



Consumer Participation and Culturally and
Linguistically Diverse Communities:
A Discussion Paper

Panayiota Romios
Tony McBride
Jackie Mansourian

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Health Issues Centre Inc.
Level 5, Health Sciences 2
LA TROBE UNIVERSITY VIC 3086

☎ (03) 9479 5827

Fax: (03) 9479 5977

Email: info@healthissuescentre.org.au

Websites:

www.healthissuescentre.org.au

www.participateinhealth.org.au

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Pamela Freeman	Recreation Coordinator Munzer Community Residence
Olga Kanitsaki	Adjunct Professor Division of Nursing and Midwifery RMIT University

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DEFINITIONS

In order to be consistent with the Victorian Department of Human Services' (DHS) participation policy, the following definitions have been adopted for this paper (Department of Human Services, 2006a:75-77).

Advocates – people or groups who assist the consumer, carer or community member to have their views and ideas heard and understood.

Consumers – people who are current or potential users of health services. This includes children, women and men, people living with a disability, people from diverse cultural and religious experiences, socioeconomic status and social circumstances, sexual orientations, health and illness conditions.

Carers – families and friends providing unpaid care to consumers. Carers may often be receiving a government benefit or allowance.

Communities – groups of people who have interests in the development of accessible, effective and efficient health and aged care services that best meet their needs.

Participation – occurs when consumers, carers and community members are meaningfully involved in decision-making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your view, and listening to the views and ideas of others. In working together decisions may include a range of perspectives.

Consumer, carer or community representatives – consumers, carers or community members nominated by, and accountable to, an organisation of consumers, carers or community members. Hence, representatives are there to represent the formal view of a particular group and report back to that group.

Consumer, carer or community nominees – people who are representative of or have links with a particular group(s). They are not accountable in the way that a representative is but are participating because of their links with a group(s).

Health services – publicly funded organisations that provide health care. These include hospitals, rehabilitation centres, aged care services, community health centres and primary care services.

Other concepts used in this paper are:

Culture – Culture is "an historically transmitted pattern of meanings embodied in symbols, a system of inherited conceptions expressed in symbolic form by means of which [people] communicate, perpetuate, and develop their knowledge about and attitudes towards life" (Geertz, 1973).

Cultural and linguistic diversity (CALD) – refers to the wide range of cultural groups that make up the Australian population and Australian communities (Multicultural Mental Health Australia, cited in NHMRC 2005:7). This acronym is used by governments and service providers but may not represent the way ethnic communities or ethno-specific organisations refer to themselves. The terms NESB (Non-English speaking background) or "ethnic communities" are also used by government, service providers and ethno-specific organisations.

Cultural competency – a set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals and enable that system, agency or those professions to work effectively in cross-cultural situations. (Cross et al., cited in NHMRC, 2005:7). Cultural competency is much more than awareness of cultural difference, as it focuses on the capacity of the health system to improve health and wellbeing by integrating culture into the delivery of health services.

Equality and equity – Equity in health means that all people have an equal opportunity to develop and maintain their health, through fair and just access to resources for health. Equity in health is not the same as equality in health status. Inequalities in health status between individuals and populations are inevitable consequences of genetic differences, of different social and economic conditions, or the result of personal lifestyle choices. Inequities occur as a consequence of differences in opportunity; for example, unequal access to health services (WHO 1998, cited in NHMRC, 2005:8).

1. INTRODUCTION

This discussion paper is intended to assist in the implementation of culturally and linguistically diverse (CALD) consumer, carer and community participation in the Victorian health care system. The paper builds on existing Victorian Government policies regarding participation in health care as well as ethnic health policy. It also draws on the Victorian Government's cultural diversity policy to steer the analysis process and the development of supplementary participation actions.

This paper is written for community organisations and health services, both in the acute and primary care sectors, and the Victorian Department of Human Services (DHS).

First, the paper reviews the principles of community participation in health and outlines the Victorian consumer, carer and community participation and cultural diversity policy contexts.

Second, the paper examines some of the barriers and enablers to CALD consumer participation. This section includes information emerging from a literature review and information included in the 2005 report written by the Centre for Culture, Ethnicity and Health, *Consumer Participation and Culturally and Linguistically Diverse Communities*.

Third, the paper outlines the commonalities across Victorian Government policy on cultural diversity and participation in health care, and proposes a participation framework for CALD consumer, carer and community participation at the individual, program and department level, health service level, and DHS level.

Current practice examples for involving consumers, carers and communities from CALD communities and a brief analysis in terms of their capacity to address barriers is included in Appendix 1.

2. CONSUMER PARTICIPATION IN THE VICTORIAN POLICY CONTEXT

Increasing interest in implementing consumer participation in the design, planning, implementation, delivery and evaluation of health services in Victoria follows a broader national and international trend.

There are five over-arching reasons for promoting consumer participation in Victoria's health services:

- The growing commitment at all levels, including consumers and community members, health services and state government, that consumer participation is an ethical and democratic right.
- The evidence that consumer participation improves people's health outcomes.
- The developing experience by health services that consumer participation improves their service quality and safety and ensures that their services are appropriately responsive to the health needs of the communities they serve.
- The rich and diverse voices and perspectives of consumers and community members in health matters.
- The clear policies and accreditation standards in place by the Victorian Government on consumer, carer and community participation in health services.

An extensive body of literature has accumulated which suggests that consumer, carer and community participation in health is beneficial for all those involved in the provision and use of health services (Consumer Focus Collaboration, 2000a). It has been recommended that active participation in care and self-management, education, and written action plans leads to reduced hospital admissions, visits to emergency departments, unscheduled visits to the doctor, and days off work/school (Lahdensuo, 1999; Lorig 1999).

Further, it has been argued that consumer feedback and participation in the planning for new services or resource allocation are useful for the provision of services more in tune with community needs (National Health Strategy, 1993; Draper, 1997; National Health Service, 2005; Consumer Focus Collaboration, 2000b; Department of Health et al., 1999; Department of Human Services, 2000; Department of Human Services, 2005; Department of Human Services, 2006; Baldini et al., 2001; The Cochrane Library, 2006). There have also been developments in the area of consumer participation in research, where consumers and carers are integral to the research process as members of research teams (Oliver et al., 2004; Telford et al., 2004).

