cancer Education Program'²⁵ to meet the needs of members of the Greek and Italian communities in Victoria.

Since its initiation, the volunteer-run Chinese Cancer Society Network has evolved to provide accredited support groups, support and education services provided by trained volunteers (hospital visits, telephone support, counselling, practical assistance), fund raising, recreational and social events, a quarterly newsletter containing community member stories, a library of Chinese language resources, short courses (Tai Chi and art) and community education sessions. However, despite this impressive array of activities, only narrative evidence of the impacts of the society (in regards to improvements in social networks and support; the ability of people to talk about and deal with grief and loss; raised awareness of cancer and associated issues; decreased stigma; and overall increased community awareness and discussion) is reported.²⁴

The 'Living with Cancer Education Program', adapted for the Greek and Italian communities, provided a case study of the development and evolution of program strategies (8-week patient program; accredited training of facilitators; quality improvement activities and the introduction of dedicated NESB staff to improve the sustainability of the program). However, the evaluation provided only qualitative feedback in regards to participant reports of improved understandings of cancer and improved support.

Question 5: Models of palliative care services

What models or programs have been effective in improving the quality and delivery of palliative care services to cancer patients from CALD backgrounds? How has the experience of cancer patients from CALD backgrounds improved as a result of these programs?

The search identified only one relevant journal article or report regarding palliative care. Feser and Bon Bernard³⁶ conducted formative research regarding the utility of translated resources to improve the quality and delivery of palliative care to cancer patients from CALD backgrounds.

The paper provided results from a cross-sectional survey which sought the opinions of elderly Chinese patients (n=23) in Canada regarding the usefulness of translated palliative care assessment and educational tools and brochures. These included those frequently utilised within the Calgary health service: The Calgary Interagency Pain Assessment Tool (CIPAT), Edmonton Symptom Assessment Scale (ESAS), and a Palliative Care Services brochure. The evaluation of the resources was conducted by cross-sectional survey. Overall 62.5% believed the CIPAT would help them to communicate about pain to a healthcare professional who did not speak the same language. However, less than half (44.4%) found the questions easy to understand. The ESAS was perceived as easier to understand (66.6%). The palliative care brochures were also perceived as difficult to understand by almost half of those surveyed (45%). Despite this 42.8% thought the information gave them a better understanding of the palliative care service. Despite some degree of acceptability of the resources and perceptions that they may improve communication and understanding, the resources were not tested as part of an intervention with cancer patients and as such their utility to improve the quality and delivery of palliative care to Chinese cancer patients is not known.

4 Discussion

Overall, the literature identified was limited in scope, size and quality – consisting of mainly qualitative, observation or quasi-experimental studies. As such the ability to draw conclusions regarding effective models of prevention, screening and care to improve cancer outcomes for CALD communities is extremely limited.

Knowledge, attitudes and beliefs across the cancer care continuum

Nineteen of the 26 relevant studies explored cancer knowledge attitudes and beliefs of Chinese speaking populations. Results underscore the presence of beliefs and faith in both Western and traditional medicine, with the latter particularly strong for the older generations. A sense of fatalism about cancer and illness was evident in those community members surveyed. This was to some degree informed by religious (Buddhist) concepts of karma, and also by Chinese beliefs concerning energy (ying/yang) and a cyclical view of life. Participation in screening was not a natural extension of views, also informed by fatalism and physical sensations.

Numerous barriers to screening in the Chinese populations were reported including fear, shame and low awareness. Misunderstandings also in regards to the role of genetics and the dominance of the paternal line may also be potentially significant to screening behaviours (and may differ from the non-CALD population who for breast cancer at least see the mother's history as most significant).⁵³ In non-CALD populations there is a substantial body of research that the greater a woman's perceived risk, the more likely she is to comply with screening recommendations. For example, in their survey of 3,000 Australian women Jones et al.⁵³ found that among the 28% who perceived themselves to be at lower risk than average for breast cancer, the primary driver of their perception was the absence of a family history.⁵³ However, the significance of perceived risk on women as a driver of mammography is yet to be established in the priority CALD communities of this report.

Within the Vietnamese community similar themes in regards to illness being associated with an imbalance of energy and life forces, karma and higher powers were evident. Hierarchy and limited power in the context of doctor-patient relationships for females was also highlighted as a barrier to requesting screening, and the roles of the family and communication as important throughout the cancer care continuum. However, fewer studies have been conducted and further research with these communities would be beneficial.

There were only two papers from a single study exclusively conducted with the Arabic community. Whilst this study suggests the presence of stigma, fear and shame surrounding a diagnosis of cancer, there was some evidence of knowledge in regards to personal and family health history as important in understanding cancer risk and susceptibility. Further research is required to inform engagement and interventions with these communities throughout the cancer care continuum.

For other CALD communities surveyed screening was also not a behaviour that was prioritised. As for the Chinese and Vietnamese, for those who did participate the role of the doctor or health worker was important in both promoting and administering screening test. Self-administered kits for colorectal cancer were not favoured, caused alarm for some and were unlikely to be administered unless instructed and supported by a doctor.

Language and communication issues also impacted on the participation of CALD communities and the outcomes they associated with cancer treatment. For some, issues concerning poor communication lead to a preference for being treated by staff from a similar cultural background and to the family playing a central role in the treatment process.

Only two studies reported on beliefs and attitudes in regards to palliative/end of life care - an important part of the cancer care continuum^[36, 41]. These reports highlighted the taboos around death and dying in the Chinese and Vietnamese communities, and also the importance of inclusive language and models of care that incorporate cultural beliefs, understandings and preferences.

Finally, whilst cancer beliefs and attitudes were described within the included studies, few measured the strength of any association between knowledge or beliefs and the use of cancer screening or treatment services. As such the evidence of an association between knowledge, beliefs and actual help-seeking behaviours is relatively low. That said the consistent reporting across studies, particularly in the Chinese population, suggests that in the minds of participants and researchers these beliefs are important and should be further investigated in future research, as well as utilised to inform the conduct of culturally appropriate interventions and programs.

Cancer Prevention

In regards to cancer prevention models for CALD communities there is some limited evidence that multi-component programs (media plus intervention and referral support)may have some effect on influencing smoking rates. In regards to other prevention programs there was insufficient evidence available to draw any conclusions about effective models of engagement. Evidence from the research with CALD communities reviewed for this report indicates the need for interventions that incorporate and acknowledge both traditional and biomedical world views and the role they may play in determining cancer related behaviours. In light of this, there appears a significant need for interventions that can improve CALD community knowledge regarding lifestyle factors for high risk cancers and therefore challenge the associated fatalism.

Early detection of cancer and increasing the uptake of cancer screening services

Due to the limitations in both the scope and quality of the available literature it is not possible to draw any strong conclusions in regards to models or programs to promote early detection and/or uptake of screening services or practices. However, according to the limited evidence available, the effectiveness of multi-component interventions (incorporating both media and other education), the use of personal and mail invitations, and the delivery of face-to-face education and personal invitations hold promise and should be further explored. The training of community cancer advocates/champions showed high acceptability^{17,18} and therefore should be also further explored. On the other hand the use of media alone and other passive distribution of translated materials are likely to be ineffective. 19, 20, 23

The use of formative research with community groups and cultural insights should be more explicit to ensure cultural relevance in interventions to promote screening in CALD communities. From the research reviewed for this report, there is a need for programs which improve CALD communities' knowledge of signs and symptoms and the efficacy of screening programs to improve cancer-related outcomes. Such interventions could engage with both ethno-specific and Western beliefs, to challenge the fatalism associated with cancer and improve the perceived status and importance of screening within CALD communities. For many cancer is also associated with shame, stigma and an experience (or at least an expectation) of social exclusion. Thus interventions which address fatalism and aspects of the view that cancer is 'curse' or 'punishment' (and thus experienced by the those of discreditable character) may also go some way to addressing cancer-related stigma.⁵⁴

Alternatively programs designed to promote screening could explore ways to make positive links within cultural worldviews and aim to position screening as a positive and virtuous act, associated with positive energy or values of personal responsibility.

Models or programs to improve the quality and delivery of cancer care services to people from CALD communities

The lack of high quality evaluation makes it difficult to draw any firm conclusions in regards to models or programs that have been effective or would be effective in improving the quality and delivery of cancer care services to people from CALD communities. That said relationship based networks which provide practical, educational and social support achieved high satisfaction and community support.²⁴ It would also appear that programs designed for non-CALD populations may be satisfactorily adapted for use within CALD communities, but may require additional support and infrastructure of bicultural workers to sustain.²⁵

In response to the community research reviewed, cancer care service providers should be seeking to develop models of care that view the patient within their family roles and structure. Equally models of care which identify or target the employment of bicultural health workers, or seek to work in partnership with bicultural health practitioners (such as family GPs) could also be explored.

