

Strengthening services for children with cancer and their families from a culturally and linguistically diverse (CALD) background

Summary Report

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Executive summary

Victoria is Australia's most culturally diverse state with over 24% of the population being born overseas, of whom 74% come from a non-English speaking country.

Given that there are few resources to support children with cancer and their families from culturally and linguistically diverse backgrounds (CALD), the Paediatric Integrated Cancer Service (PICS) has established this Project to develop a strategy to address the needs of CALD children and families. A particular focus has been placed on the services at the Royal Children's Hospital (RCH) and the Monash Medical Centre (MMC) Children's Cancer Centres.

This Project was informed by evidence from the literature, evidence of current services and practices and consultation with key staff from the Children's Cancer Centres and from interpreter services.

Although just over 20% of all parents of children diagnosed between January 2007 to June 2008 (n=215) were born in one of 27 non-English speaking countries, only 3% of all families were formally identified as needing an interpreter.

Whilst a range of strategies are used to support CALD families, there is some evidence that more consistent and pro-active approaches need to be integrated into care. In addition, few staff had been provided with formal training on cultural diversity or on how to work with interpreters.

Interpreters play an important and highly valued role in facilitating access to information for CALD families. However there are a number of challenges for interpreters and Children's Cancer Centre staff. These challenges include the demands on interpreter services, interpreters being unprepared for '*bad news*' consultations, dealing with sensitive information, translating complex medical information and concerns about the quality of the information translated.

Few paediatric cancer related local or national resources are available in other languages in either written or audio-visual formats.

Finally a number of opportunities do exist that could inform or facilitate the implementation of a service model for CALD children with cancer and their families.

The service model and strategy

The proposed service model articulates a series of principles to guide practice and a tailored approach to responding to the needs of all CALD families, regardless of their English language proficiency.

Other key aspects of the model include:

- creating a '*diversity friendly*' environment
- strategies to strengthen the service system, its policies, protocols and processes
- strengthening the workforce through training and education
- assessing and responding to cultural and language needs
- developing resources to support families and staff including :
 - key resources in five priority languages (Vietnamese, Cantonese / Mandarin, Arabic, Turkish and Cambodian)
 - pictorial resources to support all families with limited English
- developing internal and external partnerships.

A series of goals and suggested performance indicators have also been put forward to facilitate and monitor the implementation of the strategy over time.

An implementation strategy is proposed. While a significant investment in terms of time and resources is required, this investment will result in a range of resources that will be available over time, and position PICS and its service sites as leaders in this complex area within the PICS partner agencies as well as with children's cancer services nationally.

Recommendations

The following recommendations are made to support the implementation of the PICS strategy for strengthening services for children with cancer and their families from CALD backgrounds.

1. That the PICS Steering Group endorses the overall directions for the development, implementation and monitoring of the CALD strategy.
2. That funding be allocated or a strategy developed to attract funding to support the full implementation of the CALD strategy.
3. That mechanisms are developed to ensure effective leadership and coordination of the strategy within and across PICS service sites.
4. That priority be given to:
 - participation of staff in formal cultural diversity training programs being offered through the relevant health services
 - the development of a minimum set of information resources in up to five language groups
 - the development of other pictorial resources to aid communication with families from all language groups
 - ensuring that the specific cultural and linguistic needs of CALD families are adequately assessed and the responses to these needs are agreed and integrated into individual care plans
 - the development and implementation of strategies to prepare and support interpreters for difficult or distressing consultations
 - ensuring staff adopt pro-active approaches that will better enable families to access the range of services available
 - a range of strategies to facilitate the support and coordination of care for all CALD families.
5. That all PICS service sites implement mechanisms to create a more culturally aware and welcoming environment for CALD children and their families.
6. That PICS services further strengthen their relationships with interpreter services and those responsible for the organisation's overall cultural diversity policies and procedures for mutual benefit and to reduce duplication of effort.
7. That PICS takes a leadership role in developing partnerships with other children's cancer services and the Australian and New Zealand Children's Haematology Oncology Group (ANZCHOG) to address the needs of CALD families affected by cancer to optimise the best use of limited resources.
8. That this plan be reviewed periodically and new goals established to ensure that all CALD families have access to resources and services to optimise their active involvement in decision-making, informed consent and care of their child.

1. Introduction

The Paediatric Integrated Cancer Service (PICS) was established in 2004 as a partnership between the Royal Children's Hospital (RCH), Southern Health (Monash Medical Centre – MMC) and Peter MacCallum Cancer Centre (Peter Mac). The aim of PICS is to improve the quality of and access to cancer care for children and adolescents with cancer and their families across Victoria.

Given Victoria's significant multicultural background and the complexity of treatment of childhood cancers, responding to the needs of children and adolescents with cancer and their families from culturally and linguistically diverse backgrounds (CALD) presents another significant challenge to health care professionals. This Project has evolved due to recognised gaps in services for CALD families who have a child or adolescent diagnosed with cancer.

This report provides an overview of the Project and summarises a range of evidence which is then used to inform the development of the proposed service model and strategies for enhancing services in the future.

Box 1 provides definitions for key terms used within this document.

Box 1: Definitions

Cultural and linguistic diversity refers to the wider range of cultural groups that make up the Australian population and Australian communities. The term acknowledges that groups and individuals differ according to religion and spirituality, racial backgrounds and ethnicity as well as language (NHMRC, 2006).

Cultural competence is 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 professionals to work effectively in cross-cultural situations. Cultural competence is much more than awareness of cultural differences, as it focuses on the capacity of the health system to improve health and wellbeing by integrating culture into the delivery of health services (NHMRC, 2006).

To become more culturally competent, a system needs to:

- value diversity
- have the capacity for cultural self-assessment
- be conscious of the dynamics that occur when cultures interact
- institutionalise cultural knowledge
- adapt service delivery so that it reflects an understanding of the diversity between and within cultures (NHMRC 2006).

2. The Project purpose

The Project's purpose was to develop a strategy to address the needs of CALD children and families across PICS services with particular priority being placed on the Children's Cancer Centre services at The Royal Children's Hospital and Monash Medical Centre.

The objectives were to:

- undertake a brief literature review of recent evidence of the needs of CALD families with a child with cancer, and effective strategies to address these needs. This builds on the literature review undertaken as part of an earlier project¹
- identify the priority language and cultural groups
- identify the needs of service providers working with CALD families and include Children's Cancer Centre staff as well as other staff such as interpreters
- identify the current resources available for CALD families through PICS services, The Royal Children's Hospital, Monash Medical Centre and other paediatric oncology services in Australia.

2.1 Project method

The following key activities were undertaken.

- **Identifying the population** involved three strategies:
 - an audit of children diagnosed over an 18 month period to identify the country of birth, preferred language and English language skills of the child and their parent(s)
 - an analysis of the use of interpreters at both RCH and MMC. At MMC we were able to access information about interpreter usage for the Children's Cancer Centre, whereas at RCH data was only available for all in-patient and outpatient interpreter usage across all patient groups
 - a review of population data from the Australian Bureau of Statistics with a particular focus on language groups relevant to the Children's Cancer Centres.
- **A brief review of recent literature** published in peer review journals and key policy documents. The full literature review is available in a separate document with key information from the review being included in this main report.
- **Consultation with key stakeholders.** This included:
 - interviews with the Manager of Interpreter Services at both RCH and MMC
 - structured interviews with three interpreters from different cultural backgrounds
 - group discussions with the medical consultants, one group each with RCH Children's Cancer Centre nursing staff and psychosocial staff, and a mixed staff group at MMC Children's Cancer Centre. Individual interviews were undertaken with a dietitian and a pharmacist.
- **Identification of CALD resources;** this included collecting resources currently available within the CCC as well as interstate children's cancer services. The English language versions of CALD resources developed by the Cancer Council of Victoria, for the general cancer population, have also been identified.

¹ This study explored the needs of CALD and non-CALD families with a child with cancer. It was undertaken by the RCH Social Work Department in conjunction with the University of Melbourne and key providers in the Children's Cancer Centre. The study also included a survey of staff needs.

- **Review of the evidence** gathered in the earlier RCH study of the needs of families and staff undertaken through the RCH Social Work Department¹.

Some population data has been identified for the indigenous community. However given the very small numbers of children from an indigenous background with cancer, the differing cultural and social perspectives and sensitivities when working with the indigenous population and the availability of indigenous liaison officers, the focus of this work has been on CALD children and families.

Some of the future strategies for CALD families may have some relevance for indigenous children and families but would need further discussion with the appropriate indigenous health liaison units at both RCH and MMC.

3. Victoria's diverse population

Victoria is Australia's most culturally diverse state (CEH, 2005). The most recent population data (ABS 2006) shows that:

- 24% (1.17 million) of the total Victorian population were born overseas coming from over 200 different countries
- of these people born overseas, 74% were born in a non-English speaking country
- 17.6% of the total Victorian population were born in a non-English speaking country
- of those Victorians who were born in Australia, 14.1% (n=482,919) had both parents born overseas and 14.2% (n=488,603) had one parent born overseas
- in 2006 there were 30,143 Aboriginal and Torres Strait Islanders living in Victoria, which equates to 0.6% of the total Victorian population.
- **one in five** Victorians speak a language other than English (LOTE) at home.

Recent migration trends to Victoria (2001-06) from non-English speaking countries indicate that:

- the largest populations are from India and China (>20,000 each)
- populations of between 4-10,000 are from South East Asia (Malaysia, Sri Lanka, Philippines, Indonesia, Vietnam, Hong Kong) South Africa and the Sudan.
- other populations of interest include Iraq (>3000), Afghanistan and Pakistan (>2000).

A proportion of the recent migrants come from a refugee background and may be different from other migrants in a number of ways. Refugees are:

- younger and have a higher proportion of children aged under 14 years
- less likely to have family and community support in Australia to assist them in accessing health care services
- often have lower literacy levels in their first language as well as lower levels of English proficiency
- may also have experienced significant direct or indirect trauma (DHS, 2008).