However, there is a scarcity of literature documenting CALD consumer participation practice. The Centre for Ethnicity, Culture and Health (CEH) argues that, compared with the growing developments in consumer participation in general, there is little documented work on consumer participation models, methods and strategies for CALD communities (CEH, 2005:6-7). In general, lack of research and evidence based on CALD communities' health is also reported by the NHMRC, arguing that "mainstream research frequently excludes consideration of people from CALD backgrounds due to perceived methodological difficulties and costs" (2005:22), and that: "programs are unlikely to succeed unless they are based on mutual respect and understanding, and are adopted as shared responsibility by the community.

The limits of an exclusive top-down approach can also apply to CALD background community structures, so that use of informal networks as well as working through community leaders may be needed to encourage the participation of all community members" (NHMRC, 2005:23).

In the last decade, the Victorian Government has developed a series of key policy documents that provide an overarching policy context to consumer participation. Policies that identify principles for consumer, carer and community participation as a pillar for democratic processes of government are set out in *Growing Victoria Together* (Victorian Government, 2001) and *A Fairer Victoria* (Victorian Department of Premier and Cabinet, 2005).

Other more recent government policy documents published by DHS, which outline participatory models and argue for meaningful consumer participation in health services, are:

Directions for Your Health System: Metropolitan Health Strategy (DHS, 2003)
Primary Care Partnerships Strategic Directions 2004–2006 (DHS, 2004a)
Community Health Services – Creating a Healthier Victoria (DHS, 2004b)
Participation Indicators (DHS, 2005a)
Doing it with us not for us (DHS, 2006a)
How to Develop a Community Participation Plan (DHS, 2006b)
Community Advisory Committee Guidelines: Victorian Public Health Services (DHS, 2006c)

Two of the most recent DHS policy documents, *Participation Indicators* and *Doing it with us not for us*, identify a series of principles for participation. The nine principles of participation identified by DHS are:

- Trust
- Equal opportunity
- Dissemination
- Openness
- Shared ownership and accountability
- Respect
- Advocacy and support
- Evaluation
- Responsiveness.

(DHS, 2006a:20)

These principles acquire additional complexity when applied to CALD consumer, carer and community participation. Differences in CALD consumers' culture, value systems, education, backgrounds, arrival in Australia—whether as migrants or refugees—and their settlement experience all impact on how they approach participation and how they make decisions regarding their health care.

DHS expects that health services should adopt such principles and report against a minimum set of indicators for quality improvement purposes. The minimum participation indicator set identified by DHS includes:

- Governance – the governing body is committed to consumer, carer and community participation; there is participation in higher level decision-making (e.g. Community Advisory Committees [CACs] as subcommittees of Health Services Boards).

- Accountability – the service reports openly to its communities on quality and safety, and the participation in its processes (e.g. annual quality of care reports).
- Health care and treatment – there is consumer, and, where appropriate, carer participation in clinical care (e.g. patient informed consent). (DHS, 2005a:14)

It is expected that implementation towards the above principles and indicators by health services requires further work to develop and integrate operational guidelines, processes and strategies for participation with CALD consumers, carers and communities. Some of these strategies are explored in Parts 4 and 5.

Levels and types of participation

The following definition of participation provides a context for participation proposed by DHS:

Participation encourages consideration and debate through processes that allow people to be involved in decision-making about their health care and that of the community. Through involvement, decisions are made that may accommodate a range of perspectives. (DHS, 2005: 47)

The abovementioned DHS consumer policy document outlines two frameworks for a better understanding of participation. Participation can occur at different levels, which will influence the methods used. Participation methods also imply greater or lesser degrees of involvement and empowerment of consumers. A spectrum of five key types of participation and four levels where participation should occur in health services are:

Levels	Types
Individual	Information
Program/department	Consultation
Health service/organisational	Partnership
Department of Human Services (or state-wide)	Delegation
	Control

All types of participation are relevant and integral to each level of participation.

As stated earlier, the implementation of CALD consumer participation at these levels, and according to the diverse types of participation, will be influenced by CALD consumer, carer and communities' histories, backgrounds and needs. Different organisations and programs will need to work to dismantle cultural and communication barriers to health care through participation interventions which involve CALD consumers and carers, promote health system redesign, and train health care providers to better understand and manage social and cultural factors that affect health beliefs and behaviours.

3. VICTORIAN CULTURAL DIVERSITY POLICY CONTEXT

People coming to live and settle in Victoria are a very diverse group. They comprise migrants, refugees and asylum seekers, and stem from an extraordinary range of countries and ethnic backgrounds.

It has been suggested that: "migration is a complex phenomenon and the individual immigrant goes through a series of stages of adjustment and response to a number of stressors related to the preparation, process and post-migration adjustment" (Bhugra cited in NHMRC, 2005:16).

Further, the health status of migrants varies according to a series of factors, including birthplace, fluency in English, process of migration, stage of life, whether the individual is part of an established, emerging or refugee community, and each individual's balance of protective and risk factors (NHMRC, 2005:17).

The Longitudinal Survey of Immigrants to Australia (DIMIA 2003, cited in NHMRC, 2005:18) reveals that health outcomes for humanitarian entrants are generally poorer than for other groups of migrants (NHMRC, 2005:18). Small and emerging communities may be particularly disadvantaged as they contend with issues of poverty, unemployment and under-employment, lack of affordable housing, lack of English language skills, social isolation and exclusion, discrimination and racism (NHMRC, 2005:21).

In this context, it is essential to acknowledge that while migrants arrive in Australia with good health, some refugees, asylum seekers, and people in detention centres present with more health problems than other communities. A recent study by the Victorian Foundation for Survivors of Torture (2004:23-24) argues health issues of concern for refugees include mental health, psychosocial issues and nutrition deficiencies, as well as a variety of other health issues such as intestinal parasitic disease, infectious diseases, chronic disease and women's health concerns.

Thus, as well as diversity stemming from cultural, language and migration history factors, CALD consumers, carers and communities have considerable diversity in both health needs and, crucially, in access to health services according to their entry and visa status. For a detailed explanation of these entitlements see Victorian Foundation for Survivors of Torture (2004:50, 62-63).

Victorian Government policies regarding cultural diversity in Australia acknowledge the full tapestry of traditions, values and beliefs that CALD communities represent and the valuable contribution that people from other countries make to the social life in Australia (for details on ethnic communities and demographic details see Department of Immigration and Cultural Affairs, 2005 and the Victorian Office of Multicultural Affairs, 2002).