One systematic review of US based interventions (not included in the review) suggests that patient navigation and decision making aides may also be useful to improve the participation of women with cancer and their communication with health professionals.⁵⁵ However, further research would be needed within Australia or other countries with similar healthcare systems (e.g. UK, New Zealand, Canada) to confirm the impact of such interventions within these distinctly different health systems.

Palliative Care

Unfortunately there were no evaluated interventions with CALD communities to improve the quality and delivery of palliative care outcomes. Formative research conducted³⁶ suggests the potential usefulness of translated pain and symptom assessment scales to improve communication between health professionals and older Chinese patients. However, whilst the tools appeared to have some perceived value – they were not tested as part of an intervention with cancer patients and as such further research is required to determine their utility.

Summary of Barriers and Potential Enablers

Barriers

- Fatalism informed by religious (Buddhist) concepts of karma, and by (Chinese) beliefs concerning energy (ying/yang)
- A cyclical view of life
- Fear, shame and stigma associated with cancer
- Taboos surrounding death and dying
- Low awareness of the need and benefits of screening
- Misunderstandings in regards to cancer causes
- Hierarchy and limited power in the context of doctor-patient
- Poor communication between care providers, patients and family

Potential Enablers

Doctors or health workers promoting and administering screening tests

- Involvement of staff from similar cultural background
- Taking an approach to care planning and communication that is inclusive of family members
- Multi-component interventions (media plus referral and support to services)
- Multi-component interventions (media plus education)
- Use of personal invitations to promote screening
- The training and support of community members as cancer care advocates/champions
- Relationship based cancer networks (providing support, advice and education)
- Application of cultural insights to tailor mainstream programs
- Partnerships with bicultural health workers
- Use of translated pain and symptom assessment scales to improve communication within palliative care

Identified gaps in the literature

- Prospective studies which measure the association between particular cultural cancer beliefs and cancer-related behaviours to determine the extent and significance of these to cancer-related behaviours (from prevention to screening to treatment and palliative care)
- Studies which utilise rigorous research designs (e.g. RCTs or well-designed observational studies that yield large and consistent estimates of the magnitude of an intervention effect) to better determine the effectiveness of interventions which attempt to address knowledge and attitudes to improve cancer-related behaviours
- Studies which explicitly apply multicultural health principles of participation and recognise cultural needs
- Models of care that are inclusive of needs and that incorporate cultural beliefs, understandings and preferences. For example, models of screening that are inclusive of cultural needs and that incorporate cultural beliefs, understandings and preference such as:
 - o challenging fatalism
 - o addressing stigma and shame
 - o addressing poor outcome expectancies
 - $\hbox{$\circ$} \quad \hbox{positioning and promoting screening within the cultural worldview}. \\$

5 Overall Recommendations

This review revealed that there are significant gaps in the evidence base required to inform programs and strategies to improve engagement with CALD communities and ultimately their cancer outcomes. Overall, we recommend that what is required is a systematic approach to applying the established principles of good multicultural health practice to the funding and support of research, program implementation and program evaluation with CALD communities across the cancer care continuum. The specific recommendations below have been made in order of priority to guide actions in response to the review.

The establishment of expert consensus to guide current best practice in engaging with CALD communities

Due to the limited published literature currently available to guide evidence-based cancer programs with CALD communities there may be value in the facilitation of a process to gain expert consensus in regards to current best practice principles and strategies.

Whilst the research intervention literature was of limited use, current policy and practice within the Australian context suggests the engagement of CALD consumers should be underpinned by agreed multicultural health principles of participation, as well as the rights of individuals to access to appropriate health information and quality health services that recognise their cultural needs. ⁵⁶ Whilst not consistently emphasised in the cancer research literature reviewed in this report, the participation of CALD communities can be approached utilising an array of strategies – depending on the context and purpose of the engagement. ⁵⁷ Current Australian practice and policy statements focus on ways to gain participation throughout all stages of a program (from planning, to implementation and evaluation) ⁵⁷ and also emphasise the importance of building trust, capacity and showing respect. ⁵⁸ Examples of participation strategies include ⁵⁷:

- Participation on management boards, project reference and steering groups
- Planning/consultation days⁵⁷
- Consumer Advisory groups⁵⁷
- Focus groups⁵⁷
- Provision of information sessions and educational materials.⁵⁷

Important issues for health organisations to consider include:

- Engaging communities early in the planning process^{57,58}
- Gaining effective representation⁵⁷
- Commitment to the language needs of consumers planning for and use of translation and interpreter services^{57,58}
- The degree to which communities are given ownership⁵⁷
- The use of culturally appropriate venues and promotional channels⁵⁷
- The need for support, resources, education and mentoring to facilitate participation and improve knowledge and awareness^{57,58}
- The importance of pilot testing project and evaluation materials for cultural appropriateness and relevance⁵⁷
- The importance of providing feedback to communities regarding research and program outcomes^{57,58}

• The need to build cultural competency and overcome systemic and organisation barriers within health services.^{58 59} According to the NHMRC (2006) health organisations should place CALD communities at the centre of their approach, including: community engagement; data collection and research; training and practice standards; and professional development - prioritising partnerships with ethnic communities and working together to develop culturally appropriate service delivery that is effective and sustainable.

Proposed outcomes from improved CALD participation include:

- Organisations are more likely to be responsive to the needs of communities and develop more effective programs, policies and services⁵⁷⁻⁵⁹
- Individuals and communities are better informed about programs and services^{57,58}
- Communities are strengthened and services are delivered more effectively and equitably.⁵⁸

However, it is important to note that whilst these principles and outcomes are consistently articulated within CALD policies and programs, they have not been established or tested utilising traditional experimental designs and are therefore not emphasised within published health research or clinical guideline development protocols.

Apart from referencing and establishing consensus from within a broader literature, another strategy to inform working with CALD communities in relation to Cancer Services specifically could bathe facilitation of a process to establish expert consensus. Techniques such as Delphi Surveys or Nominal Groups of recognised practice and academic experts have been used successfully in the past to reach consensus on cancer-related research and practice issues where the published literature is inconclusive^{60,61} and may be prove useful to facilitate a process to gain valid and reliable consensus in relation to cancer services for CALD communities.

Whilst a panel of 'multicultural' experts could guide this overall strategy, it is likely that the establishment of culture and cancer specific panels to guide large scale individual programs may also be of value.

The need for independent rigorous evaluation of current funded programs and strategies

Due to the current limitations in the published literature available to guide evidence-based cancer programs and services with CALD communities, the authors suggest that as a first step, funding should be directed towards independent and rigorous evaluation of current large and small scale programs with a CALD focus that aim to improve the participation or quality of outcomes for CALD populations. Whilst strategies currently employed by government departments, research centres and cancer councils designed to increase participation among CALD communities have been identified²¹, without independent rigorous evaluation, conclusions cannot be confidently reached regarding the effectiveness of these funded strategies either individually or collectively. Where possible programs that distinguish between cultural groups and cancer types are more likely to provide new evidence in regards to the diversity of approaches, which may be required to improve participation and cancer outcomes in different cultural groups for different types of cancers.

The expert panel could be well utilised to assist in the identification of relevant cancer programs for evaluation, as well as programs that may have been successful within other contexts that they believe have transferability to the cancer context.

The need for further research to establish the significance of cancer knowledge, attitudes and beliefs to cancer outcomes

Prospective studies which measure the association between particular cultural cancer beliefs and cancer-related behaviours are required to determine the extent and significance of these to cancer-related behaviours (from prevention to screening to treatment and palliative care). Given the dearth of research among the priority groups specified (particularly Vietnamese and Arabic), and the likely difference in beliefs about different types of cancers (and their associated screening and treatment services), it is important that this research is culturally and cancer specific. There is also a need for more rigorous research designs (e.g. RCTs, or well-designed observational studies that yield extremely large and consistent estimates of the magnitude of an intervention effect) to better determine the effectiveness of interventions which attempt to address knowledge and attitudes to improve cancer-related behaviours.

The need to establish new research paradigms inclusive of CALD communities

Finally, the emphasis of the recommendations in this report rests on the funding, support and conduct of research with CALD communities. This is by no means an easy task, with documented evidence of the numerous barriers to the participation of members of CALD communities in all health and specifically cancer-related research.^{62,63} As such a commitment to the development of new research paradigms and the requirement to engage communities and ensure that funding programs and research schemes are inclusive and follow the principles outlined above are also required to increase CALD participation in research itself.⁶³

Once again, whilst a panel of experts who specialise in research with CALD communities could guide the development of these policies and approach – it is likely that the establishment of culture and cancer specific research panels to guide large scale individual research projects may also be of value.