3.1 English language skills

Given that services working with children and families need to consider the language skills of both the child and parent, Table 1 looks at the English language skills of all Victorians who speak a language other than English at home by age group. The age group 26-44 years is particularly relevant in terms of the English proficiency of the parents of children with cancer.

The table includes a total of eighteen languages which includes both the top ten language groups spoken at home for the whole Victorian community and the top ten languages used at RCH (across all patient groups) and at MMC for the Children's Cancer Centre. There is some overlap between these two sets of language groups.

Not surprisingly given the migration history, for language groups such as Italian, Greek, Macedonian and Croatian the overwhelming proportion of those with low English proficiency are aged 45+ years. The proportion of Italian and Greek speakers with low proficiency in English who are aged over 65 years is 78% and 60% respectively. These older members in the community are likely to be the grandparents or great grandparents of young children today.

Other key points about the data that are of relevance to this Project include:

- In all languages other than Punjabi (8%) and Karen (78%), the proportion of those who speak a LOTE at home and have poor English proficiency ranges from 17-38%.
- Across the top ten larger language groups for the whole community, between 21-34% who have low English proficiency are aged 26-44 years. These language groups are:

○ Vietnamese	34%
○ Khmer / Cambodian	32%
○ Turkish	28%
○ Arabic	26%
○ Mandarin	25%
○ Cantonese	21%
- In the smaller language groups listed, the proportion of those with poor English skills and aged between 26-44 years ranges from 17-49%.
- The children's English language skills improve as they get older
 - In 12 language groups only 10% or less of the total population who speak LOTE at home and have poor English skills are aged 12-25 years
 - However 31% of the Karen population and 19% of the Dinka population with low English proficiency are aged 12-25 years.

These current adolescents / young adults may be the parents of children diagnosed with cancer in the future.

Table 1: English language proficiency by age group of all Victorians who speak a language other than English at home.

LOTE spoken at home	Total population who speak LOTE at home	Total number with low English proficiency	% of those who speak LOTE at home and low English proficiency	% of total with low English Proficiency by age group					
				0-11 years	12-25 years	26-44 years	45-64 years	65+	% over aged 45 years
Vietnamese	72,161	25,518	35%	17%	4%	34%	33%	11%	44%
Italian	133,327	22,640	17%	3%	2%	3%	14%	78%	93%
Greek	117,874	22,606	19%	6%	1%	2%	30%	60%	90%
Cantonese	66,853	16,606	25%	11%	7%	21%	38%	24%	62%
Mandarin	64,374	14,066	22%	12%	13%	25%	32%	18%	51%
Arabic	55,931	9,442	17%	27%	10%	26%	22%	15%	38%
Turkish	29,748	6,551	22%	15%	4%	28%	37%	15%	53%
Macedonian	30,771	5,791	19%	7%	1%	6%	44%	42%	87%
Croatian	22,961	3,853	17%	5%	1%	6%	35%	53%	88%
Khmer / Cambodian	9,981	3,604	36%	16%	10%	32%	33%	10%	43%
Assyrian	7,051	1,972	28%	30%	9%	27%	22%	12%	34%
Dari	4,563	1,342	29%	29%	12%	33%	20%	6%	26%
Dinka	2,211	837	38%	58%	19%	32%	5%	1%	6%
Somali	4,240	805	19%	43%	6%	30%	16%	5%	21%
Punjabi	8,202	692	8%	33%	8%	17%	21%	21%	41%
Karen	391	305	78%	30%	31%	23%	13%	3%	16%
Tingrinya	858	205	24%	23%	14%	40%	17%	6%	22%
Burmese	826	185	22%	18%	12%	49%	17%	3%	21%

Source: Australian Bureau of Statistics. Census data 2006.

Note: the bolded languages are those languages mostly commonly requiring interpreter services at the Royal Children's Hospital (for all patient groups) or at Monash Medical Centre, Children's Cancer Centre.

4. The service context

This section briefly profiles the PICS service sites, summarises the evidence from the literature and provides an overview of the earlier RCH CALD Strategy.

4.1 The PICS service sites

An estimated 160-180 Victorian children or adolescents² are newly diagnosed with childhood cancers at the RCH or MMC Children's Cancer Centres.

Over 80% of all Victorian children with cancer across all diagnostic groups are treated at the RCH Children's Cancer Centre which is the largest paediatric oncology service in Australia. The RCH Children's Cancer Centre also provides services to children and families from Tasmania and through international referrals.

MMC Children's Cancer Centre treats about 30 children newly diagnosed with cancer each year (19% of the total). While RCH children may come from anywhere across Victoria, MMC serves a more discrete community with its immediate catchment area being one of the most culturally diverse communities in Victoria. MMC also provides services to families from Gippsland.

Almost half of all children newly diagnosed with childhood cancer are aged under 5 years. However at MMC Children's Cancer Centre approximately 67% of their children are aged 5 years or younger. This is important as younger children who speak a language other than English at home may have poorer English skills than older children (see Table 1).

Peter Mac provides radiotherapy services to children with cancer. Approximately half of all the children treated at one of the Children's Cancer Centres are referred to Peter Mac for radiotherapy as part of their active treatment or for palliation.

4.2 The evidence from the literature

4.2.1 The impact of culture on children and families with cancer/chronic illness

The term culture refers to the values, beliefs, traditions, symbols, language, and social organisation that become meaningful to a group's way of life (Taylor, 1980, as cited in Munet-Vilaro, 2004). People use cultural beliefs as a body of knowledge to make judgments about their own and others behaviour, to guide their actions, and support their decisions (Brink, 1983, as cited in Munet-Vilaro, 2004).

Behaviours based on cultural beliefs and values become more apparent in ill health as people draw on their cultural values in order to conceptualise, explain, and respond to an illness (Kleinman, Eisenberg, & Good, 1978, as cited in Munet-Vilaro, 2004). Similarly how a family responds to caring for a child with cancer is significantly influenced by their cultural environment.

Regardless of the child's illness, paediatric care comprises of a triad of child, provider and parent involvement with the family providing a considerable amount of the daily care to children with an illness, such as cancer (Sobo, 2004). The family's cultural context may directly influence how they define and manage their child's cancer. Knowing and being aware of this dynamic can guide health professionals in delivering holistic, culturally competent care (Thibodeaux and Deatruck, 2007).

Differences exist in cultural attitudes toward the disclosure of a cancer diagnosis to patients. In Australia, universal disclosure is practiced, but in countries such as Italy, Egypt,

² This project scope includes both children and adolescents. For brevity, the term children is mostly used throughout the text but must be read to include both children and adolescents.

and Japan, being truthful about a patient's diagnosis is seen by many as a cruel and untactful act (Navon, 1999). Similar results were found in a study undertaken by Martinson et al, 1994 (as cited in Thibodeaux and Deatrck, 2007) which found that in China, there was a belief that bad news or sadness should not be discussed with children or extended family. Understanding such cultural beliefs and family structures may help health professionals provide culturally competent interventions to address fear, anxiety, and support concerns (Thibodeaux and Deatrck, 2007).

Surbone (2008) talks specifically about how Italian adult patients' information and involvement in decision-making regarding their cancer care has been steadily increasing since the 1980's in Italy. However, whilst there has been a shift towards truth telling, research has persistently revealed that partial and non-disclosure are still supported. Many southern Italians said they knew their diagnosis and yet would not write it down, powerfully demonstrating how the word 'cancer' is still a metaphor for intense suffering, death or social stigma in certain cultural contexts. Furthermore, there has been some research which shows that in certain communities, no words for 'cancer' exist, while in others, uttering any '*bad words*' is believed to negatively affect patient outcomes (Levy, 1997, as cited in Surbone, 2008). Being truthful to cancer patients about prognosis without taking away hope is a major challenge for all health professionals working in oncology, regardless of the patient's cultural background (Surbone 2008).

With Greek parents of children with cancer, Patistea et al, (2000, as cited in Munet-Vilaro, 2004) found that communication between parents and the healthy siblings was a difficult process during the diagnostic stage of a child with cancer. Parents were not amendable to establishing an *open* communication pattern with the healthy siblings and wanted to be the ones deciding the content and amount of information disclosed.

Health professionals therefore must be aware that communication strategies that include the child, and / or other family members or siblings during information and communication sessions might not be appropriate for all CALD groups.

4.2.2 Working and communicating with CALD families

The care of families who have a child with a chronic illness is maximised by taking a culturally competent approach, blending family and cultural values. Optimal care therefore occurs within a family-centred, culturally competent context (Thibodeaux and Deatrck, 2007). A clear understanding of the child / family's cultural background and the factors that influence their response to treatment is vital to the delivery of this care (Azis & Rowland, 2002, as cited in Munet-Vilaro).

Cultural differences also impose strain on health professional's interactions with their clients if both parties misunderstand each other's conceptions of gender and familial roles, intimacy, spatial distance, and non-verbal communication. For example, physical contact between a nurse and patient, such as a touch or a hug, is socially accepted in Western cultures but is not in a conservative country such as Egypt (Navon 1999).

Communication affects people's factual understanding of the situations. Good communication is a complicated interpersonal process entailing mutual respect, trust, and empathy and these elements are essential prerequisites for satisfactory information exchange and collaboration with both CALD and non CALD families (Sobo, 2004).

Providing culturally competent health services to CALD families requires health related information to be transmitted clearly and effectively. This communication process becomes even more relevant when health professionals are explaining treatment protocols and the physical and psychosocial ramifications of cancer treatments (Munet-Vilaro, 2004). Accurate and effective explanations of childhood cancer treatment

protocols are best achieved when clinical care teams are both culturally and linguistically competent (Kagawa-Singer & Kassim-Lakha, 2003, as cited in Munet-Vilaro, 2004).