Several Victorian Government policies on cultural diversity have been launched in the last years including:

Growing Victoria Together (Victorian Government, 2001)

Valuing Cultural Diversity (Victorian Office of Multicultural Affairs, 2002)

Framework for responding to the needs of refugees and asylum seekers within Primary Care Partnerships (Ethnic Communities' Council of Victoria and Centre for Culture, Ethnicity and Health, 2002)

Improving the Use of Translating and Interpreter Service: A Guide to Victorian Government Policy and Procedures (Victorian Office of Multicultural Affairs, 2003)

Cultural Diversity Guide: Multicultural Strategy (DHS, 2004d)
Language Service Policy (DHS, 2005b)
Health Service Cultural Diversity Plans (Victorian Government, 2006)

In 2002 the Victorian Office of Multicultural Affairs launched the *Valuing Cultural Diversity* policy, aimed at acknowledging the cultural diversity of communities in Victoria. The policy establishes the commitment of the government to a multicultural society that values diversity, encourages participation and promotes equality among all members of society.

The government recognises that the diverse cultural backgrounds, languages and abilities of Victorians provide some of the state's greater strengths. To ensure that all members of our community are treated with fairness and respect, and can participate in the state's social and governmental institutions, the Victorian Government promotes the following principles:

- Valuing diversity
- Reducing inequality
- Encouraging participation
- Promoting the social, cultural and economic benefits of cultural diversity for all Victorians.

(Victorian Office of Multicultural Affairs, 2002:7)

In 2004, DHS published the *Cultural Diversity Guide, Multicultural Strategy* outlining the Department's multicultural strategy (DHS, 2004). The strategy adheres to the principles of *Valuing Cultural Diversity* and outlines a range of strategies for programs and agencies to improve cultural responsiveness. It offers examples of best practice, advice for the implementation of diverse strategies, and resources and links for further information. The strategy identifies the following principles and action areas for improvement:

- Understanding clients and their needs by gathering accurate data on cultural diversity.
- Developing partnerships with multicultural and ethno-specific agencies by creating collaborative relationships with ethno-specific organisations to assist mainstream health services to be responsive and effective in delivering services.
- Establishing a culturally diverse workforce by employing bilingual staff or staff who have an understanding of other cultures.
- Accessing professional language services for service users not proficient in English.
- Encouraging participation and decision-making by providing opportunities for participation and decision-making at an individual and group level to address the needs of service users better.
- Promoting the benefits of a multicultural Victoria by recognising and promoting the cultural diversity of Victoria.

Participation of CALD consumers, carers and communities in the Victorian health system is essential. They constitute a significant part of the Victorian population. Health services will need to develop specific and deliberate participation

interventions to involve CALD consumers and carers in service planning, development, delivery and evaluation from the beginning. This will assist health agencies:

- To meet the needs of all their service users. The involvement of CALD consumers, carers and communities makes an especially valuable contribution because of its capacity to define generalised as well as more CALD-community-specific barriers of access and use of services. It will also guide health policy and program decision-makers on the advantages and shortcomings of different approaches, including generating more culturally-appropriate information.
- At an individual level, participation can enable individuals to become involved in decisions about their own care and treatment that is responsive to their own needs. It has been highlighted above that complex factors further impose themselves on the lives of CALD consumers, carers and communities. These need to be taken into account when considering appropriate participation processes, including at this individual level.

The barriers and enablers to CALD consumer, carer and community participation in the Victorian health system are discussed in the following section.

4. BARRIERS AND ENABLERS FOR CALD CONSUMER PARTICIPATION

This section of the paper outlines some of the main barriers and enablers regarding CALD consumer, carer and community participation emerging from a literature reviewed by Health Issues Centre (see Appendix 1: Current practice examples) and an analysis of case studies of current practice provided in the Centre for Culture, Ethnicity and Health (CEH) report: *Consumer Participation and Culturally and Linguistically Diverse Communities*. First, some of the broader socio-cultural barriers to CALD consumer, carer, and community participation are addressed; second, systemic and organisational barriers are addressed. Enablers are also discussed.

4.1 Barriers

These barriers are inter-connected and reinforce each other.

4.1.1 *Lack of understanding of socio-cultural factors*

Insensitivity to the needs of CALD consumers, carers and communities has been pointed out as a barrier for participation. The NHMRC (2005:24) argues that service providers need to: “understand the concept of culture and its impact on human behaviour, and recognise how specific problems are experienced, expressed and defined by consumers and carers of diverse cultural backgrounds (Procter cited in NHMRC, 2005:24).

Culture and belief systems are also important considerations to services working with CALD consumers (Rice et al., 1994; Dawson & Gifford, 2001; O'Regan, 2005). Conceptualising what it means to be ‘sick’ and what it means to be ‘healed’ or ‘cured’ is also culturally constructed and can affect an individual’s health beliefs and behaviours (Helman, 1985; Dawson et al., 2000).

4.1.2 *Lack of effective communication*

Effective communication is critical for effective health care. There are a number of aspects of communication that can create problems when working with CALD consumers, carers and communities. Communication and decision-making styles, interactions and information sharing, privacy and confidentiality, responsibility and accountability, perceived benefits and health care needs are all culturally mediated.

At the individual level, inability to communicate with health care providers clearly creates a barrier to accessing health care. Further, understanding the English language and/or having an interpreter is a necessary pre-condition but does not always ensure that CALD consumers receive appropriate care. There are a number of other factors—such as cultural misunderstandings, lack of reciprocal communication with service providers, and not understanding how the health system works—that are barriers to receiving appropriate care.

At the organisational level, consumer, carer and community participation may also be affected by socio-cultural factors. CEH argues that: “health systems in other countries may be vastly different, so the concept of consumer participation itself may be very unfamiliar” (CEH, 2005:10-11). For example, membership of committees, answering feedback questionnaires or responding to patient satisfaction surveys may be quite unknown to some communities. A cultural

practice such as providing feedback to service providers, or speaking up in a public situation may not be shared by some CALD communities. The CEH report refers to the difficulty in speaking up at meetings that some CALD consumers and carers may have, or the issue that surveys may only elicit positive feedback, in spite of people having negative experiences (CEH, 2005: 10).

4.1.3 Systemic and organisational barriers

Systemic barriers, which include lack of cultural competency on the part of health service providers, lack of data reflecting CALD health issues, lack of language services and lack of awareness and access to multilingual health information all affect the capacity of CALD consumers, carers and communities to effectively participate at the individual, program, organisational and DHS levels. Among the most clearly identified barriers to consumer and carer participation are:

Lack of language services – the inability of a health care provider to communicate with CALD consumers clearly impacts on the quality of care received, and decreases the likelihood of follow-up.