The need for the development of models and approaches that apply consumer insights

Insights gained from qualitative and quantitative research with CALD community members should be utilised to inform the conduct of culturally appropriate interventions and programs. To facilitate this, funding of future cancer interventions with CALD communities should be prioritised towards those programs that undertake new formative research with target communities and/or clearly apply cultural insights within the program/intervention strategies.

6 References

- 1. Brushin B, Gonzalez M, Payne R. Exploring cultural attitudes to breast cancer: towards the development of culturally appropriate information resources for women from Greek, Italian, Arabic and Polish speaking backgrounds: executive summary. Woolloomooloo: NHMRC National Breast Cancer Centre. 1997.
- 2. Goldstein D, Thewes B, Butow P. Communicating in a multicultural society. II: Greek community attitudes towards cancer in Australia. Int Med J 2002; 32(7): 289–296.
- 3. Manderson L, Allotey P. Storytelling, marginality, and community in Australia: how immigrants position their difference in health care settings. Med Anthropol 2003; 22(1):1–21.
- 4. Butow P, Sze M, Dugal-Beri P et al. From inside the bubble: migrants' perceptions of communication with the cancer team. Suport Care Cancer 2010; 19(2):281–290.
- 5. Guyatt G, Oxman AD, Akl EA et al. GRADE Guidelines: 1. Introduction—GRADE evidence profiles and summary of findings tables. J Clin Epidemiol 2011; 64(4):383–394.
- 6. Girgis S, Adily A, Velasco MJ et al. Feasibility, acceptability and impact of a telephone support service initiated in primary medical care to help Arabic smokers quit. Aust J Prim Health 2011; 17(3):274–281.
- 7. Perusco A, Poder N, Mohsin M et al. Evaluation of a comprehensive tobacco control project targeting Arabic-speakers residing in south-west Sydney, Australia. Health Promot Int 2010; 25(2):153–165.
- Department of Health and Ageing. National tobacco campaign more targeted approach culturally and linguistically diverse audiences. [online] 2011 [cited 2012 19 Sep]. Available from http://www.quitnow.gov.au/internet/quitnow/publishing.nsf/Content/mta-2011-12
- 9. Ramos V. Reducing smoking in migrant and refugee communities. Quit Victoria Report [online] 2009. Available from http://www.quit.org.au/downloads/multiculturalreport09.pdf
- 10. Bull F, Bauman A, Bellew B et al. Getting Australia active II: an update of evidence on physical activity for health. Melbourne: National Public Health Partnership (NPHP). August 2004.
- 11. Bauman A, Bellew B, Vita P et al. Getting Australia active: towards better practice for the promotion of physical activity. Melbourne: National Public Health Partnership (NPHP). March 2002.
- 12. Wood B, Ross K, Kouris-Blazos A. Healthy eating for nutritionally vulnerable groups: some health promotion initiatives, in Healthy Eating Healthy Living Program. Victoria: Monash University. 2000.
- 13. McAvoy BR, Raza R. Can health education increase uptake of cervical smear testing among Asian women? BMJ 1991; 302(6780):833–836.
- 14. Turnbull D, Irwig L, Adelson P. A randomised trial of invitations to attend for screening mammography. Aust J Public Health 1991; 15(1):3336.
- 15. Mitchell H, Hirst S, Mitchell JA et al. Effect of ethnic media on cervical cancer screening rates. Aust N Z J Public Health 1997; 21(3):265–267.
- 16. Del Mar C, Glasziou P, Adkins P et al. Do personalised letters in Vietnamese increase cervical cancer screening among Vietnamese women? Aust N Z J Public Health 1998; 22(7):824–825.
- 17. Koo FK, Kwok C, White K et al. Strategies for piloting a breast health promotion program in the Chinese-Australian population. Prev Chronic Dis 2012; 9:E03.
- 18. Kwok C, Foo FK, D'Abrew N et al. East meets West: a brief report of a culturally sensitive breast health education program for Chinese-Australian women. J Cancer Educ 2011; 26(3):540–546.
- Fernbach M. Uptake of cervical screening messages by Macedonian and Spanish-speaking women: an evaluation of the PapScreen Victoria multicultural media campaign, 1999, in PapScreen Victoria Evaluation Report Volume One 1997–2000. Melbourne: Centre for Behavioural Research in Cancer, Anti-Cancer Council of Victoria. 2001.
- 20. Fernbach M, Jones J, Clarke V et al. Vietnamese women, health concerns and cervical cancer screening: knowledge, beliefs and behaviours at two time periods, in PapScreen Victoria Evaluation Report Volume One 1997–2000. Melbourne: Centre for Behavioural Research in Cancer, Anti-Cancer Council of Victoria. 2001.

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- Barbaro B, Brotherton J, Gertig D. Improving cancer screening participation in under-screened, never-screened and hard-to-reach populations: environmental survey results for participants. Carlton South: Victorian Cytology Service, 2010.
- 22. King E, Ball J, Carroll T. Evaluation report for the 2000/2001 phase of the BreastScreen Australia Campaign. Canberra: BreastScreen Australia, Australian Government Department of Health and Ageing 2003.
- Mullins R. Evaluation of the impact of PapScreen's campaign on Culturally and Linguistically Diverse (CALD)
 women. Prepared for PapScreen Victoria. Centre for Behavioural Research in Cancer, Melbourne: The Cancer
 Council Victoria. 2006.
- 24. Yiu D, Kirsner A. The Chinese Cancer Society of Victoria: building support networks in Melbourne's Chinese community. Cancer Forum 2002; 26(1):21–24.
- 25. Todd K, Roberts S, Black C. The Living with Cancer Education Programme. I. Development of an Australian education and support programme for cancer patients and their family and friends. E J Cancer Care (Engl) 2002. 11(4):271–279.
- 26. Barlow-Stewart K, Toward cultural competence in cancer genetic counseling and genetics education: Lessons learned from Chinese-Australians. Genet Med 2006. 8(1):24–32.
- 27. Eisenbruch M, Yeo SS, Meiser B et al. Optimising clinical practice in cancer genetics with cultural competence: lessons to be learned from ethnographic research with Chinese-Australians. Soc Sci Med 2004; 59(2):235–248.
- 28. Huang X, Butow P, Meiser B et al. Attitudes and information needs of Chinese migrant cancer patients and their relatives. Aust N Z J Med 1999; 29(2):207–213.
- 29. Kwok C, Sullivan G. The concepts of health and preventive health practices of Chinese Australian women in relation to cancer screening. J Transcult Nurs 2007; 18(2):118–126.
- 30. Lui CW, Ip D, Chui WH. Ethnic experience of cancer: a qualitative study of Chinese-Australians in Brisbane, Queensland. Soc Work Health Care 2009; 48(1):14–37.
- 31. Yeo SS, Meiser B, Barlow-Stewart K et al. Understanding community beliefs of Chinese-Australians about cancer: initial insights using an ethnographic approach. Psychooncology 2005; 14(3):174–186.
- 32. Kwok C, Cant R, Sullivan G. Factors associated with mammographic decisions of Chinese-Australian women. Health Educ Res 2005; 20(6):739–747.
- 33. Kwok C, Sullivan G. Influence of traditional Chinese beliefs on cancer screening behaviour among Chinese-Australian women. J Adv Nurs 2006; 54(6):691–699.
- 34. Chui Y-Y, Donoghue J, Chenoweth L. Responses to advanced cancer: Chinese-Australians. Journal of Advanced Nursing, 2005; 52(5):498–507.
- 35. Hislop TG, Teh C, Lai A et al. Pap screening and knowledge of risk factors for cervical cancer in Chinese women in British Columbia, Canada. Ethn Health 2004; 9(3):267–281.
- 36. Feser L, Bon Bernard C. Enhancing cultural competence in palliative care: perspective of an elderly Chinese community in Calgary. J Palliat Care 2003; 19(2):133–139.
- 37. Cheek J, Fuller J, Gilchrist S et al. Vietnamese women and pap smears: issues in promotion. A N Z J Public Health 1999; 23(1):72–76.
- 38. McGrath B, Truong B, Reymond L et al. Training and supporting GPs in providing palliative care to a Vietnamese-Australian community. Aust Fam Physician 2004. 33(3):167–168.
- 39. Donnelly TT. The health care practices of Vietnamese-Canadian women: cultural influences on breast and cervical cancer screening. Can J Nurs Res 2006.;38(1):82–101.
- 40. Migrant Information Centre (Eastern Melbourne). Palliative care for culturally & linguistically diverse communities. Melbourne: Migrant Information Centre (Eastern Melbourne). 2009.
- 41. Migrant Information Centre (Eastern Melbourne). Palliative care for culturally & linguistically diverse communities. Melbourne: Migrant Information Centre (Eastern Melbourne). 2009.
- 42. Saleh M, Barlow-Stewart K, Meiser B et al. An exploration of the cultural context of kinship and genetics amongst Arabic-Australians: implications for practice. J Genet Course 2011; 20(5):465–475.
- 43. Saleh M, Barlow-Stewart K, Meiser B et al. Knowledge, attitudes and beliefs of Arabic-Australians concerning cancer. Psychooncology 2012; 21(2):195–202.