Clearly good communication is more difficult when linguistic diversity occurs between the health professional and the patient and / or family and is the primary obstacle in developing a culturally competent, caring relationship (Pergert et al, 2007). While a hospital environment can be stressful for all people, information in paediatric cancer care is generally very complex and emotionally charged, setting the stage for miscommunication. This emotionally charged communication affects the CALD families' factual understanding of the situation (Sobo, 2004) and their capacity to communicate in their second language (ie English) (CEH, 2003).

In addition, much of the usual caring '*chatting*' that takes place between patients or families and health professionals that is commonly intertwined into the everyday conversations in the hospital wards and clinics is constrained when there are language barriers between health professionals and the patient or their family. As a result, the relationship between staff and people from CALD backgrounds tends to lack close contact (Pergert, 2007).

When working with CALD families, it is essential that health professionals spend more time and resources during the informed consent process to ensure the information is clearly understood (Munet-Vilaro 2004) and to facilitate general communication. Furthermore, avoiding miscommunication during assessment will support safe, appropriate and effective care interventions and will ultimately result in appropriate referrals to other health services (CEH, 2003).

Enhancing communication

Joseph-Di Caprio et al, (1999) undertook research which looked at physicians' perceptions of the impact of the family's ethno-cultural background on the health care of school-aged children with chronic conditions. Language barriers between the physician and child and family made it difficult to establish a good relationship and to find resources for the family. Recommendations from physicians for improving care for CALD children with chronic diseases included:

- ensuring good communication between the physician and the family
- the need to educate both providers and families
- the need for improved support for CALD families
- improved access to and delivery of services (Joseph-Di-Caprio et al 1999).

Challenges arise for health professionals where an interpreter is offered to a CALD family but this is refused. Factors influencing this refusal include:

- family concerns about confidentiality and privacy, particularly in smaller ethnic communities
- family concern about the gender, religion or ethnic background of the interpreter (DHS, 2005).

Where an interpreter is refused, health professionals require the skills to best deal with this situation e.g. understanding why the interpreter has been refused or explaining to the patient or family the consequences of not using an interpreter (DHS, 2005).

Other challenges that have been identified when using an interpreter include:

- health professionals lose control over the information that is given to the family and also the family's responses, resulting in uncertainty relating to whether the information provided to the family is accurate and complete. This may particularly occur where interpreters do not know the medical terms being used or that they may add or omit information (Pergert, 2007)
- the amount of information that is interpreted in a session. Accessing an interpreter often results in a tendency to seize the opportunity to provide large amounts of information, about various issues on the same occasion. This results in information overload for the patient and family (Pergert, 2007).

Information resources to aid communication

Translating written information into other languages can be an effective method of aiding communication and may be crucial in situations where informed consent is required (DHS, 2005). In addition, there is a need to provide translated information about:

- hospital routines and medical and nursing information (Pergert 2007)
- medication instructions (Lodge 2001).

However even if information is translated into other languages, attention must be given to the concept, equivalency, language, reading and literacy levels of the child and parents (Munet-Vilaro and Egan, 1990, as cited in Munet-Vilaro, 2004).

If literacy is an issue, using alternative methods such as videos, audio tapes and hands-on demonstrations, are likely to be useful (Munet-Vilaro, 2004). In addition, drawing has been shown to aid communication. In a study which examined how to enhance communication among children with cancer, the use of drawings indicated that children, regardless of their cultural background, respond to the childhood cancer experience in a similar manner with drawings enhancing communication through direct visual expression (Rollins 2005).

4.2.3 Health professional skills

Cultural sensitivity will be enhanced in cancer care when it is accompanied by changes in health professionals' own views and treatment patterns, with education being crucial (Navon, 1999). Not only should culture-related issues be integrated into health professionals' education programs, but emphasis also should be placed on health professionals understanding that their own professional values are socially and culturally constructed. This would enhance tolerance toward health beliefs and practices of cancer patients from other cultures, their relatives, and the general public (Navon, 1999).

The Centre for Culture, Ethnicity and Health (CEH, 2005) recommends that organisations arrange education and training for staff that is relevant to their role and professional responsibilities. Staff need to be trained to assess patients and their families in a culturally sensitive and appropriate manner with these skills increasing the ability to interact and communicate across cultures (DHS, 2004).

Health professionals should also receive training that:

- improves their understanding of the role of culture and ethnicity in their patients' lives and how they can use this understanding in their clinical work with young people who have chronic conditions
- makes them aware of diversity within ethnic and minority communities and avoids stereotyping families within these groups
- enables them to develop effective techniques that easily incorporate cultural issues into clinical practice

- enables them to appreciate culture is much more than language and affects all of their interactions with patients (Joseph-Di Caprio 1999)
- enables them to:
 - assess their own cultural self awareness and knowledge about other cultures
 - recognise the effects of culture on communication between providers and patients, adherence to treatment, patient satisfaction and health outcomes (Pesquera et al 2008)
 - adapt messages on cancer diagnosis and treatment to each community's unique way of thinking by addressing any prevalent misconceptions about these issues and using culturally familiar concepts and language (Navon, 1999).

The workforce also needs an increasing awareness of available language services and the skills to use them appropriately for achieving good practice in language services delivery (CEH 2005). This includes staff:

- knowledge of the relevant systems, policies and procedures
- skills to assess the need for when to use an interpreter and how to work with interpreters to ensure that language services are employed in the right way at the right time.

Ongoing training systems need to be established to facilitate staff development and support in a way that can be sustained and will meet organisational needs over time.

4.3 RCH CALD study

In 2005 the RCH Social Work Department in partnership with Melbourne University and other staff from the Children's Cancer Centre embarked on a research study to:

- examine the psychosocial needs of families from diverse cultural backgrounds
- explore staff experiences of working with CALD families and how this differs from non-CALD families.

Twenty families who were either born in Australia or overseas but spoke English, and 11 families who were born overseas and did not speak English participated in the study. In addition 55 staff completed an on-line questionnaire.

The key findings from this study were as follows.

Maintaining relationships between families and staff: language was seen as a barrier to both CALD families and to staff. Families in all four groups reported high levels of regard and satisfaction with the staff, whereas 73% of staff indicated that it was much more difficult to establish a relationship with CALD families, with both language and culture being a barrier.

Access to information: all families accessed verbal information but English speaking families were much more likely to have accessed written information. Families with no or limited English were much more reliant on medical staff and the interpreters. Staff identified issues with the lack of written information and needing to rely on high quality interpreting to facilitate information transfer. Staff were also aware that their conversations with CALD families were much more truncated due to access and timing difficulties with interpreters.

Family involvement in decision-making: English speaking and non-English speaking families were both satisfied with their involvement in decision-making whereas staff perceived CALD families were less involved in decision-making than non-CALD families.

Engagement with support services: all families reported high use of social work services. English speaking families reported more access to art, music and play therapy. Staff did not perceive any differences in access to social work, nurse coordinators or allied health staff across all family groups. Staff did however perceive that CALD families made less use of mental health services, art, music and play therapy and chaplaincy services.

5. Current needs, services and practices

This section considers the CALD profile of children and families within the Children's Cancer Centres, interpreter use and how services are currently offered. It then considers some of the challenges facing staff working with CALD families and some of the opportunities.

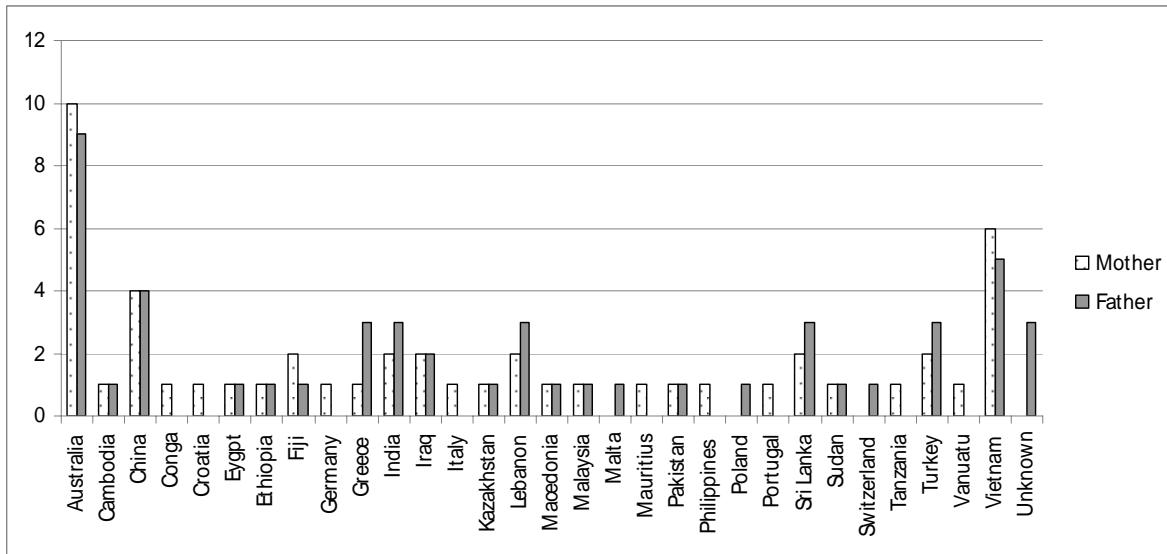
5.1 CALD families within the Children's Cancer Centres

An initial review of the Children's Cancer Centre database and the RCH Information System (CLARA) has enabled us to review the numbers of children from a CALD background who were diagnosed with cancer from January 2007 – June 2008³. From these figures we can identify that:

- just over 20% of all families had one or both parents born overseas in a non-English speaking country
- only seven out of 215 families (3.2%) were identified as needing an interpreter. Of these families:
 - one child was born in a non-English speaking country (Vietnam)
 - six children were born in Australia
 - both parents were born in a non-English speaking country
 - the languages identified for interpreter purposes were: Amharic, Assyrian, Cambodian, Lebanese (Arabic), Punjabi and Vietnamese
- in a further 19 families, both parents were born in a non-English speaking country but reportedly did not require interpreters
- 18 families had one parent born in a non-English speaking country
- parents born in a non-English speaking country came from 27 different countries (see Figure 1).