Lack of data – The absence of accurate information about health status and health care needs of CALD communities and subgroups in these communities can prevent effective planning for service provision.

Lack of awareness of and access to health information – The absence of culturally and linguistically appropriate health education materials about health care options, services available and health issues means that CALD consumers, carers and communities are disadvantaged and lack access to the choices available to them.

4.1.4 Ongoing issues for CALD participation

After their analysis of case studies on CALD consumer participation practice, CEH (2005) concluded that there are a series of interrelated factors acting as barriers to CALD consumers', carers' and communities' participation. It is important to note that most of the issues identified by CEH as barriers to CALD community participation also affect the broader community's capacity to participate. However, these acquire relevance for CALD communities when combined with the broader socio-cultural barriers referred to above.

Issue of representation – giving some members of a community a 'voice' and/or inviting them to participate in a mentoring scheme may create a hierarchy within a community, where some other members may feel marginalised and powerless; in fact, community 'leaders' may not lead all in the community.

Unequal partnership – most commonly, the health service has more resources and professional expertise, benefits from and instigates consumer participation activities and sets the agenda in terms of community needs, thus creating a barrier to a partnership approach to consumer, carer and community participation.

Funding for consumer participation – frequently, organisations focus mainly on the demands that consumer participation imposes on the organisation and not on the benefits it offers. Organisations perceive they are inadequately resourced to implement CALD consumer participation in a meaningful way. This argument is related to the priority-setting of the organisation; if organisations acknowledge the benefits of consumer participation, it may become a priority and funding would be allocated appropriately.

Reimbursement for participation – some organisations experience difficulties when deciding to reimburse community members for participation on committees. This decision may mean supporting only a few members of the community, to the disadvantage of others who may not be able to dedicate time to participation because their priorities may be elsewhere; for example, housing and employment needs.

4.2 Enablers

These enablers are inter-connected and reinforce each other.

A series of enablers have been identified by Health Issues Centre through the literature reviewed for the purpose of writing this paper.

Most effective participation depends on a series of enablers including cultural competency, comparative analysis of demographic and service utilisation data, accessible and appropriate language services, development of equal partnerships between health services and CALD community members and their organisations and groups, availability of accessible health information, workforce diversity, whole-of-community approach and organisational commitment with adequate resourcing.

4.2.1 Cultural competency

The implementation of appropriate cultural competency 'training' is critical.

This 'training' needs to integrate reflection, which allows health service providers and managers at all levels of the service to consider their own personal, professional and organisational cultures and values. Often when cultural diversity is discussed it is done so in reference to 'the other'. Yet this level of reflection and 'training' acknowledges that diversity is inherent and generalised. It is an important beginning point to cultural competency.

This does not deny the importance of learning about the beliefs and behaviours of different cultural and linguistic communities as they affect their health and wellbeing. However, this needs to be augmented by learning that includes recognition of the health inequities experienced by people from CALD communities and the complex barriers they face as migrants (both longer term and/or newly arrived) and/or refugees in the Australian context.

Further, it is important that such 'training' does not stereotype people. There is great diversity of both individual and collective experience within any specific CALD community. There exists a dynamic tension and development of people's cultures, even as a 'minority culture' within a dominant social context.

A culturally competent health system has the potential to overcome cultural and linguistic disparities and inequities. This is integral to the quality of health care received because the objective of culturally competent care is to secure the provision of appropriate services, reduce the incidence of error and improve the efficiency of care.

4.2.2 Comparative analysis between demographic and service utilisation data: knowing who is out there and who is and isn't using the services

It is important to collate and analyse demographic data and health service utilisation information. A match between health service utilisation of CALD people

and their representation in the catchment area of the health service is an important indicator of an accessible service. A mismatch suggests barriers to access and the need for strategies that effectively encourage reaching out and working with relevant CALD communities and organisations to identify and address these barriers.

4.2.3 Accessible and appropriate language services

Access to appropriate language services does have an impact on health outcomes for CALD consumers and carers not able to communicate in English.

A common view is that organisations delivering treatment and care to CALD communities should strive to provide interpreting and translating services to patients and their families, and that this would mean a reduction in the cost of service provision to these patients (Department of Victorian Communities, 2002:10; Action on Disability with Ethnic Communities, 2001:30). For example, patients with access to interpreters are less likely to be re-admitted to emergency departments and more likely to keep follow-up appointments; patients who do not have access to language services may stay longer in emergency departments and have a higher number of diagnostic tests administered; lack of explanation of side effects means negative compliance with medications (Bahro, 2002:5).

4.2.4 Developing equal partnerships with multicultural and ethno-specific agencies, organisations and multiple community groups

Building relationships based on mutual trust with a long-term commitment to the partnership is critical.

Effective outreach to initiate dialogue and partnerships with organisations and community groups becomes the responsibility of the health service. Health services need to make efforts to understand communities and identify appropriate and ongoing channels, modes and means of communication.

Outreach to CALD communities may include the provision of health care in identifiable cultural settings and neighbourhoods and in partnership with ethno-specific agencies. This approach focuses on reducing barriers to care by offering services within geographical locations regularly visited by targeted CALD communities, including those that have flexible hours of service. Outreach may also be necessary on particular health issues that cut across geographical boundaries. Strong links with ethno-specific agencies and community leadership across multiple community groups become even more relevant.

Several studies have argued that developing questionnaires, surveys and interviews in collaboration with partner organisations, including bilingual workers, consumer consultants or training bilingual participants to become researchers themselves, have proven to be effective for consumer participation (Karantzas-Savva & Kirwan, 2004; Brisbane Inner South Division of General Practice, 2001; Var, 2004; Queensland Government et al., 2003; Consumer Focus Collaboration, 2000; Royle et al., 2001; Steel, 2004).

Equality in the partnership means that the same value is placed on the expertise of consumers in their organisations and groups as on the health service's organisational and professional expertise. It is important that partner organisations, community groups and their members are able to define the priorities and agenda in terms of their needs and experience. Equal partnerships need to be mutually

beneficial directly to community group members, their organisations as well as the health service.