- 44. Mitchison D, Butow P, Sze M et al. Prognostic communication preferences of migrant patients and their relatives. Psychooncology 2012; 21(5):496–504.
- 45. Gulati S, Watt L, Shaw N et al. Communication and language challenges experienced by Chinese and South Asian immigrant parents of children with cancer in Canada: implications for health services delivery. Pediatr Blood Cancer 2012; 58(4):572–578.
- 46. Oliffe J, Thorne S, Hislop TG et al. "Truth telling" and cultural assumptions in an era of informed consent. Fam Community Health 2007; 30(1):5–15.
- 47. Die Trill M, Holland J. Cross-cultural differences in the care of patients with cancer: a review. Gen Hosp Psychiatry 1993; 15(1):21–30.
- 48. Department of Health and Ageing. A qualitative evaluation of opinions, attitudes and behaviours influencing the bowel cancer screening pilot program: Final Report. Canberra: Australian Government Department of Health and Ageing 2004.
- 49. Javanparast S, Ward PR, Carter SM et al. Barriers to and facilitators of colorectal cancer screening in different population subgroups in Adelaide, South Australia. Med J Aust 2012; 196(8):521–523.
- 50. Watt L, Dix D, Gulati S et al. Family-centred care: a qualitative study of Chinese and South Asian immigrant parents' experiences of care in paediatric oncology. Child Care Health Dev 2011; 2013:39(2):185–193.
- 51. Brown W, Lee C, Oyomopito R. Exercise and dietary modification with women of non-English speaking background: a heart health program for Greek-Australian women. Health Promot Int.1996; 11(2):117–25.
- 52. Brown W, Lee C, Nasstasia Y. Heart health for migrant women: a short intervention with Macedonian Australian women. Health Promot J Austr 1997; 7(2):134–137.
- 53. Jones SC, Magee CA, Barrie LR et al. Australian women's perceptions of breast cancer risk factors and their own risk of developing breast cancer. Women's Health Issues 2011; 21(5):353–360.
- 54. Lebel S, Devins GM. Stigma in cancer patients whose behavior may have contributed to their disease. Future Oncol 2008; 4(5):717–733.
- 55. Harun A, Harrison J, Young J. Interventions to improve patient participation in the treatment process for culturally and linguistically diverse people with cancer: a systematic review. Asia Pac J Clin Oncol 2012; doi: 10.1111/j.1743-7563.2012.01531.x.
- 56. NSW Health. NSW Health Policy and Implementation Plan for Culturally Diverse Communities 2012–2016. Sydney: Government of NSW. 2012.
- 57. Centre for Culture Ethnicity and Health. How to: a practical guide to CALD consumer participation. Richmond: Centre for Culture, Ethnicity and Health 2012.
- 58. Department of Communities. Engaging Queenslanders: an introduction to working with culturally and linguistically diverse (CALD) communities. Brisbane: State of Queensland (Department of Communities) 2007.
- 59. National Health and Medical Research Council. Cultural competency in health: a guide for policy, partnerships and participation. Canberra: NHMRC. 2006.
- 60. Robotin MC, Jones SC, Biankin AV et al. Defining research priorities for pancreatic cancer in Australia: results of a consensus development process. Cancer Causes Control 2010. 21(5):729–736.
- 61. Johnson K, Jones S, Iverson D. Guidelines for the development of social marketing programs for adolescents' and young adults' sun protection. Public Health 2009; 123 Supplement(1):e6—e10.
- 62. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: Race-, sex-, and age-based disparities. 2004; 291(22):2720–2726.
- 63. Moreno-John G, Gachie A, Fleming CM. Ethnic minority older adults participating in clinical research: developing trust. J Aging Health 2004; 16(5 suppl):93S–123S.

7 APPENDICES

APPFNDIX A

Quality grading

The Grading of Recommendations Assessment, Development, and Evaluation (GRADE) guidelines (Guyatt et al. 2011) is a well-recognised system for rating the quality of evidence in systematic reviews. It takes into account:

- 1. **Study design** randomised controlled trials receive a higher initial quality score compared with observational studies
- 2. **Risk of Bias** there can be a risk of misleading results if the study design or conduct is flawed (e.g. poorly developed eligibility criteria, failure to control for confounding)
- 3. **Imprecision** optimal approach to imprecision is the examination of the 95% confidence interval (CI). CI informs the impact of random error on the evidence quality.
- 4. **Inconsistency** a body of evidence is not rated up in quality if studies yield consistent results but may be rated down in quality if inconsistent
- 5. Indirectness Evidence can be indirect in 4 ways. Patients may differ from those of interest, tested intervention may differ from intervention of interest, outcomes (or 'surrogate outcomes') differ from those of primary interest and when clinicians must choose between interventions that have not been tested in head-to-head comparisons. When there is no head to head comparison of the study, the quality of evidence decreases as the use of indirect comparison is needed. Rating down occurs when there is a large discrepancy between these 4 points of indirectness
- 6. **Publication bias** even if individual studies are perfectly designed and executed, synthesis of studies may provide biased estimates. This is partly since there may be a bias in journals against publishing negative or no results (e.g. overestimating effect size)
- 7. Rating up the quality of evidence Most common reason is evidence of a large effect. Rate up 1 level if study shows at least a 2-fold reduction or increase in risk, and rate up 2 levels for at least a 5-fold reduction or increase in risk. Consider rating up if a systematic review shows evidence of a dose response gradient. Need to consider other criteria for rating down quality of evidence before employing this concept though.

APPENDIX B – SUMMARY TABLES

Table 1: Summary of cancer knowledge, attitudes and beliefs in CALD communities

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
Chinese						
Barlow-Stewart 2006	Journal	Australia, NSW	Chinese Cantonese, Mandarin, Hokkein and English speaking Country of birth: Hong Kong, China, Malaysia, Singapore, Indonesia and Australia	Hereditary	n=15, 4 male and 11 female, aged mid 20s– mid 80s. In depth interviews.	Nature of cancer: Shameful and considered a taboo topic. Talking about it may make it happen. Causes of cancer: Bad luck, fate, or some evil deed committed by an ancestor. The Buddhist views of retribution in this life for wrong-doing committed in this or a previous life. Susceptibility to cancer: Older community members are less likely to know or understand that risk factors for cancer can be hereditary. Bad luck, fate, or some evil deed committed by an ancestor. The Buddhist views of retribution in this life for wrong-doing committed in this or a previous life. Males are considered the dominant authority in a Chinese family and therefore are considered the dominant force in passing down illnesses. Some believe cancer to be contagious. Awareness of/attitudes towards screening & prevention programs: Many would consider genetic counselling and testing if recommended by a doctor. Knowledge of/approach to treatment: Diagnosis of cancer often kept secret within the family. Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative care: NA
Eisenbruch 2004	Journal	Australia, NSW	Chinese Mandarin, Cantonese and English speaking Country of birth: Australia, Burma, Canton, East Timor, Hong Kong, Malaysia, Shanghai, Taiwan, and Vietnam	Hereditary cancer	n=16, 14 females, 2 males, aged 28–69 years. In-depth interviews.	Nature of cancer: Some believe cancer is contagious. Talking about cancer may aggravate it or cause it to happen. Causes of cancer: Mix of western and traditional Chinese explanations. Most attributed ill health to the result of an imbalance of the positive and negative life force (yin-yang) in the body. Others attributed it to supernatural beliefs such as: Mystical explanations: (i) Heaven's or God's will (ii) karma (iii) bad luck or fate (iv) offending the gods or deities requiring prayers or offerings for appeasement (v) feng-shui. Magical explanations included kong-tau (spells invoked through human intervention). Animistic (mediated by personalised supernatural agent) explanations referred to evil spirits and loved ones seeking reunion with the living in the other world. Some believe cancer is contagious.