³ It should be noted that these numbers appeared very low to some staff. This may reflect an error in the identification of children on the Children's Cancer Centre database or the hospital information system. Given the small numbers of children diagnosed each year with cancer and the relatively smaller proportion who will be from a CALD background, it may also be that for this 18 month period, very few CALD children were newly diagnosed. Finally it should be recognised that many children stay within the hospital system for several years and so the overall numbers of CALD children currently having treatment will be higher.

Figure 1: Country of birth for parents of children diagnosed with cancer



The following are the top eight countries of birth of the children's parents:

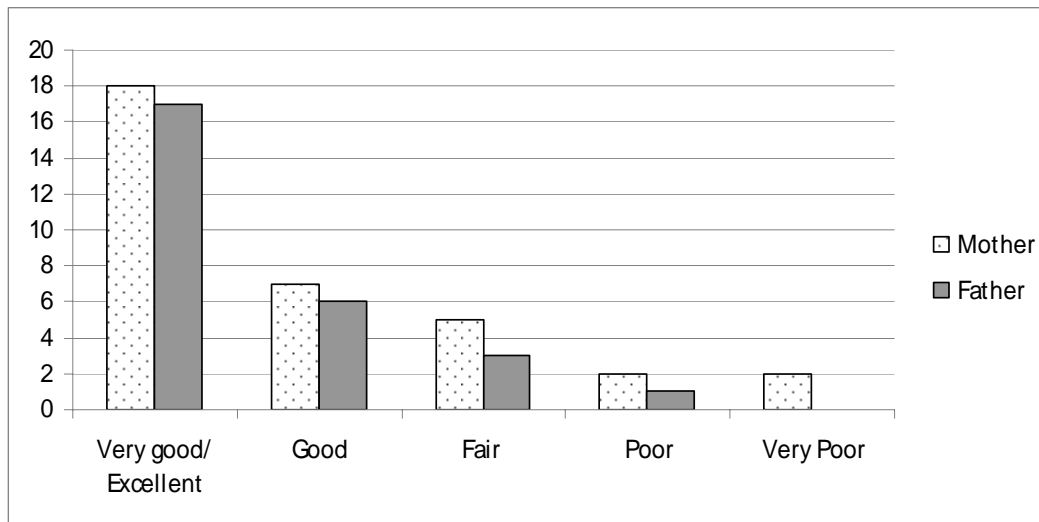
- Vietnam 11 parents
- China 8 parents
- Sri Lanka 5 parents
- Turkey 5 parents
- Lebanon 5 parents
- India 5 parents
- Iraq 4 parents
- Greece 4 parents

5.1.1 English language skills

The English proficiency of the above families was assessed by staff with input received from both the nurse coordinators and one social worker. An assessment of English skills was made for 34 mothers (68% of all mothers from a CALD background) and 27 fathers (54% of all fathers from a CALD background).

While criteria were established to assist in this assessment from excellent to very poor English skills, the assessment was subjective and some differences were identified in the assessments by different providers. Where more than one service provider assessed the English language skills, there was a difference in the assessment for six parents. Where this occurred the lower assessment level has been used. Figure 2 identifies the parent's English skills as assessed by staff.

Figure 2: Assessed English skills of parents born in a non-English speaking country (n=61)



From this we can estimate that 21% of parents (n=13) from a CALD background have fair or lower than fair English proficiency skills as assessed by service providers.

5.2 Interpreter usage

In addition to the above data, we have some evidence of the use of interpreters across RCH as a whole and within the MMC Children's Cancer Centre. Unfortunately it is not possible to identify the use of interpreters specifically for families attending the RCH Children's Cancer Centre. Overall, the most common languages for interpreters at the MMC Children's Cancer Centre were Vietnamese, Turkish, Dari, Arabic and Punjabi. Overall RCH data revealed that the most common languages for interpreters included Vietnamese, Arabic, Turkish, Cantonese and Mandarin, although these languages are not specific to the RCH Children's Cancer Centre

5.3 The patient pathway – current practice

While there is some variation in the ways in which services are currently provided between RCH and MMC Children's Cancer Centres, the following outlines how the needs of CALD families are addressed throughout the patient pathway, with a particular focus on those with limited English proficiency.

The diagnostic consultation

The diagnostic consultation is the first key opportunity for the family, the medical consultant, other service providers (e.g. nurse coordinator, social worker) and the interpreter to meet together. As with non-CALD families, this consultation is often very distressing for the parents and it is difficult for families to absorb significant amounts of additional information.

As part of this consultation, parents may be given the Children's Cancer Centre Parents Information Book and information about any clinical trials that the medical consultants are recommending. These information resources are only available in English, and are provided with the view that at least some families may have access to family or friends who may be able to read and translate the information for them. As with non-CALD families, parents are asked to give their consent to their child's participation in a particular clinical trial or treatment protocol.

Initial education, information and discharge planning

Following this diagnostic consultation, the interpreter is then booked for subsequent patient / family education, information and support sessions which may be coordinated through the nurse coordinators or social workers. The number of sessions booked through

the early initial admission and discharge planning period may vary from one to three sessions.

At these sessions efforts are made for a number of professionals to provide information to the parents / family. There is a tension and a need to balance the following:

- prioritising the critical information
- optimising the use of the interpreter to ensure as much information as possible is communicated to the parents
- providing information overload.

Information that was seen to be essential to be communicated includes:

- managing fevers and infection management
- when and how to present to the Accident and Emergency Department
- when and how to contact the ward when they have problems including how to gain access to an interpreter.

Early in this initial hospitalisation, families are given a tour of the Children's Cancer Centre, which can be done visually and an interpreter is usually not needed.

The level of interaction that other staff (e.g. allied health providers) may have with the CALD child or their family may be dependent on a variety of factors. For example, given that *'music is a common language'* the music therapists may be able to engage CALD children quite readily in musical sessions. For other providers, language differences and limited resources available in other languages to support general and specific conversations create significant barriers to working with CALD families.

While art, music and play therapy are *'universal languages'*, staff indicated that a lack of understanding of the therapeutic [rather than the play / entertainment] role of these approaches may mean that some CALD families reject services particularly when children are very ill.

Finally while chaplaincy services may not be directly accessed by families, they sometimes play an important role in accessing the appropriate spiritual leader for a particular family.

Following discharge

Some families need interpreters for all medical consultations and at least for initial day oncology appointments. Depending on the level of English language skills the family may have, interpreters may or may not be used for all or some other clinic appointments.

Staff are aware that while they may be able to communicate *'reasonably well'* with parents who have a level of English proficiency, there are critical times when an interpreter is needed. These include *'bad news'* consultations, where there is a significant change in the treatment plan or treatment phase and when parents request an interpreter. Conversely some families with a level of English may use an interpreter initially, but as their confidence grows in being able to understand the service provider in English, they no longer wish to have one.

In addition to using an interpreter, staff identified the following strategies that they currently use to support CALD families:

- two information sheets are available in other languages to assist families. These are *'When your child is ill'* and *'What to bring for an admission / before you go home'*. These resources are available in 13 languages (see 5.4.4)
- other family members or the child themselves who have a level of English may be used to facilitate more everyday conversations between the parents and health service providers
- discussion amongst other staff members at the psychosocial meetings
- strategies to avoid confusion about ongoing appointments including:

- consistent appointment times given for treatment needed on multiple days
- avoid changing appointments
- interpreters may telephone families to remind them of clinic appointments
- staff play a stronger coordination role for appointments with other units external to the Children's Cancer Centre
- using bilingual students to work with CALD families
- using gestures and visual images
- providing brief written information in English that potentially a family member would be able to translate
- providing bilingual story books for children who do not speak English or speak a language other than English at home (from RCH play therapy library)
- linking in with the child's school community (see case study).

While a range of strategies have been used there did not appear to be a consistent approach to their use with CALD families.

5.4 Challenges in current practice

Key stakeholders identified a number of challenges when working with CALD families and these are discussed in more detail below.

5.4.1 Addressing different cultural perspectives

The challenges staff experience may be related to the differing level of English proficiency that members of the families have or to broader cultural perspectives. Issues that were identified related to:

- the stigma associated with cancer for families from some cultural groups which resulted in a level of secrecy about the child's illness and increasing isolation of the family within their own community. This isolation was further exacerbated if the parents had limited English skills
- modifying the timing of medication in response to religious traditions – this could usually be readily accommodated
- concerns that the staff members' gender (particularly for non-medical staff members) may influence how they are viewed by some families
- large families visiting particularly when a child is very sick and how to manage this in the best interests of the child, family and other families within the Children's Cancer Centre
- the role of the extended family in decision-making and caring for the child (eg child care and food preparation at home) for some families.

While staff were mindful of the diversity within communities, they were interested in mechanisms that:

- would enhance their general knowledge of different cultural perspectives that may exist for at least some members of different communities
- ways in which they could more effectively identify and address the specific cultural needs of the individual and their family
- would manage one self in areas of potential '*cultural conflict*' between one's own values and those of the family.

5.4.2 Working with interpreters

Given the complexity of childhood cancer and its treatment, and the emotional context of having a child with cancer, interpreter mediated communication presents challenges for both service providers and for interpreters.

There was some commonality in the challenges experienced by both groups as summarised in Table 2.