4.2.5 Availability of accessible health information

The availability of culturally and linguistically appropriate health education materials about services and health issues are important to ensure differences in language and sensitivity to cultural beliefs and behaviours are addressed. For example, reporting quality and safety data to ethnic communities needs to be instigated in collaboration with ethno-specific organisations to ensure understanding and appropriateness of the messages and the means of dissemination.

4.2.6 Workforce diversity

It is important that health services reflect the consumers, carers and communities they work with as well as their broader catchment. The presence of bilingual and bicultural staff in health services increases access by health consumers and also builds on organisational cultural competency.

A key issue for bicultural workers, whether in their direct service provision and especially in their role of access and liaison with CALD communities, is that they can feel and be easily marginalised. Such workers are often having to respond to the barriers and inequities that CALD consumers have faced. Bicultural health workers need to be appropriately supported.

It is also necessary to acknowledge that the work with CALD communities is the responsibility of the whole-of-health service and staff and integrated into the provision of mainstream services.

4.2.7 Whole-of-community approach

Acknowledging diversity within a particular CALD community, even if they speak the same language or dialect, is essential for successful consumer participation.

Historical background, past conflicts, gender roles, political and socio-economic differences, generational barriers and settlement experience, may determine the way in which different members of the 'same' community responds to a health service's invitations to participate.

People can be marginalised even within their own culturally-specific groups and it is important that the multiple voices and experiences of members are heard and acknowledged.

For health services working with CALD community leadership and representatives every effort should be made to get to know the nature of the representation; for example, where is the consumer positioned in that community, and how will the person seek feedback from the community when needed? (Queensland Government, Queensland Health, 2003; Var, 2004; Brisbane Inner South Division of General Practice, 2001; Karantzas-Savva & Kirwan, 2004).

4.2.8 Organisational commitment with adequate resourcing

Most literature on consumer participation affirms that participation should be included in a whole-of-organisation policy and that written policies are needed for its meaningful implementation (DHS, 2005, 2006; Department of Health et al., 1999; Government of South Australia, 2005).

Having a clear understanding of the rationale for consumer participation in general, and CALD consumer, carer and community participation specifically—and why it is important for a health service —would establish the foundations for a commitment to invest human and financial resources in participation.

5. FRAMEWORK FOR CALD CONSUMER CARER AND COMMUNITY PARTICIPATION

The current Victorian Government's cultural diversity policy addresses issues of access and equity, arguing that all consumers need to be able to access health services and that the responsibility is on services to develop policies to ensure access and equity.

Current consumer participation policies also aim to ensure accessible and appropriate service development; that is, to make sure services are relevant to health consumers' and carers' needs.

What both policies are identifying is the need for a cultural shift by the health care system, which is aimed at better health outcomes. This would necessitate the integration of components of cultural competence into various aspects of consumer, carer and community participation. That is, in order to adhere to DHS participation principles, health services need to implement supplementary actions acknowledging CALD consumer, carer and community diversity.

An analysis of the six principles and actions outlined by the *Cultural Diversity Guide* and the nine principles of consumer participation outlined in the *Doing it with us not for us* policy demonstrates that a framework for the participation of CALD consumers, carers and communities would require:

- Reviewing current methods of consumer, carer and community participation and identifying benefits
- Identifying supplementary participation actions
- Identifying key components of cultural competence and developing recommendations for supplementary participation actions.

Supplementary participation actions for CALD consumer, carer and community participation must address all levels of the health service system: individual; program/ward; organisational level; and DHS levels. This section of the paper offers a framework for effective CALD consumer, carer and community participation. The framework is based on the levels of the health service system and types of participation outlined by the DHS *Doing it with us not for us* consumer participation policy. The supplementary participation actions suggested respond to the current cultural diversity policy recommendations and are based on the literature review, the CEH report, and the analysis of current practice examples.

5.1 Prerequisites

A whole-of-health care system approach to dealing with CALD consumers, carers and communities is essential to ensure that each health care service plans for and delivers to our diverse community. The same requirement applies to DHS program areas and the services they fund to serve culturally and linguistically diverse population groups. It is essential that all health services therefore develop and implement *Health Service Cultural Diversity Plans* (Victorian Government, 2006) and report annually on their performance against those plans to DHS.

There must also be strategies to ensure the involvement of CALD consumers, carers and communities, and potential CALD service users in the development of these plans and on the health services' cultural diversity committees.

In order for health care services' participation initiatives and ongoing efforts to be meaningful with CALD consumers, carers and communities, key processes need to be developed. These are:

1. Health care services and providers that reflect the diversity of communities served.
2. Communication that aims at overcoming language barriers.
3. Consideration of CALD consumers, carers and community members as 'experts' on how to best serve them, consult and work in partnership with them regularly about service delivery planning and evaluation.
4. Health provider sensitivity to their own cultural beliefs and behaviours that may marginalise CALD consumers, carers and communities.
5. Increased health provider knowledge of cultural and ethnic variation in health beliefs and behaviours among and within communities and sub-groups.
6. Health services that benchmark their consumer, carer and community participation to enhance their practice; for example, their consultation strategies and relationships and networks with ethno-specific organisations and community groups.
7. Allocation of extra health service funding for more comprehensive interpreting and translating services and written information.
8. Relationships and partnerships with ethno-specific agencies and engage them in the early stages of consumer, carer and community participation planning.
9. Ethno-specific agencies' capacity building to work collaboratively with health services.
10. Ongoing provision of grants to ethno-specific agencies, with a focus on engagement and participation, especially with emerging communities or ageing communities (high users of health care services).

5.2 Strategies for CALD consumer, carer and community participation: according to levels of participation

This section outlines the key priority action strategies in the DHS participation policy *Doing it with us not for us*, and suggests some additional and necessary participation actions for CALD consumers, carers and communities.

1. Individual care level

- 1.1 Promote the rights and responsibilities of patients to the community, consumers and carers.
- 1.2 Communicate clearly and respectfully with consumers and carers.
- 1.3 Provide accessible information to consumers, carers and community members about health care and treatment.
- 1.4 Communicate and provide evidence-based information about treatments and care to consumers and carers developed with consumers and, where appropriate, carers.
- 1.5 Listen and act on the decisions the consumer, and, where appropriate, their carer(s) make about their care and treatment.