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
						Susceptibility to cancer: Mismatch between western and Chinese notion of 'risk'. Inheritance/genetics was also perceived as a retribution for ancestral misdeeds. Awareness of/attitudes towards screening & prevention programs: Paying respects to the ancestors and making offerings would ensure the protection from ill health and good fortune of descendants. Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative care: NA
Huang 1999	Journal	Australia, NSW	Chinese Cantonese, Mandarin and English speaking Country of birth: China, Australia and Other	Non-specific	n=36 patients with cancer and n=12 relatives, age >30 years. Focus groups & phone interviews.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: Preference for non-disclosure if poor prognosis. Emphasis on family liaison between patient and health professionals. Desire for incorporation of Chinese culture and treatments into care. Need for interpreters and psychological and spiritual support. Palliative care: NA
Kwok 2007	Journal	Australia, NSW	Chinese	Non-specific	n=20, women aged 50–69 years. In-depth interviews.	Nature of Cancer: NA Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: Focus on preserving and promoting health and overall well-being not detecting hidden disease by screening. Health and illness are taken-for granted. If not symptomatic, no reason to suspect diseases. Short & long term outcomes: Fatalistic view of cancer. Knowledge of/approach to treatment: NA Palliative care: NA
Lui 2009	Journal	Australia, QLD	Chinese	Non- specific	n=24 (8 cancer patients, 5 carers, 11 service providers and community leaders),	Nature of Cancer: Extremely unfortunate and negative. Incurable and related to improper deeds or practices. Stigmatised as a social disgrace for both the sick individual and his/her family. Causes of cancer: Most had a basic knowledge of the causes of cancer. However,

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
					males and females. In depth interviews.	folk or mythic accounts play a role in their understanding of the disease. Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: Cancer is incurable. Knowledge of/approach to treatment: Range of approaches to treatment – passive & stoic; belief in fate and luck; Families important in day to day care; medical decisions, interpreting, transport, emotional support etc. Barriers to support – may decline external help due to stigma/privacy until burden of care is no longer manageable. Palliative care: NA
Yeo 2005	Journal	Australia, NSW	Chinese Cantonese, Mandarin, Hokkein and English speaking Country of birth: Various	Non- specific	n=31, 15 from cancer clinics, 16 from community, 25 females, 6 males. Mid 20s – mid 80s. In depth interviews.	Nature of Cancer: The majority incorporated both western biomedical and traditional Chinese explanations of cancer. Causes of cancer: Explanations of illness including cancer referred to the following concepts (i) karma (yeh) (ii) retribution (bao ying) (iii) fate (mingy un) 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 and offerings (viii) kong-tau (spells invoked through human intervention). Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative care: NA
Kwok 2005	Journal	Australia, NSW	Chinese	Breast	n=20, women aged 50-69 years. In-depth interviews.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: Facilitators of screening: Organisational factors (written invitations from BreastScreen NSW, Seniors' club activities); Influence of significant others (family members – encouraged attendance or arranged in on receipt of letter). Barriers to screening: Fear of mammography (physical damage from mammography, concerns about radiation, doubts about efficacy); Modesty (dislike of others viewing their private parts); Fear of stigmatisation (cancer not discussed outside the family). Short & long term outcomes: NA Knowledge of/approach to treatment: NA

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
						Palliative care: NA
Kwok 2006	Journal	Australia, NSW	Chinese Country of birth: Hong Kong	Breast	n=20, women aged 50-69 years. In-depth interviews.	Nature of Cancer: NA Causes of cancer: Disease, (including cancer) is inevitable and there is no way to prevent it. Susceptibility to cancer: Lifecyle, ageing; sickness an inevitable cycle; death as natural and preordained; Negative thinking brings negative outcomes. Awareness of/attitudes towards screening & prevention programs: Barriers to screening: fatalism; low belief in efficacy of screening; cultural norms do not reinforce screening. Short & long term outcome: Fatalistic view of cancer Knowledge of/approach to treatment: NA Palliative care: NA
Hislop 2004	Journal	Canada, British Columbia	Chinese Cantonese and Mandarin speaking	Cervical	n=528, women, mean age=49.7 years. Interview.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: Low knowledge about cervical cancer risk. Higher knowledge associated with higher education, having a female GP, and having had a Pap test. Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: Fatalistic view of cancer. Knowledge of/approach to treatment: NA Palliative care: NA
Chui 2005	Journal	Australia, NSW	Chinese Country of birth: Mainland China and Hong Kong	Advanced cancer (terminal)	n=11, 4 men and 6 women, mid-aged (30- 60 years), with advanced cancer. Grounded theory.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: 4 modes of responses to cancer: - Acute crisis - Despondency - Waiting for death - Combat* *Strategies associated with combat approach to treatment: - Traditional Chinese medicine

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
						 Chinese beliefs on use of food Qi gong (a form of exercise) Feng shui (paying attention to spatial organisation) Worship of ancestors & gods Influenced by, philosophy of harmony and balance of yin and yang and qi. Believe in integration of Chinese herbal medicine and western medicine. However, priority is given to advice of doctors. Palliative care: NA
Feser 2003	Journal	Canada, Calgary	Chinese Cantonese speaking	All palliative care	n=25, >70 years of age	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative care: Chinese do not have terms from 'palliative' or 'hospice'. More appropriate words convey 'care focussed on comfort as one approached the end of life' and 'a place of comfort towards the end of life'. To speak of death and dying is often taboo. Linear models of palliative care are likely to be less understood than cyclical models focusing on harmony and balance.
Vietnamese						
Donnelly 2006	Journal	Canada, Calgary	Vietnamese	Breast, Cervical	n=21, 15 Vietnamese- Canadian women (49– 78 years), 6 health care providers (4 male Vietnamese physicians, 2 female community nurses). In depth interviews.	Nature of Cancer: NA Causes of cancer: Conceptualisation of health and illness. Importance of health in fulfilling social obligations. Disease and illness are caused by an imbalance within the body, bacterial invasion and predetermined by a higher power. Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: Cultural factors that influence participation in screening include: - Cultural knowledge and values with regard to women's bodies as private. Breast or cervical examination causes great embarrassment. Health-seeking is guided by physical sensations i.e. do not think they have a health problem unless experiencing unusual physical discomfort. - Conceptualisation of health and illness. Importance of health in fulfilling social obligations. Disease and illness are caused by an imbalance within the body,

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
						Beliefs and values concerning patient/provider relationship. Hierarchical relationship. Women often feel too intimidated to ask for information or request screening. Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative care: NA
Cheek 1999	Journal	Australia, SA	Vietnamese	Cervical	n=199, women, > 18 yrs. Cross-sectional survey.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: 87% had heard of a Pap smear. Screening rates increased with age, education level, marriage and length of stay in Australia. Family doctor most important source of information, Friends and family also important. Majority would have a Pap smear if recommended by their doctor. 75% had had a test. Of those who had heard of a Pap smear: 96% knew it indicates pre-cancerous changes in the cervix; 47% knew test 'should be conducted every 2 years'; and 25% knew that 'women aged 18-70 who have ever had sex should have a routine test. Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative care: NA
McGrath 2004	Journal	Australia, NSW	Vietnamese	Terminal cancer	n=?, unknown number of carers, 4 GPs, 2 palliative care nurses. Case study revolving around the experience of and with one family.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative Care: Palliative care barriers: pain is seen as payment for previous misdeeds and must be accepted; patient reluctance to disclose symptoms; reliance on family members; inappropriate presentations to hospital; variability in the role played by GPs; complexities in revealing & discussing prognosis; and family preference for patient to not be informed of prognosis.
Arabic			`			
Saleh 2011	Journal	Australia,	Arabic	Non-specific	n=38, 27 females, 11	Nature of cancer: Having a family history of cancer has an adverse impact on