Table 2: Interpreter mediated consultations - challenges for CCC staff and interpreters

Service provider group	Challenges
Children's Cancer Centre staff	<ul style="list-style-type: none"> • Demands on interpreter time make access difficult at times and for the amount of time and frequency that would be desirable. • Working with telephone interpreters as non-verbal cues cannot be picked up which can be in a face-to-face consultation. • Concern about the accuracy of the interpretation in some instances • Concern about the interpreter being too emotionally close to the family or becoming distressed because of the family's distress. • Ensuring the interpreter is prepared for the nature of the consultation – in outpatient clinics if they have already met up with the family, it is more difficult to talk to the interpreters privately before the formal consultation. • Not knowing how much or how little the family have really understood. • Accessing an interpreter for families that have some English skills but need an interpreter for some complex or difficult consultations.
Interpreters	<ul style="list-style-type: none"> • Significant demands on time to meet the need of all services. • Clinics that run behind time resulting in delays in clinical appointments. • Being unprepared for the nature of a specific interpreter session e.g. routine versus a '<i>bad news</i>' consultation. • Emotionally challenging interviews – dealing with the family's emotions as well as one's own, particularly if interpreters have built up a relationship with the family over time. • Use of very technical language. • Needing to interpret very sensitive information e.g. <ul style="list-style-type: none"> ○ information that would not be publicly discussed between community members ○ clinical information that is provided in a manner that is insensitive to the cultural values. • Lack of clarity about what information is publicly disclosed to which family members. • Encouraging the families to ask questions. • Families with limited understanding of the interpreter role and wanting them to provide additional information, express their opinion or advocate on their behalf. • Ensuring that families understand the confidential nature of the interpreter role. • Dependency of the family on the interpreter at times • How to manage when families complain to other providers about the interpreter service.

The health care professionals clearly identified that they worked with some exemplary interpreters in whom they had an excellent relationship and great confidence in their interpreting skills. They also valued interpreters' flexibility and the role that some played in negotiating appointments with families and in ensuring that families attend their appointments. There was also recognition of the very difficult role the interpreter had to play when working with families with a child with cancer.

A number of key challenges that face health care professionals and interpreters alike and some actual or potential mechanisms to address these are as follows.

Facilitating timely access was identified by Children's Cancer Centre staff and by the interpreters with the latter being very aware of significant demands for their services. CCC staff really valued when the interpreter was able to turn off their pager so that they could concentrate on the family consultation.

Interpreting complex medical terms was problematic in some consultations with a potentially unrealistic expectation that interpreters know all the technical language used.

Some terms e.g. radiotherapy versus radiology may be confused. Actual or potential strategies that were thought to be valuable included:

- the service provider speaking in simple terms *'in plain English'* and explaining technical terms (either pro-actively or in response to a query from the interpreter) to the interpreter
- interpreters also highlighted the potential value of having a glossary of terms with translations that could be useful for both the interpreters and for families
- potential in-services for interpreter staff about childhood cancer and clarification of some of the technical terms.

Linked with this was the **uncertainty about the accuracy** of the interpretation particularly where there appeared to be a significant time discrepancy between what the service provider had said and the interpretation. Some of this discrepancy may be linguistic differences with some languages being more direct or more discursive than English.

One interpreter highlighted that because of the relatively low educational level of some in their community, at times interpreters had to make judgements to ensure that the content being provided was at the right educational level for the specific family. For another interpreter when asked to translate very sensitive information that would normally not be discussed within their community, she would preface the translation with *'an apology and recognition of the sensitivity of the information she was being asked to translate'*.

Given the strong focus of the role of interpreter services on translating only what has been said by the service provider, these comments provide some clarity on why discrepancies may occur. However they were rarely discussed with the health care professionals directly.

An important strategy may be the need to create a safe space to enable *'sensitive'* conversations between health professionals and interpreters to take place to facilitate better understanding of the issues.

Loss of control of the consultation process occurred for some health care professionals with interpreter mediated consultations. Mechanisms to manage this might include discussion with interpreters after the consultation and also managing one's own anxiety when *'not in control!'*

Ensuring comprehension by the CALD family. Whether using an interpreter or directly speaking to families in simple English, service providers indicated that they were not always sure of the level of the family's comprehension. In an interpreter mediated consultation, some interpreters would indicate to the service providers when they thought the family had not understood the information and that it needed to be provided in a more specific way.

Staff indicated that where families had some English, they often asked them to repeat back to them what they had been told. Staff also indicated that where families had some English skills, it may be appropriate to routinely offer them access to an interpreter at key points in the pathway. The primary purpose of this was to ensure that the family did understand their child's general progress.

Managing emotionally distressing interviews is clearly challenging for all service providers. It was particularly difficult for the interpreters if they had:

- no prior notice of the planned interview content
- developed a close relationship with the family.

One interpreter spoke of how challenging this could be at times.

'you know if you are translating something that is particularly emotionally difficult, then sometimes I have experienced 'the words have stuck in my throat' – I have looked at the professional and have looked at the parents – I need to be able to digest the information

first – the parents can see the difficulty I am having – once I have been able to do this (digest the information) I am then able to translate’.

The need to prepare interpreters for the consultation was identified by both interpreters and Children's Cancer Centre staff. This should be flagged at the time of booking the interpreter as well as having time before the consultation to discuss the focus of the family consultation with the interpreter.

While interpreters indicated that they had a range of strategies to help them deal with distressing interviews, including support from their manager, there was interest in some more formal '*debriefing*' with Children's Cancer Centre staff.

5.4.3 Strengthening other approaches with CALD families

From the consultation findings and from the earlier study, service providers commented on the relative isolation of CALD families within their communities, within the Children's Cancer Centre and with children's cancer support services. Staff commented that they perceived that their relationship with CALD families was not as close as it might be with a non-CALD family.

The language barrier not only stopped verbal communication between families and service providers but also appeared to be a barrier to non-verbal communication or general contact. Some service providers commented that they '*observed from a distance*'. In addition, non-CALD families as well as CALD families are encouraged to contact particular service providers if and when they had specific issues. Given the limited English skills of some CALD families and potentially a lack of familiarity with the concept of '*support services*', it is not surprising that CALD families are not seen to access the range of services that are available.

At a more system wide level, some staff commented on the physical environment in which they worked e.g. there was no signage in other languages, the images used were very mono-cultural and that '*all the dolls are blonde*'.

Similarly while interpreter needs are identified on the Children's Cancer Centre /CLARA databases, there did not appear to be other mechanisms that could potentially alert staff to the family's need of an interpreter e.g. a prominent sticker on the medical record.

Potential strategies:

- Resources in other languages that describe the range of services that are available and how to contact them.
- The availability of visual information to facilitate non-verbal communication.
- Staff taking a much more pro-active approach to CALD families e.g. regular '*routine check-ins*' by social workers, '*Comfort first*' staff, dietitians and other service providers to support children / families through additional procedures.
- Staff training to encourage active engagement with CALD families.
- Consider ways in which the environment and associated resources can better reflect the diversity of the community.
- Consider other options for alerting service providers of the need for an interpreter, in line with other broader organisational directions.

5.4.4 Access to CALD resources

Very little written or audio-visual information is available to support families with a child with cancer within the Children's Cancer Centres. The only specific resources that could be identified were the two resources identified in 5.3. These were translated some years ago into 13 languages:

- Arabic
- Chinese
- Croatian
- Macedonian
- Serbian
- Somali

- **Dari**
- Indonesian
- Greek
- Italian
- Spanish
- **Turkish**
- **Vietnamese**

The languages most relevant to the current Children's Cancer Centres' population, as reflected by the recent data, are bolded.

Contact with interstate children's cancer services identified no cancer specific resources for CALD families with a child with cancer.

The staff identified a range of information that would be useful to be available in a number of languages (see section 7.5) and their interest in developing or having access to:

- educational DVDs including dubbing the current educational DVD into a range of languages and developing a purely visual resource to support families from the many smaller language groups
- a range of simple picture resources (similar to those available for adults at Monash Medical Centre) that would assist staff to communicate with children and families on a more day-to-day basis.

5.4.5 Staff training and using staff skills

Potential areas for training identified in the consultations included:

- understanding some of the cultural differences within and across different communities and being sensitive to needs
- understanding perceptions of cancer in diverse communities
- ways of communicating sensitively with CALD families for all providers including front-line staff e.g. if a family do not understand, speaking louder will not help
- how to work effectively with families including assessing English language skills.

In addition to formal training, staff identified the need to maximise informal discussion about the needs of specific families through ward meetings, the psychosocial meetings, and informal in-services. This could include in-service exchanges with Interpreter Services to provide:

- an update on childhood cancer including technical terms for the interpreters
- information and approaches for working with CALD families for Children's Cancer Centre staff.

Finally some staff identified that they themselves came from a CALD background and /or had specific linguistic skills. Some staff felt that these resources were not well used or that there was a lack of clarity about how their skills could be used to work with families from a similar cultural background. In another context a bilingual medical fellow played an important role in working with a family from a similar cultural background, with the paediatric oncologist playing a more '*background consulting*' role.

From previous experiences another staff member who had additional language skills, tended to play down these skills so that she would not be called on inappropriately to undertake interpreting work that would take her away from her primary role.

Service managers expressed some issues about the use of staff from a specific CALD background. For example, they did not want CALD staff members being seen as '*the staff member for all families from a similar CALD background*'. In addition, concerns were expressed for the privacy of the CALD family and staff member.

This area presents a potential opportunity but requires further clarification (see 7.6.2)

6. Opportunities for the future

There are a number of opportunities that would potentially complement future work to strengthen services for CALD families.

6.1 The size of the CALD community

The relatively small numbers of CALD families with a child with cancer and the diversity of their language groups presents some challenges to the Children's Cancer Centres. It also presents an opportunity.

Given the small numbers it will be possible to develop some generic strategies or principles for working with CALD families but also to tailor the response to the needs of the individual family. This tailoring may be based on a range of factors including language skills, migration experience and family or community support.

This tailoring approach will also enable staff to address the needs of new migrant groups as they arrive in Victoria, should a child be diagnosed with cancer.

6.2 Key national and state policy directions

At both a national and state level there are significant policy directions to guide health services in improving their capacity to respond effectively to the needs of the multicultural community. These policies stress the importance of developing initiatives at different organisational levels as recently identified by NHMRC (2006).

Systematic: Effective policies and procedures, mechanisms for monitoring and sufficient resources are fundamental to fostering culturally competent behaviour and practice at other levels.

Organisational: The skills and resources required by client diversity are in place. A culture is created where cultural competency is valued as integral to core business and consequently supported and evaluated.

Professional: Cultural competence is identified as an important component in education and professional development.