CALD strategies

Establish cross-cultural communication at the individual level and culturally-competent health services by:

- Developing staff and management cultural competencies, including training which explores multiple elements; from exploring cultural values of staff and the health service as well as specific CALD communities, to how to work with interpreters.
- Providing translated resources and materials about consumers' rights and responsibilities, and culturally-appropriate information about the health care system and services.
- Using ethnic media (radio, newspapers) to distribute health information.
- Providing interpreting and translating services.
- Employing bilingual, bicultural staff and providing adequate support
- Establishing culturally-specific health care practice; for example, offer family interviews rather than just individual interviews to engage consumers and carers in decision-making.
- Employing CALD liaison officers and providing adequate support.

2. Program/department level

- 2.1 Involve consumers, carers and community members from the planning stage through to evaluation and monitoring.
- 2.2 Create welcoming and accessible services for the diverse members of your community.
- 2.3 Provide training to staff in communication skills and how to involve consumers and carers in decision-making.
- 2.4 Promote the importance of consumers and carers providing feedback to improve services.
- 2.5 Establish links with community organisations to provide emotional support and ongoing information to consumers and carers.
- 2.6 Involve consumers, carers and community members in the development of clinical guidelines and research.

CALD strategies

Consultation/involvement of CALD consumers and communities by:

- Promoting health services and consumer participation through translated materials; for example, brochures, videos, CDs, websites.
- Using ethnic media (radio, newspapers) to disseminate information about health services, health issues and invite participation.
- Initiating and developing relationships and partnerships with ethno-specific agencies, organisation and community groups
- Auditing existing CALD participation in the health service, programs and departments.
- Providing access to interpreting and translating services and training on the use of language services.
- Establishing a process for recruitment and appropriate support, including language services, to CALD consumers and carers as part of participation developed by programs and departments within the health service. It may be appropriate to have CALD-specific consultation and participation initiatives or to integrate CALD consumers and their experiences within the more generic process.
- Establishing feedback and complaints mechanisms outside the health services; for example, discussions about health services held at community settings.
- Promote dialogue and cross-cultural discussion between diverse cultural groups, English and non-English speaking, and between CALD communities about health and culture.

3. Health service organisational level

- 3.1 Integrate participation of consumers, carers and community members, representatives or nominees into the quality and safety program.
- 3.2 Community representatives or nominees to be involved in the review of system level issues regarding consumer and carer feedback and complaints.
- 3.3 Include the involvement of consumers, carers, community members, representatives or nominees in all aspects of the organisation's planning and development.
- 3.4 Provide staff training and education on how to use the different types of participation.
- 3.5 Ensure position descriptions include participation components.
- 3.6 Evaluate, monitor and report on participation to the community and the Department of Human Services.

CALD Strategies

Development of health service policy/CALD framework by:

- Integrating CALD consumer, carer and community participation within generic participation policy and procedures.
- Developing organisational 'Access and equity' policies and procedures that are strongly linked to participation policies.
- Obtaining sign-off of these policies by the Board or Committee of Management.
- Ensuring organisational business plans, position descriptions, staff appraisals and work plans include CALD participation components.
- Engaging CALD consumer and carers in developing job descriptions and/or selection panels.
- Promoting health services and consumer participation through translated materials; for example, brochures, videos, CDs, websites.
- Establishing relationships and partnerships with ethno-specific agencies, organisations and community groups with a long-term commitment.
- Establishing processes for recruitment and support of consumers and carers from CALD backgrounds in all aspects of the organisation's planning and development. It is important that CALD consumers are integrated and included fully as part of their participation experience. It is very easy to be marginalised.
- Learning from CALD community groups and ethno-specific organisations on appropriate methods of participation with diverse parts of the community and on particular health matters and services.

4. Department of Human Services level

- 4.1 Use the same processes of working with and accessing consumers, carers, and community members, representatives or nominees across the Department of Human Services.
- 4.2 Provide support, guidance and resources to health services and consumers, carers and community members on participation.
- 4.3 Provide training and education to Department of Human Services' staff on how to use the different types of participation and evidence-based participation and communication.
- 4.4 Encourage health services to evaluate and monitor participation within a quality improvement framework.
- 4.5 Encourage the inclusion of participation skills and knowledge in the tertiary education of health professionals.
- 4.6 Advocate for a whole-of-Department of Human Services policy on participation.

CALD strategies

Develop a Department of Human Services' CALD participation framework by:

- Developing policies and protocols regarding CALD consumer, carer and community participation across the Department of Human Services.
- Establishing mechanisms for recruitment and support of consumers and carers from CALD communities involved in ministerial or DHS advisory committees (e.g. orientation to current government cultural diversity policies; provide examples of how CALD communities have been involved in other services).
- Integrating cultural competence into consumer participation indicators.
- Link CALD participation to health services' quality improvement framework; for example, use specific CALD consumer participation indicators.
- Celebrating partnership work with CALD organisations publicly.
- Establish feedback and compliant mechanisms outside the health services; for example, discussions about health services held in community settings.

5.3 Strategies for CALD consumer, carer and community participation: Types of participation

Approaches	Description
<p>Information (needed for participation)</p>	<p>Aims to support participation, convey facts, and educate. <i>Strategy: Provide information in a variety of translated formats (CDs, videos, diagrams, pictures, brochures, website); provide language services; develop staff and management cultural competency; disseminate information through local ethnic media; develop information in collaboration with CALD communities; develop information that acknowledges cultural practices and beliefs; acknowledge barriers that exist for CALD people's access to health services and health; develop decision aids that are culturally sensitive; use international symbols for those with written and/or spoken language difficulties and use the National Interpreter Symbol (Victorian Office of Multicultural Affairs, www.voma.vic.gov.au)</i></p>
<p>Consultation</p>	<p>Aims to gauge reaction to a proposal, a care plan or a treatment plan and invite feedback. Consultation is only participation when information gathered can influence subsequent policy, care and treatment choice.</p> <p><i>Strategy: Gather information about best consultation mechanisms for specific CALD communities, including diverse parts of each ethno-specific group; establish relationships and partnerships with ethno-specific organisations and community groups with a long-term commitment; outreach and be present in settings used by CALD communities; integrate a consultative process that fits in with CALD communities' own agenda and processes; provide information about the health service and invite to participate through a diverse range of translated means (videos, CDs, websites, brochures, personal contact); give feedback to people who have been consulted about how their priorities and ideas have been integrated into decisions</i></p>
<p>Partnership</p>	<p>Aims to involve consumers, carers and representatives in aspects of government or health service organisational decision-making, and to involve consumers, carers and representatives in health care or treatment decision-making.</p> <p><i>Strategy: Provide information about the service and invite to participate through a variety of translated formats (CDs, videos, brochures, website); use local ethnic media to provide information about the service and participation; provide language services; clarify existing decision-making structures and systems within the health service and how CALD community participation sits within and enhances; support the development of leadership of CALD community groups in health matters; strengthen relationships and partnerships with ethno-specific organisations and community groups; develop and integrate the priorities and participation ideas of CALD communities in direct program development and ensure their participation at every stage of planning, implementation and evaluation; ensure decisions are mutual and transparent between health service and partner organisations and community members from CALD communities</i></p>