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
Saleh 2012	Journal	Australia, NSW	Arabic	Non- specific	males, >18 years recruited from both a cancer clinic and the general community. Ethnographic interviews. n=38, 27 females, 11 males, >18 years recruited from both a cancer clinic and the general community. Ethnographic interviews.	marriageability. Causes of Cancer: NA Susceptibility to cancer: Some reported an outdated belief within the community of patrilineal inheritance and that the father's genes are stronger than the mother's. All noted the importance of understanding one's family and personal health history in understanding the risk of cancer for future generations. Awareness of/attitudes towards screening & prevention programs: Stigma a barrier to screening. Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative Care: NA Nature of cancer: Stigma associated with cancer diagnosis. Desire to avoid people with cancer. Not talked about and associated with bad luck. Use of other words rather than cancer. Cancer is fatal- though clinic patients were less likely than the general community to believe this. Causes of cancer: Genetics Lifestyle factors Stress Spirituality/ higher power. Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: Stigma, fear and secrecy are barriers to accessing health services. Some families expressed a desire for non-disclosure of diagnosis.
						Palliative Care: NA
Multiple or Non-	specific CA	LD communi	ties			
Butow 2011	Journal	Australia, NSW and VIC	Arabic, Greek, Chinese (Cantonese and Mandarin speaking)	Non-specific	n=91, 73 cancer patients and 18 carers, 70% female, mean age 56. Focus groups and semi-structured	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
					interviews.	 Knowledge of/approach to treatment: Language and communication difficulties include: Difficulty understanding verbal and written information. Implications include missed appointments, non-adherence to treatment or clinic procedures and poor self-care. Cultural isolation. Wanted to be treated by 'one of their own' and would travel long distances to accomplish this. Being treated differently. Some feel they receive inferior care, less information. Lack of skill with English language. Unable to advocate on their own behalf, difficulty forming a relationship and building trust. Palliative Care: NA
Die Trill 1993	Journal	Review of inter- national literature	Non-specific	Non-specific	NA, Review article.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: Major cultural issues that should be considered in cancer patients: family function; sex roles; language; disclosure of information; pain; attitudes towards illness and health practices; immigration; religion; autonomy/dependency; death, and bereavement.
Gulati 2012	Journal	Canada, Ontario	Chinese, South Asian (Mandarin, Cantonese, Hindi, Punjabi, Urdu)	Non-specific	n=50, parents of a child with cancer. Face to face and telephone interviews.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: Communication challenges influenced parents' role in caring for their child and made it difficult to learn complex medical terminology. Interpreting services were sometimes inadequate or not accessible. Parents occasionally missed out on services and resources, reported limited availability of linguistically and culturally appropriate information, and experienced a lack of social integration in the healthcare process.

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
						Palliative Care: NA
Mitchison 2012	Journal	Australia, NSW	Chinese, Arabic and Greek	Non-specific	n=73, oncology patients (including 20 Chinese; 11 Greek; 11Arabic). n=65 relatives (including 23 Chinese 11 Arabic; 7 Greek). Males and females, over 30. Interviews.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: Patient preference for caring & sensitive prognostic disclosure from an authoritative oncologist. Discordant with families' preference for non-disclosure to patients and desire to actively influence oncologists – meeting with them separately and directing what and how information should be conveyed to patients. Palliative Care: NA
Oliffe 2007	Journal	Canada, British Columbia	Chinese, Persian, Jamaican, Dutch Indonesian, Filipino, First Nations/Aborig- inal	Non-specific	n=21, 18 female, 3 male, 27-80 years. In depth interviews.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: Want the content and volume of information shared by healthcare professionals to be 'titrated' in culturally sensitive ways. Need to have information 'channelled' to family members and directly involving them when making decisions. Palliative Care: NA
DOHA 2004	Govern- ment Report, Bowel Cancer Screening Pilot Program	Australia, VIC and SA	Cantonese Vietnamese, Greek and Italian	Bowel	n=60, equal numbers of men and women. In depth interviews.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: CALD groups less familiar with 'do it yourself' health checks such as FOBT - greater reliance on GP or doctor to conduct - GPs were respected and trusted as the expert - CALD groups more likely to screen if advised by their GP - some alarm at receiving FOBT in mail and seeing the word 'cancer' – did not understand why they had been sent the kit - reluctant to call the 1300 number - did not know if they could trust the

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
						translator. Motivations to participate in taking an FOBT test - belief in efficacy of screening to prevent death from disease - social acceptance and encouragement to take part - desire for quality of life - motivated by involvement with grandchildren and the community - family history of bowel cancer - perceived ease of use of screening kit, particularly when compared to colonoscopy. Recommendations – there is a need for - knowledge and awareness raising for bowel cancer and for FOBT testing prior to the kits being distributed - translation of promotional and kits materials and components - support from GPs and health workers to encourage and conduct FOBT screening - use of ethnic media to create awareness of program in language and broadly in the community - community organisations also good avenue for creating discussion and awareness raising . Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative Care: NA
Javanparast 2012	Journal	Australia, SA	Greek, Vietnamese, Iranian, Indigenous and Anglo-Australian	Colorectal	n=121 men and women, aged 50-75 years. Interviews.	Nature of cancer: Very fearful of a cancer diagnosis. Causes of cancer: Unpreventable. Health and disease and life and death were in God's hands, and so not preventable (Greek and Vietnamese). Susceptibility to cancer: CALD groups had a fatalistic view about susceptibility to cancer. Awareness of/attitudes towards screening & prevention programs: Barriers to screening: low knowledge of bowel cancer and screening; fatalism about cancer; language barriers; low self-efficacy to perform FOBT; tests viewed as undesirable; privacy important. Possible facilitators: belief that prevention better than cure; moral obligation and responsibility to care for own health; belief that cancer could be prevented by lifestyle choices. Short & long term outcomes: CALD groups have a fatalistic view about the outcomes of cancer.

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
						Knowledge of/approach to treatment: Fear. Cancer as unpreventable and fatal. Want health worker support to complete. Palliative Care: NA
King 2003	Report, Breast- Screen Australia	Australia, ACT	NESB – Arabic, Chinese, Croatian, Greek, Italian, Macedonian, Maltese, Mandarin, Polish, Portuguese, Serbian, Spanish, Turkish and Vietnamese	Breast	CATI survey NESB women40–69 years. Pre-campaign n=122. Post campaign n= 106. *Boosted NESB sample for never screeners and under-screeners.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NESB less likely than OESB and AESB to - cite breast cancer as a health problem - rate screening as a very good idea - suggest biennial screening - perceive screening mammograms and breast self-examination, and GP examination as effective - have been screened in the last 2 years. Barriers to mammogram (no difference to AESB) - Lazy/not got around to it - discomfort - not thought about it not at risk - no symptoms. Short & long term outcomes: NA Knowledge of/approach to treatment: NA Palliative Care: NA
Watt 2011	Journal	Canada, Ontario	Chinese (Cantonese& Mandarin speaking) South Asian (Urdu, Punjabi, Hindi)	Paediatric oncology	n=50, first generation, parents of children with cancer. Semi- structured interviews.	Nature of Cancer: NA Causes of Cancer: NA Susceptibility to cancer: NA Awareness of/attitudes towards screening & prevention programs: NA Short & long term outcomes: NA Knowledge of/approach to treatment: Parents do not always see themselves as a member of the medical team. Parents are sometimes uncomfortable with healthcare providers communicating sensitive health-related information directly with their child. Limited English proficiency was a cause of confusion and distress. Family-centred, relationship approach to care was appreciated Palliative Care: NA

1 st Author/ Year	Туре	Country, State	CALD community	Cancer Type	Sample size and characteristics	Summary information
Migrant	Report,	Australia,	Chinese, Vietnamese	Palliative care in	NA.	Nature of Cancer: NA
Information	cultural	VIC		general	Discussion paper.	Causes of Cancer: NA
Centre 2009	profiles					Susceptibility to cancer: NA
						Awareness of/attitudes towards screening & prevention programs: NA
						Short & long term outcomes: NA
						Knowledge of/approach to treatment: NA
						Palliative care: Chinese attitudes to palliative care: Family members may be reluctant to tell the patient their prognosis. Tendency to assume a passive sick role. Negative emotions associated with hospitalisation, residential and hospice care. Older generation may be uncomfortable with health professionals in the home.
						Vietnamese attitudes to palliative care: health professionals welcome in the home; do not question the doctor's authority; diagnosis and prognosis given to family not patient; family plays a strong role in communication and decision making, and will most often request that information be given to them rather than directly to the patient; hospitalisation is acceptable, but it is considered to cause bad luck for the family if the patient does not die at home.