Individual: Individual health professionals feel supported to work with diverse communities to develop relevant, appropriate and sustainable health promotion programs.

DHS (2005) has also developed a framework for organisations to develop their own cultural diversity plan.

6.3 Institutional directions

The RCH is currently developing its own organisation wide cultural diversity plan. This plan will be aligned with the DHS framework (see full literature review). Any strategy that PICS develops also needs to align and complement broader work being undertaken at each service level.

Strategies that are currently developed or being developed as part of the RCH Diversity Plan include:

- development of the overall organisational cultural diversity policy
- a multicultural welcome visual at the RCH Entrance Hall
- development of the RCH information resource in up to 16 languages
- development and provision of staff training in 2009
- potential introduction of a performance indicator to measure the uptake of the training by service unit⁴.

⁴ Elizabeth Young, RCH cultural diversity officer. Personal communication. October 2008.

Clearly these important initiatives at RCH provides an opportunity for the RCH Children's Cancer Centre staff. Peter Mac is also currently developing its own cultural diversity plan that may provide other opportunities for staff at Peter Mac.

6.4 Linking with other organisations

There are a number of opportunities to link in with other organisations.

Other national children's cancer services

Given that there appear to be few specific resources available for CALD families, an opportunity exists to link in with other paediatric cancer services or through ANZCHOG to develop resources in a range of languages that could be used nationally.

Linking in the Cancer Council of Victoria (CCV) resources

The CCV have a wide range of written resources about cancer and cancer treatment in up to 15 languages. While oriented to adults with cancer, resources of potential relevance are:

- Diagnosing cancer
- What is cancer?
- Treating cancer
- Cancer that cannot be cured
- Learning to relax when you have cancer.

The English versions of the resources are available and there is potential to identify relevant sections as a starting point for translations. The content could be modified or new content added for relevance for the Children's Cancer Centre population.

There are likely to be some cost benefits to this approach.

Health Translations Directory

This DHS directory of multilingual resources provides a wide range of resources in many languages. While no resources are available specifically related to childhood cancer, other useful resources may be available. For example, by searching under the language 'Dari', 40 resources were identified covering a range of topics including:

- cue cards to aid communication
- Hepatitis B
- Buying fruit and vegetables
- Calling CentreLink

The directory can be accessed at www.healthtranslations.vic.gov.au

Ethno-specific agencies

There are a wide range of state-wide and local organisations that respond to the needs of their communities. There is a state-wide service directory which social workers already have access to. In addition, some schools that serve communities with very diverse populations may also be able to assist these children and families.

Opportunities to link in with such schools and ethno-specific organisations need to be maximised.

7. The future service model and strategy

This service model includes the vision, principles and key approaches to practice. It is complimentary to the overall vision and service model for PICS.

7.1 The vision for working with CALD families

Working within a family centred approach to care, all children and families have the rights to be cared for in an environment and manner that is respectful, sensitive and responsive to their differing cultural and linguistic needs.

7.2 The principles guiding practice

The following principles will guide the care of CALD children and families.

Child and family centred principles

- All children / adolescents and their families who are facing a cancer diagnosis are assessed for their specific cultural and linguistic needs as part of initial and ongoing assessments. This includes:
 - identification of their first language spoken at home
 - an assessment of their English language skills.
- The response to the identified cultural and linguistic needs of the child and family are clearly integrated into their overall care plan.
- All families are provided with information in a culturally and linguistically appropriate manner which will facilitate their informed decision-making and the care of their child.
- All families who speak a language other than English at home will be provided with information about interpreter services and will be routinely offered access to an interpreter.
- All families are able to access interpreter services when they request this.

The service system

- An environment is created which recognises and values the diversity of the Victorian community and the population that the PICS service sites serve.
- Consistent and high quality policies, processes and systems will be available to ensure:
 - the timely and consistent identification of the specific cultural and linguistic needs of the child and family
 - that the service response is tailored appropriately to meet these diverse needs
 - that these needs and responses are agreed with and communicated between all members of the team
 - that all staff adopt specific and pro-active strategies to ensure that CALD families can access the range of services available including information and support services
 - that priority is given to optimise the coordination of care for CALD families
 - that children and families are linked in with relevant ethno-specific services as appropriate.
- Children's Cancer Centre staff will work in partnership with interpreter services to optimise services for individual families and to facilitate improved understanding of cultural diversity and children's cancers across services.
- All staff (Children's Cancer Centre and interpreter staff) will be skilled and supported to provide culturally appropriate care.

7.3 Developing a tailored approach

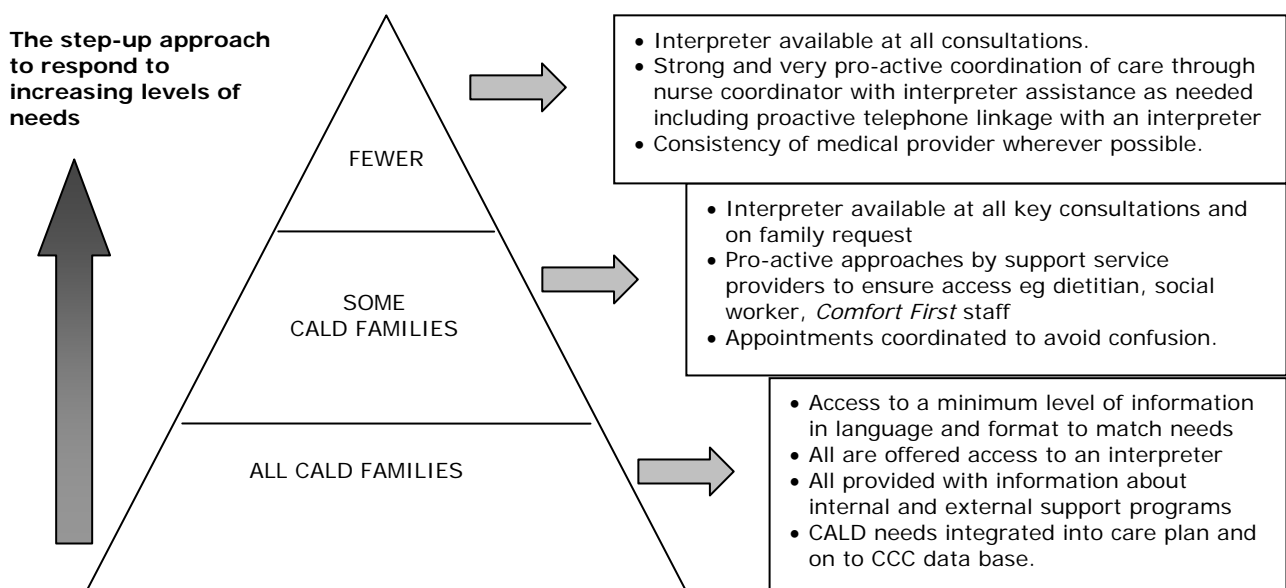
At a system level, it is appropriate to consider a tiered or step-up approach to responding to the needs of CALD children and families. Through this, the needs of three broad groups of families may be identified based on:

- What **all** CALD families will need
- What **some** CALD families will need; this would be focussed on the additional needs of those families who have some English language skills
- What a **fewer** number of CALD families will need; this level focuses on the more intensive needs of families that have no or very limited English skills.

While significant resources and energy may be focussed on those '*fewer*' families, the model allows a service to ensure that the needs of other CALD families are not overlooked because they have some skills in English.

Figure 3 illustrates this step-up approach with some suggestions about the range of strategies that could be implemented for the different levels of need.

Figure 3: The stepped approach to responding to the needs of CALD families.



The following sections discuss specific aspects of the service model and identify some clear **goals** and suggested **performance indicators** in relevant areas. These goals and suggested performance indicators need to align with those established at an organisation wide level.

7.4 Creating a '*diversity friendly*' environment

A range of strategies could be undertaken to create a more welcoming environment for CALD children and their families including:

- welcome signs in other languages
- images of children / families from diverse backgrounds
- increased access to multicultural resources and toys
- celebrating / acknowledging multicultural festivals or significant days
- actively participating in organisation-wide cultural diversity events.

Creating a '*diversity friendly*' environment

Goals

- A welcome sign is clearly visible in multiple languages in the entrance to the Children's Cancer Centres.
- The Children's Cancer Centres develop and implement specific initiatives as part of any organisation-wide cultural diversity events.

7.5 Strengthening the service system

There are a number of ways in which the overall service system can be strengthened to respond to CALD families needs.

Policies, protocols and processes: The PICS service sites will need to align with their own current or future organisational cultural diversity policies. Service sites may also need to develop their own protocols around specific aspects of care for CALD children and families.

Particular attention should be given to modifying those practices or processes that require the parent to initiate contact. More **pro-active** strategies need to be put in place to maximise these families' uptake of available services.

There is also a need to proactively alert staff to the particular cultural and linguistic needs of the child and family. One mechanism to achieve this would be to strengthen the information available on the Children's Cancer Centre database. This information should include more detailed information about interpreter needs (e.g. may need an interpreter for specific but not all consultations) and cultural preferences and practices. An alert will ensure that all service providers are aware that there are specific cultural needs that they need to consider.

Use of interpreters: a number of mechanisms need to be considered to strengthen the role of the interpreter including:

- Preparing the interpreter for 'difficult consultations' through:
 - flagging the nature of the consultation at the time of the interpreter booking
 - spending time with the interpreter on their own to provide information on the exact nature of the consultation
 - allowing time to debrief after the consultation.
- Enhancing communication between interpreters and Children's Cancer Centre staff would help to clarify or address any concerns that may have arisen during an interpreter mediated consultation for the Children's Cancer Centre service provider or interpreter.
- Developing an agreed planned schedule for the post-diagnosis education with an interpreter over a number of days (see below).

Family education sessions: Building on current work, an educational framework should be developed to guide the family education sessions. Decisions should be made about the

minimum number of interpreter-mediated sessions to be held with each family over a number of days. Discharge of the child should be avoided until these sessions have been achieved. Following discharge it may be appropriate to have initial and ongoing telephone follow-up with the family (see below -coordination of care).