<p>Delegation</p>	<p>Aims to hand control to a board of community representatives within a specified framework and to ensure policy options are formulated at arms' length from partisan politics.</p> <p><i>Strategy: strengthen partnerships with ethno-specific organisation and their leadership; consult and mutually define a process with CALD communities and partner organisations about hand-over; be available to provide ongoing support as defined by partner organisations and community groups; stand-by partner organisations during challenging work; be and advocate for partner organisations and their health initiatives</i></p>
<p>Control</p>	<p>Aims to hand control of an issue to the electorate and to hand control to the consumer of health care.</p> <p><i>Strategy: establish relationships and partnerships with ethno-specific organisations and their leadership; consult CALD communities about appropriate mechanisms of effective control and management of issues; support the development and resourcing of health initiatives by partner organisations; respond to their initiatives and provide resources(organisational, technical, human and opportunities for funds) where possible</i></p>

6. DISCUSSION

This paper has argued that to implement the Victorian Government's policies regarding participation in health within CALD consumers, carers and communities the health system needs to address more actively and deliberately a series of barriers experienced by this group of Victorians.

This would involve the development of awareness and emphasis of cultural competence issues during the establishment phase of the proposed framework.

Given the structure of the health system and service delivery arrangements and the structural barriers experienced by CALD consumers, carers and communities, it is clear that only through participation and partnership with these groups of consumers can the health system be re-oriented and quality health care attained. For example, a better understanding of cultural variations in health beliefs, values and behaviours would ensure that the health needs of CALD consumers and carers are addressed, and an optimal quality of care is delivered across the health system.

The process of engaging CALD consumers, carers and communities in the design, planning, implementation and evaluation of health services and at the individual level of treatment of care will need to take into consideration important contextual issues. These include:

- Developing a shared definition of what participation means; that is, health providers and consumers and carers sharing an understanding of consumer participation in health services and individual care.
- The need of organisational commitment to support CALD consumer, carer and community participation based on an acknowledgment of its benefits.
- The development of organisational supports to assist CALD consumers, carers and community members to become involved.
- Acknowledgment that individual social and cultural factors and migration and settlement history may impact on the capacity of CALD community members to participate.
- Agreement to work collaboratively with ethno-specific agencies, advocacy groups and peak bodies.
- Health services' commitment to facilitate participation at individual level of care and treatment by having processes that address barriers to participation.

Issues still to be addressed include:

- Issues of representation/heterogeneity of CALD communities. When considering culturally diverse communities it is important to remain attuned to the tendency to homogenise differences in backgrounds, viewpoints and needs.
- The democratic form of participation may not be familiar to certain CALD groups and that motivation for participation needs to be addressed with individual CALD communities.

- CALD consumers', carers' and communities' lack of familiarity with the Australian health system; this may affect the expectation of involvement and participation, including individual decision-making in treatment and care.
- The perception of some health service providers that CALD consumers, carers and communities are difficult to engage and involve.
- The tailoring of existing participation approaches; that is, the need to expand standard techniques of consumer participation to meet CALD needs. This would involve consultation and a movement away from standard consumer participation modes of engagement that have primarily focused on representation of committees and consultation.

It is clear that the implementation of consumer participation through a cultural competence participation framework can eliminate ethnic and cultural disparities in health care. For example, workforce cultural competence increases the number of bilingual staff within health services and, more importantly, health services' capacity to engage with CALD consumers, carers and communities.

Expected Outcomes

Expected outcomes emerging from effective CALD consumers, carers and communities' participation and the implementation of a cultural competency participation framework are:

1. Cultural relevance and acceptability of health information and care.
2. Increased accuracy in care and treatment (of both individual and community health issues) and use of appropriate interventions at both individual and community levels.
3. Increased consumer and carer understanding of, and adherence to, treatment.
4. Increased consumer and carer understanding of, and satisfaction with, the health system.
5. Increased consumer access to quality health care.

Expected long-term health outcomes from effective CALD consumer, carer and communities' participation include:

- a decrease in inappropriate differences in characteristics and quality of care provided across population groups
- fewer safety issues and adverse events
- smaller gaps in health status across diverse population groups.

7. CONCLUSION

There are clear links between cultural competency, quality of care and the elimination of ethnic and cultural disparities in health. While acknowledging many causes for such disparities, efforts to improve appropriateness of care through participation at multiple levels is crucial. Cultural competency adjustments in participation approaches would further the quality of care as a whole and needs to occur at the systemic and clinical encounter levels.

The paper provides a framework that reflects a coordinated approach to improving participation in health care by extending the DHS approach to CALD consumers, carers and communities.

The analysis operates at two interrelated levels. At one level, it addresses the barriers experienced in health care by CALD consumers, carers and communities. These include communication barriers and lack of cultural competency of the health care workforce. At the same time, the framework makes recommendations that address the participation levels outlined in the DHS *Doing it with us not for us* policy document. It is apparent that these two levels are linked—as both cultural diversity and health policy reforms aim at increasing participation and awareness of consumers' rights in health care.

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APPENDIX 1: CURRENT PRACTICE EXAMPLES

This section of the paper describes and analyses a series of documents describing current practice in consumer, carer and community participation amongst CALD communities. The analysis identifies if the current practice examples address the barriers and enablers previously identified in this paper.

1. **Reality check** (National Mental Health Strategy, 2004) presents the findings of a series of national consultations with CALD mental health consumers. The project aimed to obtain information about the needs and concerns of CALD mental health consumers to be used for the development of strategies to deal with: barriers to effective consumer participation; the development of a CALD consumer action plan by services; and support several strategic planning and other operational and policy purposes. Key findings included the following barriers:

- Lack of information available to CALD consumers
- Isolation and stigma
- Different cultures have different understandings of mental illness
- Impact of ethnicity and language barriers in seeking information about services
- Interpreters' lack of understanding of mental health issues
- Problems finding a service and using the service
- Lack of understanding of cultural needs.