Table 2a: Summary of interventions aimed at preventing cancer in CALD communities

Publication details	Main intervention type and risk factor	Intervention components	Target (n)	Design	Data collection methods	Aims/ Outcomes	Effects	Follow- up months	Cost
Author/year: Girgis 2011 Type: Journal Country/state: Australia, NSW CALD community: Arabic Cancer type: Smoking related	Smoking cessation telephone support.	6 sessions of smoking cessation telephone support delivered by bilingual psychologists.	Case: n=213, Control: n=194. GP survey: n=19	Controlled pre-post study. Post intervention survey of GPs Quality: Low to moderate	Questionnaire	Recall of advice. Reactions to intervention.	No significant differences at 6 or 12 months between intervention and control groups in point prevalence abstinence rates (11.7% vs. 12.9%, P = 0.83; 8.4% vs. 11.3%, P = 0.68, respectively) or the mean shift in stage-of-change towards intention to quit. Most indicated that the telephone advice was acceptable, relevant, of the right amount, and was preferable to face-to-face counselling. Most GPs found the service to be acceptable (79%) and most had not encountered any problems in referring patients.	6 and 12 months	NR
Author/year: Perusco 2010 Type: Journal Country state: Australia, NSW CALD community: Arabic Cancer type: Smoking related	Comprehensive social marketing campaign. Smoking.	Three phases: media campaign (radio, billboards, newspapers, merchandise). Promotion and brief interventions/ referrals for smokers at community festivals. Small community grants. Training and funding of bilingual community educators to conduct sessions for existing Arabic-speaking groups.	Baseline: n=1102. Post- intervention: n=1104	Pre-post study Quality: Low	Telephone survey	Current smoking status, campaign recall, attitudes towards smoking, intention to quit smoking.	Significant decline in total self-reported smoking. No change in intention or confidence to quit. Significant improvement in knowledge and attitudes to tobacco smoking and hospitality at home. Prompted recall for the campaign slogan was significantly higher at 63.7% (n ¼ 703, 95% CI: 60.8–66.5) compared with the closest other campaign slogan at 41.2% (n ¼ 455, 95% CI: 38.3–44.1). Recall was highest for bus ads (44.8%), radio (40.7%) and billboards (30.7%). Over half of those who recalled the campaign (54.2%) agreed the campaign had prompted them to speak with family or friends about smoking.	6 and 12 months	Staff FTE: \$760,857, Advertising: \$167,647, Community engagement: \$43,158, Survey: \$174,468.
Author/year: DOHA 2011	CALD Health Benefits	Print ads in eight languages; radio ads in 7	18–40 years from cultural	Cross sectional	Face to face surveys	Campaign recall,	Low overall awareness of the campaign (unprompted = 3%; prompted = 43% for	NA	NR

Publication details	Main intervention type and risk factor	Intervention components	Target (n)	Design	Data collection methods	Aims/ Outcomes	Effects	Follow- up months	Cost
Type: Executive summary Country/state: Australia, NSW, VIC, QLD CALD community: Arabic, Cantonese, Korean, Mandarin, Pacific Islanders, Spanish, Vietnamese Cancer type: Smoking related	campaign. Aims to increase/ reinforce awareness of health harms associated with smoking and to generate/ reinforce intentions to quit.	languages, and online advertising in two languages.	groups with a high prevalence of smoking	study N=350, Interviews, n=50 Quality: very low		smoking status, intention to quit, encouraging others to quit.	radio; 17% for print; 13% (other). 52-64% recall that quitting smoking has health benefits. >90% exposed to ads identified specific messages. 28% of recent quitters indicated they had quit smoking as a result of exposure to the ads. 20% of recent quitters had encouraged family/friends to quit. 16% smokers reduced the amount they smoked; 10% discussed smoking with family/friends.		
Author/year: Ramos 2009 Type: Report Country/state: Australia, VIC CALD community: General Cancer type: Smoking related	Multiple small programs.	Promotional e- newsletter; ethnic media campaigns; development of ethno- specific resources; scholarships for bilingual Quit educators; recruitment of bilingual staff; information sessions; and community grants.	NR	Not specified Quality: Cannot be ranked	NR	Qualitative feedback on programs, number of resources distributed, scholarships taken up, and number of Quitline TIS calls.	Feedback suggests usefulness and appreciation of resources. Calls to the Quitline TIS service increased during ethnic media campaign.	NR	NR

Table 2b: Reviews from the grey literature describing physical activity and nutrition programs targeting CALD communities

Publication details	Main intervention type & risk factor	Results
Author/year: Bauman 2002 and Bull 2004 Type: Report Country/state: Australia CALD community: General Cancer type: Interventions not identified as cancer related	Multiple – none cancer focused.	Review of physical activity programs targeting NESB groups. Quality: Cannot be ranked. Small studies, with short intervention and follow-up periods. Insufficient to draw conclusions regarding effectiveness. Authors comments that adherence and maintenance seemed best in programs conducted by bilingual community educators in culturally appropriate and accessible venues, and where there was strong community support.
Author/year: Wood 2000 Type: Journal – literature review Country/state: Australia CALD community: General Cancer type: Not cancer specific	Multiple – none cancer focused.	Literature review. Quality: Cannot be ranked. Example programs: Ethnic meals delivered to elderly migrant groups; physical activity sessions, health information and a support group three times per week for 12 months for elderly women from an Eastern European background; healthy eating activity/story books for pre-school children of parents of Arabic, Chinese, Vietnamese, Croatian and Serbian background; diabetes prevention program – developed on the basis of a needs assessment about cultural issues related to diabetes; media, point of sale promotions in shopping centres, recipe distribution, supermarket tours, a telephone info line and education for GPs targeting Arabic families; promoting the role of diet of lifestyle in health, including the importance of maintaining traditional diets for recent arrivals from refugee backgrounds.

Table 3: Summary of interventions aimed at improving cancer early detection and screening in CALD communities

Publication details	Main intervention type and risk factor	Intervention components	Target (n)	Design	Data collection methods	Aims/Outcomes	Effects	Follow- up months	Cost
Author/year: Del Mar 1998 Type: Journal, brief report Country/state: Australia, QLD CALD community: Vietnamese Cancer type: Cervical	Media campaign and personalised invitation to promote cervical screening (Pap Test).	Local Media campaign (Vietnamese newspapers and radio, flyers (community venues) schools and community organisations) – Personalised Letter (Benefits of screening; how to obtain a smear; overcoming obstacles to screening).	n=689 women aged 18–67 years	RCT – from electoral roll resident in South Brisbane assigned to control (media campaign only) or media campaign + personalised invitation letter (in Vietnamese) Quality: Moderate	Smear data from three pathology testing laboratories, two years prior to and one year after mail- out.	Number of completed Pap Tests in the 12 months post intervention (compared to the prior 2 years).	No difference in pap smear rates.	NA	NR
Author/year: Mullins 2006 Type: Report Country state: Australia, VIC CALD community: Arabic, Cantonese, Greek, Italian, Mandarin. Cancer type: Cervical	PapScreen Victoria Media campaign targeting CALD communities.	Multicultural radio and print media campaign based on the mainstream media campaign "Don't just sit there".	All Victorian women	Pre-post study Quality: Very Low	Victorian Cervical Cytology Registry records.	Number of Pap tests (comparison of rates during the campaign and in the corresponding weeks in 2003 and 2004; comparison of LGA rates before and during the campaign; comparison of high CALD/ LGAs with low CALD LGAs).	No evidence of increased screening rates during the campaign. No difference between high and low CALD LGAs.	NA	NR
Author/year: Fernbach 2000a Type: Report chapter	PapScreen Victoria Media campaign.	Advertisements on community television, radio, and in print,	n=427 (242 in 1997, 185 in 1999), 30–70 years. Mean	Pre-post survey Quality: Low	Telephone survey.	Improvement in knowledge, beliefs and behaviours in relation	Significant increase in awareness of pap test (p<.001). Significantly more accurate at describing what a	NA	NR

Publication details	Main intervention type and risk factor	Intervention components	Target (n)	Design	Data collection methods	Aims/Outcomes	Effects	Follow- up months	Cost
Country/state: Australia, VIC CALD community: Vietnamese Cancer type: Cervical		combined with community and peer education, and other promotional activities.	age=43.44 years			to cervical screening.	pap test is and does (p<.001). No increase in screening rates. More women reported ethnic radio and newspapers as a source of prompts to have a pap test (p<.001). Most women revealed a strong preference for radio as the best way to get information about pap tests in the future (71% in 1997, 72% in 1999).		
Author/year: Fernbach 2000b Type: Report chapter Country/state: Australia, VIC CALD community: Macedonian, Spanish Cancer type: Cervical	PapScreen Victoria Media campaign.	Media campaign in language – focusing on excuses preventing women from having a pap test.	National and Victoria (2 campaigns)	Cross-sectional survey Self-report translated survey Quality: Very low	n=94 Macedonian & n=96 Spanish speaking.	Recall of pap test messages; attitudes towards pap test messages.	Effects were greater in Macedonian sample than Spanish p<0.05) for: campaign recall; remembering to have a pap test; and viewing testing as a positive experience.	NA	NR
Author/year: McAvoy 1991 Type: Journal Country/state: UK CALD community: Asian (New Commonwealth and Pakistani origin, including those from Bangladesh	Health education, cervical smear testing.	Video, leaflet and fact sheet (English and translated) and personally administered screening questionnaire. 4 groups: Written materials by post, written materials by personal visit, video	n=578/737 non-screeners, 18–52 years	Post –test survey Quality: Very low	Questionnaire.	Cervical smear test recorded within 4 months after intervention.	6/124 (5%) who received no intervention presented for screening vs.14/131 (11%) posted written materials vs.(57/219) 26% visited and given written materials vs. 80/263 (30%) who were visited and shown the video.	12 months	NR

Publication details	Main intervention Intervention type and components risk factor		Data collection methods	Aims/Outcomes	Effects	Follow- up months	Cost		
and east Africa). Cancer type: Cervical		by personal visit, no intervention.							
Author/year: Mitchell 1997 Type: Journal Country/state: Australia, VIC CALD community: Arabic, Chinese, Croatian, Greek, Italian, Macedonian, Serbian, Polish, Spanish, Turkish, and Vietnamese. Cancer type: Cervical	Media campaign.	Ethnic radio interviews, radio advertisements and prizes for radio listeners, ethnic newspaper advertisements. Conducted on three separate occasions (1992, 1993 and 1994).	Totals (1992–1994): Pre- intervention. Low NESB=31,158. High NESB=30,598. Post intervention. Low NESB=31,871. High NESB=31,871.	Pre-post with control (Intervention: high-NESB postcodes, control: low-NESB postcodes) Quality: Very low	Victorian Cervical Cytology Registry.	Pap screening rates during 3 month periods before and after each intervention.	Media coverage generated an additional 6.7% increase in screening in postcodes with high NESB populations.	3 months	\$27, 500 over three cam- paigns (1992– 1994)
Author/year: Turnbull 1991 Type: Journal Country/state: Australia, NSW CALD community: NESB Cancer type: Breast	Invitation letters for mammogram.	Invitation letters for mammogram.	n=243, aged 45–69 years	Pre-post with control group Quality: Very low	Breast X-Ray program data.	Completed mammograms.	53/163 (33%) of women who received an invitation attended for screening. Significantly different to control 7/80 (9%) (p<.001). There was no significant difference between English and non-English speakers in response to the invitations (X²=0.16; df=1, p=0.7).	Approx. 2 months	NR
Author/year: Koo 2012; Kwok 2011 Type:	Training of lay 'breast health' advocates. 4	1 day education session and a 2 hour follow-up session. 5 types of strategies	n=37	Pre-post (no control) Quality: Very low	Questionnaires, focus groups, telephone interviews	Beliefs and knowledge regarding breast cancer, breast self-examination and clinical breast	Participants showed improvements in knowledge, attitudes and beliefs about breast cancer and breast	3–4 months	NA

Publication details	Main intervention type and risk factor	Intervention components	Target (n)	Design	Data collection methods	Aims/Outcomes	Effects	Follow- up months	Cost
Journal Country/state: Australia, NSW CALD community: Chinese (Cantonese) Cancer type: Breast	Education sessions (delivered in 1 day).	used for cultural targeting (in a framework of traditional Chinese philosophies (Confucianism, Taoism, and Buddhism) to deliver breast health messages.				examinations.	health practices. Improved readiness to discuss breast health with other Chinese women. All reported spreading the message after training. Appreciated the way the training program developed their confidence and skills to discuss this topic.		
Author/year: King 2003 Type: Report Country/state: Australia CALD community: NESB (Arabic, Chinese, Croatian, Greek, Italian, Macedonian, Maltese, Mandarin, Polish, Portuguese, Serbian, Spanish, Turkish and Vietnamese). Cancer type: Breast	Media(radio) Written educational materials distributed via libraries.	1000 x 60 second radio ads targeting NESB women from (SBS, community radio stations); NESB library promotion kits (posters, fact sheets and bookmarks were made available to 1800 libraries across Australia).	Women 50–69 years with a focus on under, never and lapsed screeners from CALD backgrounds.	NESB women 40–69 years Pre-campaign n=122 Post campaign n=106 Quality: Low *Boosted NESB sample for never screeners and under-screeners	CATI survey.	Awareness of the program; improve knowledge of breast cancer and screening; improve attitudes, intentions and behaviours for screening for breast cancer.	No significant changes prepost campaign to knowledge, attitudes, intentions or behaviours. Women from NESB background remained less likely than OESB and AESB to: - cite breast cancer as a health problem - rate screening as a very good idea - suggest biennial screening mammograms and breast self-examination, and GP examination as effective - have been screened in the last 2 years.	6 months	NR
Author/year: Barbaro 2010 Type: Report	Screening programs targeting under-	NA	n=39. Government departments, research	Cross-sectional survey Quality: Cannot	Online survey.	Strategies and approaches used to engage CALD	76% had strategies to increase participation among CALD communities. Strategies included: culturally	NA	NA

Publication details	Main intervention type and risk factor	Intervention components	Target (n)	Design	Data collection methods	Aims/Outcomes	Effects	Follow- up months	Cost
Country/state: Australia, New Zealand CALD community: General Cancer type: Non-specific	screened, never- screened and hard-to-reach groups.		centres, cancer councils.	be ranked		communities.	appropriate information and advertising, bilingual interpreters, multicultural cancer information line, health promotion officers targeting CALD communities, workshops, practical assistance, liaison with peak bodies and national strategic working groups, grant funding, community presentations and displays.		

Table 4: Summary of interventions aimed at improving cancer care services for CALD communities

1st Author/ Year	Main intervention type and risk factor	Intervention components	Target (n)	Design	Data collection methods	Aims/ Outcomes	Effects	Follow- up months	Cost
Author/year: Yiu 2002 Type: Journal Country state: Australia, VIC CALD community: Chinese Cancer type: Non-specific	Development of the Chinese Cancer Society of Vic Inc (CCSOV)	TCCN accredited support groups, support and education services provided by trained volunteers (hospital visits, telephone support, counselling, practical assistance, fund raising, recreational and social events, quarterly newsletter containing community member stories, library of Chinese language resources, short courses (tai Chi and art); community education sessions (radio, Centrelink, state trustees); one-off financial assistance	Chinese people who are living with cancer and their families (VIC)	Case study Quality: Very low	NA	NA	Provision of social networks and support; ability to talk about and deal with grief and loss; raised awareness of cancer and associated issues; provision of education and practical assistance; fund raising; education; decreased stigma; increased community awareness and discussion.	NA	NR
Author/year: Todd 2002 Type: Journal Country/state: Australia, VIC CALD community: Greek, Italian Cancer type: Non-specific	Living With Cancer Education Programme (LWCEP), NESB component	8 week patient education and support program. Adapted and translated materials for each cultural group. Piloted program to ensure culturally suitable resources, video and discussion. Accreditation and training of facilitators (with previous experience and training in cancer care). Employment of an LWCEP for NESB; positions at each ethnic community welfare services; modification of training to improve cultural suitability; promotion of training to the NESB community; promotion of the program to increase patient referrals; mentoring of new trainers; introduction of peer support component.	NA	Case Study Quality: Very low	Qualitative	Aims to improve coping, adapting to and living with cancer for people with a diagnosis and their families/ friends.	Greek program: Patient reports of gains in knowledge, coping abilities improved communication with health professionals, and positive thinking/coping. Italian program: improved understanding of cancer and treatments and their emotional reactions, skill building such as particular coping strategies, mutual support and greater freedom to express their fears and worries. All participants agreed that providing the program in their language played a significant role in helping them accept their situation.	NA	Additional translation and interpreter costs. Barriers to program continuing – insufficient number of trained facilitators; lack of relationships within relevant community organisations.

Table 5: Summary of interventions aimed at improving palliative care services for CALD communities

Publication	Main intervention type and risk factor	Intervention components	Target (n)	Design	Data collection methods	Aims/ outcomes	Effects	Follow- up months	Cost
Author/year: Feser 2003 Type: Journal Country/state: Canada, Calgary CALD community: Chinese (Cantonese) Cancer type: All palliative care	Translated assessment tools	Translations of: The Calgary Interagency Pain Assessment Tool (CIPAT), Edmonton Symptom Assessment Scale (ESAS), Palliative Care Services Brochure, Consumer Questionnaire.	n=25, >70 years of age	Cross- sectional Quality: Very low	Survey	Opinions of translated materials.	CIPAT: 62.5% believed it would help them to communicate about pain to a health care professional who did not speak the same language. Only 44.4% found the questions easy to understand. ESAS: 66.6% thought the scales were easy to understand. Palliative care brochure: 45% indicated it was difficult to understand, 42.8% thought the information gave them a better understanding of palliative service.	NA	NR