Recommendations emerging from the consultation included:

- Information provision: 1800 number for CALD consumers; centralised point of contact; bilingual workers and interpreters; phone card; buddy system; consumer workers; easy-to-read information about mental illness; videos; using SBS radio; information about CALD mental health services; poster about ethnicity and mental health.
- Community education: face-to-face education; written material; SBS radio.
- Culturally-competent services: accredited cross-cultural training for health professionals; training for interpreters about mental health; training on the use of interpreters involving consumers.
- Social support services: social activities; ethno-specific support groups.

2. **The National Health and Medical Research Council** (NHMRC 2005) developed a guide to assist policy-makers and managers with culturally-competent policy and planning at all levels of the health system. The guide was based on Australia-wide consultations and identified the following barriers to culturally-competent health promotion:

- Lack of uptake of policy frameworks
- Lack of evidence base
- Inconsistent practice
- Insufficient resources
- Lack of community participation.

A health system that is culturally competent:

- Acknowledges the benefits that diversity brings to Australian society.
- Helps health providers and health consumers to achieve the best, most appropriate care and services.
- Enables self-determination and ensures a commitment to reciprocity for culturally and linguistically diverse consumers and communities.

- Holds governments, health organisations and managers accountable for meeting the needs of all members of the communities they serve.

The guide acknowledges four interrelated dimensions of cultural competency: systemic, organisational, professional and individual, and the following principles:

- Engaging consumers and communities and sustaining reciprocal relationships
- Using leadership and accountability for sustained change
- Building strengths – know the community, know how it works
- A shared responsibility – creating partnerships and sustainability.

Consumers have a right to health initiatives that respond to their social, cultural, linguistic, gender and spiritual and/or religious diversity, and promote their health and wellbeing in this context. Promotion of healthier living and environments is a reciprocal relationship—CALD communities and the health sector seeking to engage, learn and exchange at all stages of health care. Leadership and accountability for cultural competence and responsiveness to diversity begins at the highest levels of systems, organisations and professions and continues at individual development and practice.

3. *Mental Health Consumer Participation in a Culturally Diverse Society Research Project* (Sozomenou et al., 2000). The research project adopted five main strategies to investigate the factors that have facilitated or hindered CALD consumer, carer, community, and health professional partnerships:

- Conduct a literature review.
- Conduct a national survey of consumer, care and community participation initiatives currently being undertaken across Australia.
- Based on the results of the national survey and the literature review, evaluate these selected projects in more depth.
- Conduct a consumer/carer forum to create an opportunity to contribute their experiences and view points.
- Invite consumers, carers, community members and health professionals to discuss or submit in writing their experiences of being involved in participation initiatives.

The results of the research indicate that there is no current definitive model for developing successful partnerships with consumers and carers. Forming partnerships that are inclusive of the heterogeneity of consumers, carers and communities in Australia requires flexibility. One of the most critical dimensions of flexibility required concerns the nature of the support provided to participants to enable them to participate. Participation initiatives also need adequate resources and participants need training to develop skill and knowledge.

The research concludes that “there is nothing particularly special about the needs of CALD consumers” (p. xvii). Treating people equally though often requires developing participation initiatives that are tailored around individuals’ needs (p. 203).

4. *Cultural and Linguistic Diversity Strategy* (DHS Disability Services, 2004). The goals outlined in the strategy are:

- Understanding people and their needs
- Encouraging participation in decision-making
- Providing culturally relevant and accessible information
- A culturally diverse workforce

- Using language services to best effect
- Promoting the benefits of a culturally diverse Victoria.

It recommends that strategies to achieve these goals should be imbedded in existing quality processes such as the Regional Service Excellence Framework for DHS, the Quality Planning and Improvement Activity Reporting process, and the Victorian Disability Standards for Disability Funded Community Service Organisations (p. 18).

5. ***Better Ethnic Access to Services Resource Kit*** (Action of Disability with Ethnic Communities Inc., 2003) is designed for the use by Primary Care Partnerships (PCP) and individual service providers.

The Kit includes a 'whole-of-organisation approach' to assist individual service providers in PCPs to develop practical plans for improving access for CALD consumers. The service cycle includes the following:

- Stage 1: Dissemination of promotional material; networking with ethnic agencies to increase access.
- Stage 2: Location of service and a 'multicultural image' will encourage participation.
- Stage 3: Service access requires the assessment of consumer's actual needs and provides the service through trained and resourced staff; for example, translated materials.
- Stage 4: Service provision requires the development of a cultural diversity policy that covers information provision, employment practices, service delivery and resource allocation.
- Stage 5: Management/governance to encourage and support CALD members to become involved.
- Stage 6: Evaluation needs to be carried out in a comprehensive and ongoing process that involves consumers.

6. ***Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model*** (Brach and Fraser, 2000). The authors identify the following cultural competency techniques:

- interpreter services
- recruitment and retention policies
- training
- coordinating with traditional healers
- use of community health workers
- culturally relevant health promotion
- immersion into another culture
- administrative and organisational accommodations.

The techniques could assist clinicians to deliver appropriate services to diverse populations, thereby improving outcomes and reducing disparities.

7. ***Cultural Planning Framework and Resource Kit*** (Central East Primary Care Partnership, 2003). The framework presents ideas and information to agencies to assist them to better meet the needs of CALD consumers, potentially provide access to a greater number of consumers and provide more equitable services. It identifies the following five steps:

- Planning
- Language services
- Consumer feedback and consultation
- Agency capacity building
- Marketing and promotion.

8. **Health Service Cultural Diversity Plan** (Department of Human Services, 2006). Victorian health services are to introduce cultural diversity committees that will develop health service cultural diversity plans. The committees and plans must respond to the following minimum requirements:

- understanding client needs
- Partnerships with multicultural and ethno-specific agencies
- A cultural diversity workforce
- Using language services to best effect
- Encouraging participation in decision-making
- Promoting the benefits of a multicultural Victoria.

Cultural diversity plans should be linked to health services' strategic planning, implemented within a quality and safety improvement framework and reported through the *Quality of Care* reports. The establishment of cultural diversity committees will enhance the health services' capacity to respond to their CALD communities' needs through strategic coordination and planning processes. The cultural diversity committees will support the health services in the development, implementation, monitoring and reporting of their cultural diversity plans.