Psychosocial meetings: these meetings present an ideal opportunity to:

- discuss the needs of specific CALD families
- address issues and gain understanding of actual or potential cultural difficulties for the family or staff
- develop ways in which staff can work more effectively with CALD families
- ensure the agreed strategies are integrated into the child / family's care plan.

Involving the relevant interpreter in these meetings may also be an important strategy to gain insights into any cultural issues that may impact on the child's current or future care.

Coordination / continuity of care: this is particularly important for families with more limited English skills and should include:

- ensuring multi-day appointments are booked at the same time each day whenever possible to avoid confusion
- avoiding cancellation of appointments wherever possible
- linking in with the interpreter to remind families of appointments where appropriate
- nurse coordinators give high priority to more frequent follow-up of families, particularly those with very limited English. This might include pro-active and regular (say monthly) phone calls to the families at home when the child is discharged, using an interpreter
- providing greater continuity of the medical provider to facilitate enhanced relationships, wherever possible.

Linkage with other services: additional effort needs to be made to contact the child's school and any relevant community based ethno-specific organisations which may be able to provide additional support to individual CALD families.

Linkage with General Practitioners: some CALD families may have a GP who is from the same CALD background as the family. In this context, every effort should be made to link in with and encourage and support the GP to play an important role in the care, information provision and support for the CALD family.

Strengthening the service system

Goal

- The Children's Cancer Centre has a series of protocols that guide services and practices to respond to the needs of CALD families including the use of interpreters.

Suggested performance indicators

- % of **all** families in whom there is evidence that their cultural and linguistic needs have been assessed on the Children's Cancer Centre database
- % of CALD families in whom their specific cultural and linguistic needs are clearly identified on the Children's Cancer Centre database
- % of all CALD families who are provided with an interpreter at consultations in line with the agreed care plan. This should include routine consultations as well as educational programs
- % of all CALD families that are discussed within the psychosocial meetings
- % of all CALD families with no or limited English skills who have additional telephone contact with the relevant nurse coordinator at the agreed schedule (say at least monthly) during the initial and ongoing active treatment schedule.

7.6 Strengthening the workforce

A range of strategies may be undertaken to strengthen the workforce's ability to work with CALD families with a child with cancer.

7.6.1 Staff training and education in cultural diversity

This includes formal and informal educational programs for Children's Cancer Centre staff and for interpreters including:

- ensuring all Children's Cancer Centre staff participate in formal cultural diversity training and training for working with interpreters being offered at an organisational level
- providing brief but regular general information sessions about different cultural beliefs and practices in different communities, particularly if a child has recently been diagnosed from a new language group
- building up a resource file of information about different cultural communities.

The Victorian Multicultural Commission has a wide range of resources about different cultural communities. This includes brief fact sheets on different communities that provide a summary of each community's history in Australia, demographics, language spoken at home, English proficiency and religious affiliations. A more detailed report for each community gives information about the different communities by LGA, employment information, access to internet etc.

These resources are available on www.multicultural.vic.gov.au (look for community fact sheets under the 'population and migration' tab).

- creating educational interchange opportunities between the Children's Cancer Centre staff and interpreter services to provide educational updates on children's cancer for interpreters or to address cultural and language issues for Children's Cancer Centre staff.

Goals

- All Children's Cancer Centre staff participate in formal cultural diversity training
- A regular informal training program is implemented to provide staff with information about different cultural groups, their practices and beliefs
- A resource file is developed and maintained to provide information to staff about specific cultural groups
- An education program about children's cancer and terminology is provided to interpreter staff at least annually.

Suggested performance indicators

- % of all Children's Cancer Centre staff who have attended a formal cultural awareness training program within a 12 month period
- % of all Children's Cancer Centre staff who participate in the informal cultural information sessions
- % of all interpreter staff who participate in children's cancer education sessions.

7.6.2 Optimising the skills of bilingual staff

As indicated in 5.4.5, a number of bilingual staff indicated that there was a lack of clarity in how they could use their skills in supporting children with cancer and their families from their own cultural background.

This is a difficult issue as these staff are **not trained interpreters nor should they be used in the place of an interpreter**. However they may have the language skills and community understanding to support families and staff within the context of their primary role e.g. nurse, medical specialist, allied health professional.

Given that there is general agreement that CALD families are more isolated, that it is more difficult to have social conversations with them and that CALD families are less likely to access some support services, bilingual staff could play an important role in caring for the specific child with cancer from their own cultural or language group. This role could include:

- being allocated to look after the child and family as part of their usual role using their own language skills in this work
- providing support and advice to other staff looking after these specific CALD children and families.

Given the small numbers of children in any one language group, it is unlikely that any individual service provider would become over-burdened by large numbers of specific CALD families becoming dependent on them.

These roles need to be carefully negotiated with the individual service provider and potentially with the family, and should align with the overall organisational policies in this area.

7.7 Assessing and responding to cultural and language needs

While the above model provides an overall framework for addressing CALD issues at a service level, service providers need to be able to identify the needs of individual CALD families in terms of both their language skills and cultural needs.

7.7.1 Assessing language needs

Although it is relatively easy to assess the language skills of those families with little or no English, it is much more difficult to adequately assess the skills of those who speak some English because of:

- the subjective nature of the assessment based on the assessor and the context
- the English skills of the parent with a newly diagnosed child will be impacted by the stress of the situation
- the technical nature of some of the clinical information will influence the level of English skills required.

Box 2 provides some possible definitions that may be helpful to assess the child or parents level of English. However such '*assessment*' will always be subjective and may be used as a guide only.

In working with parents who have a level of English skills, some useful points to remember are:

- if in doubt, **always** offer and actively encourage access to an interpreter
- even if one parent is bilingual, book an interpreter to facilitate communication with the other parent to reduce the burden on the bilingual parent

- offer continuing access to an interpreter, even if the parents have some English
- always use / offer an interpreter at critical consultations, even if families have been able to manage routine communication
- always book an interpreter if the family requests it.

Box 2: Suggested definitions for assessing English language skills

Level of English skill	Suggested definition
Very poor	Unable to communicate at all / or only very basic 'yes , no' etc. Need interpreter always
Poor	Can communicate in a basic social way, e.g. need for toilet drink etc. Unable to really communicate / understand general conversation and health related information. Need interpreter always
Fair	Able to communicate basic health information, can make social conversation and can easily understand ' <i>next chemo due</i> '. LOTE spoken at home. Would need an interpreter for most clinical conversations.
Good	Able to communicate and understand reasonable level of health information – would need interpreter at critical times, in times of stress or for difficult consultations. May speak English and / or LOTE at home
Very good / excellent	Would understand clinical information as any English speaking parent. May speak LOTE at home but effectively bilingual or English is preferred language.

7.7.2 Assessing cultural needs

In addition to language skills, given the diversity of people within and across different cultures, it is imperative that staff have an understanding of the cultural beliefs and needs of the specific family.

Some tips to achieve this understanding include:

- starting a conversation with the family about their specific beliefs and concerns that might influence their treatment
- checking out whether other family members are or will need to be involved in decision-making and / or the child's care, meal preparation or other activities
- asking what the service can do to help meet their needs
- asking about whether the family are linked with and gain support from any ethno-specific or religious organisations
- talking with the family about who they might tell about their child's illness
- talking with the relevant interpreter to gain an understanding about the general beliefs or issues within a specific community.

Figure 4 (overleaf) provides a decision-making tree that may also assist in identifying the needs of a specific family and ensuring that these needs are addressed in the child's care plan.

Assessing and responding to cultural and linguistic needs

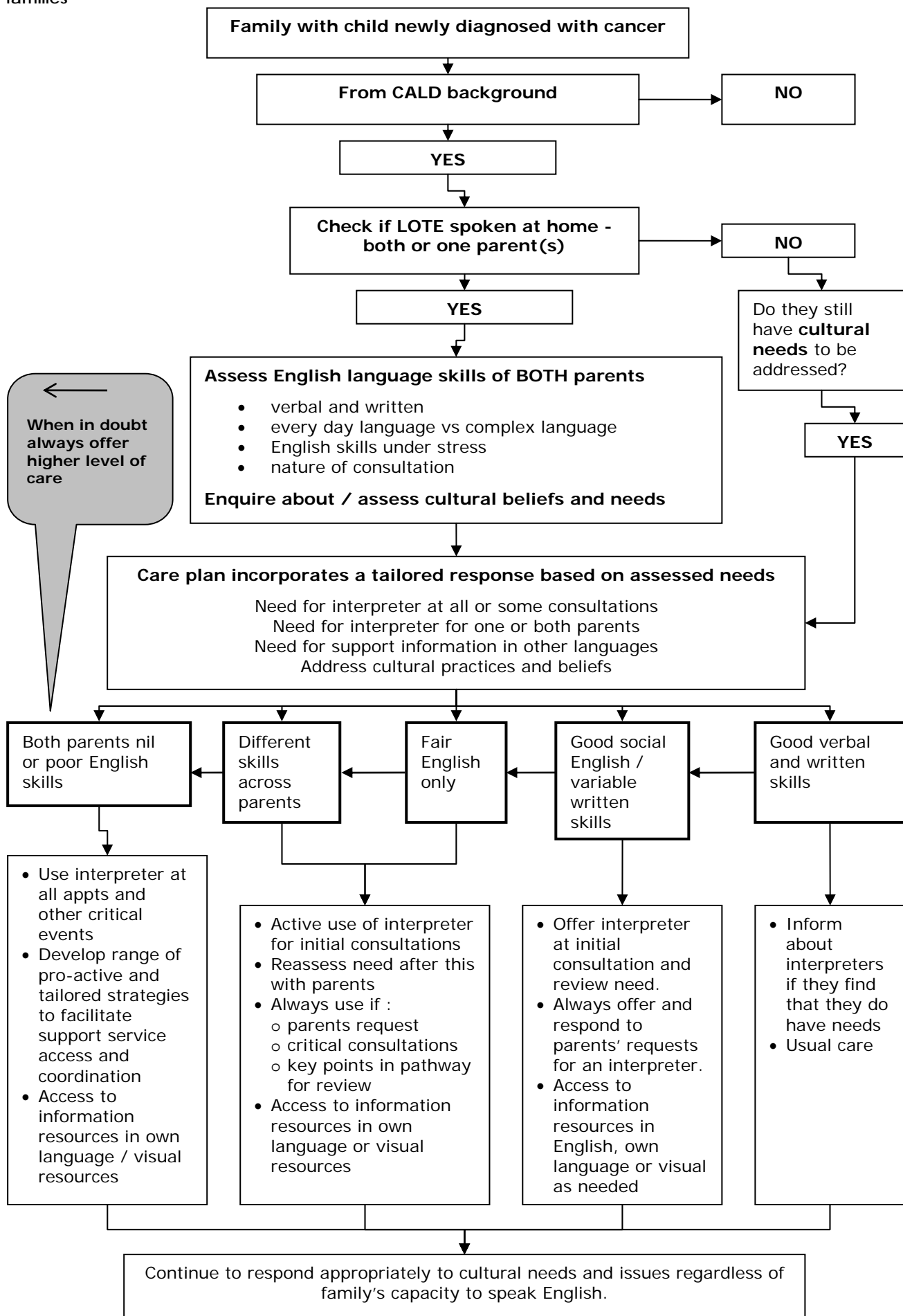
Goals:

- All children and families are assessed for their language and cultural needs as part of the overall assessment undertaken on diagnosis.
- The specific needs of all families from a CALD background and strategies to address these needs are clearly identified within the child / family's care plan.

Suggested performance indicators

- % of all children and families in which there is evidence in their medical record of a formal assessment of their cultural and linguistic needs and that these needs are clearly identified.
- % of all CALD children / families in which strategies to address their cultural and linguistic needs are clearly documented in their care plan / medical record. This should include the plan / schedule for interpreter use based on identified need.

Figure 4: Identifying and responding to the needs of culturally diverse children and families



7.8 Developing resources to support families and staff

A range of resources are required to provide additional information and support to families with a child with cancer.

The suggested core content for the resources are included in Table 3.

Table 3: Suggested core content for translated print / audiovisual resources

Category of information	Resources
Medical / disease and treatment related information	<ul style="list-style-type: none">• Information about the diagnosis and treatment• Road map / timeline of what happens when• Medication instructions• Clinical trials⁵• Glossary of terms
Managing side effects	<ul style="list-style-type: none">• Side effects of treatment e.g. hair loss, bleeding,• What to do when your child is unwell• Managing pain (procedural and non-procedural)• Nutrition, food and dietetic resources
Special care areas	<ul style="list-style-type: none">• Clean diet, home feeding / enteral tubes• Central line care• Procedural pain tips sheets for different age groups• Emergency letter and contact details
Practical aspects of care in hospital and at home	<ul style="list-style-type: none">• Ward lay-out• Day to day nursing routine e.g. taking bloods, observations• Role of the nurse and other staff members• Interpreter services• Support services• Services within the hospital e.g. family resource centre, chapel

7.8.1 Selecting language groups

Given the small numbers of children diagnosed with cancer each year from diverse CALD backgrounds, it is difficult to identify priority language groups.

A number of criteria may be used to make the decisions on priority language groups including:

- size of the population within Victoria
- the proportion of adults in the 'current parent' age group of 26-44 years (see Table 4) who have low proficiency in English
- the proportion of current adolescents / young adults aged 12-25 years (future parents) who have low proficiency in English (see Table 4)
- current usage of interpreters within RCH and MMC.

⁵ Cancer Council of Victoria website provides some information to explain clinical trials to the lay audience. This content may be useful in developing information for CALD families about clinical trials.

Table 4 assesses a range of language groups against these criteria.

Table 4: Potential priority language groups

Language	Total n with low English proficiency in population ¹	% of those with low English proficiency in current and future parent groups ¹		Current ranking in interpreter use at RCH
		12-25 years	26-44 years	
Vietnamese	25,500	4%	34%	1*
Cantonese	16,600	7%	21%	4
Mandarin	14,000	13%	25%	5
Arabic	9442	10%	26%	2
Turkish	6551	4%	28%	3
Cambodian	3604	10%	32%	9*
Assyrian	1972	9%	27%	8*
Dari	1342	12%	33%	NK
Dinka	837	19%	32%	7
Somali	805	6%	30%	6
Karen	305	31%	23%	11
Tigrinya	205	14%	40%	10
Burmese	185	12%	49%	12

¹ ABS census data 2006

* languages identified in newly diagnosed children 07-08 in Children's Cancer Centres in which interpreters were required.

Given this data, it is proposed that the following language groups are given first priority for resource development in their own language.

- Vietnamese
- Cantonese / Mandarin
- Arabic
- Turkish
- Cambodian

Suggestions for second priority language groups are:

- Assyrian
- Dinka
- Somali.

It may also be useful to consult further on the final language selection with the Managers of the Interpreter Services as well as the staff member responsible for each organisation's cultural diversity strategy.

7.8.2 Selection of resource formats

Within the priority language groups, resources may be developed in written or audiovisual format.

Audiovisual format has many benefits including:

- not being dependent on a level of literacy in one's own language
- can use a more conversational language style
- can use a range of visual images
- typing errors which can change the meaning are avoidable.

The downside to using audiovisual resources is that for some languages, the written language is common across a range of communities whose oral language includes many different dialects which are not comprehensible to others.

Key language groups that have common written but different oral languages are Arabic and Cantonese / Mandarin.

In these languages, written resources may provide greater coverage. However if the decision is made to develop audiovisual resources alone, then advice needs to be sought from the interpreter services about the most common dialects that should be used for the audiovisual materials.

Any printed materials should only be developed in electronic format so that they can be downloaded as needed. An English version of each resource should be developed and accessible for future staff.

Another option would be to produce pictorial resources with no written or oral language used. The feasibility of this needs to be explored but may require considerable development time (see below re: cue cards developed by Eastern Health Transcultural Services).

Finally the production of DVDs needs to take into consideration that not all families may have access to a DVD player at home and so may only be able to access the information resource at the Children's Cancer Centre.

Developing templates

The development of some simple resources such as a glossary of terms (see Attachment 1) may be initially developed within the priority language groups. If such resources are developed into simple templates they may then be used when a family presents from other language groups. The terms could be translated and written onto the template for use by that family during an interpreter mediated education session.

These translated words could then be transcribed into the electronic template, and would be available for families from that language group in the future.

Development of pictorial resources

Given the diversity of and the changing profile of the language groups over time, developing quality pictorial resources may be a very useful investment. These resources which could include simple words could aid in:

- providing information about the child's cancer, treatment, procedures, medication instructions and / or support services
- aid every day conversation between the child, parents and service providers.

The cue cards developed by Eastern Health Transcultural Services are an example of a visual resource that may be helpful. These cue cards which took considerable development time (including testing) are available on: www.easternhealth.org.au/language/cueCARDS.

The development of pictorial resources can be used within interpreter mediated consultations or to aid everyday conversations between staff and families. They do not replace the need to use interpreters.

Developing resources

Goals

- A small number of initial pictorial resources that can be used for any language group.
- A suite of resources is available in five languages.

Suggested performance indicators

- % of CALD families from the priority language groups who are provided with the relevant information resource suite in their own language.

7.9 Developing partnerships

There is a need to develop partnerships with a range of internal and external providers given:

- the challenges that all organisations and specifically children's cancer services face with supporting individuals from diverse communities
- the relatively small numbers of children and families from a wide range of cultural groups
- the time and resources needed in particular to develop information resources.

Partnerships may be developed with other national children's cancer services individually or through ANZCHOG, Cancer Council of Victoria and / or with particular ethno-specific organisations.

While this adds a level of complexity to an already challenging area, such partnerships would help to optimise the best use of limited resources and avoid duplication of effort.

7.10 Supporting and driving CALD initiatives within service sites

A number of different approaches could be taken to develop a core of expertise within each service site, to take responsibility for supporting staff and for developing and driving broader CALD initiatives. Options include:

- developing the area as a portfolio for a specific staff member at each site
- developing a multicultural special interest group.

Key tasks might include:

- setting goals for service improvement in this area and overseeing achievements
- liaison with other units within the broader health service e.g. interpreters, cultural diversity program, and / or with external organisations (see below)
- developing the informal educational program for Children's Cancer Centre and interpreter staff
- problem solving with the rest of the team
- driving special events or initiatives
- identifying new service / resource gaps and seeking ways to address these.

Strengthening the workforce

Goal

- Nominated staff are given clear responsibility for developing and implementing the CALD strategy.

8. Moving forward - implementation

Some structures, processes and resources will be required to facilitate the implementation of the CALD strategy.

Some strategies will be able to be implemented by linking in with overall organisational strategies e.g. RCH cultural diversity training to commence in 2009.

Other strategies may require responsibilities that could be potentially absorbed into current roles such as

- ensuring CALD issues are well addressed within the psychosocial meetings
- developing the informal education sessions and resource folders
- ensuring additional priority to CALD families' needs is integrated into the nurse coordinator role.

8.1 Timeframe

While some initiatives may be implemented over a relatively short time frame given its overall complexity, an initial twelve to eighteen month plan for developing and implementing an effective CALD strategy is proposed. While many strategies may be achieved in this time frame, given the complexity of resource development for different language groups, a three year plan may be more realistic for achieving this work.

The achievements, outstanding tasks and the need for continuing work can be reviewed at the end of the initial 12-18 months.

8.2 Leadership and coordination

Some resources may be required to lead and coordinate the implementation of the above strategies and to monitor achievements against the stated goals. The development of a **small working party** to oversee the implementation of the CALD strategy may be an important first step. Such a working party may link in with the special interest group identified in 7.8.3.

8.3 Resource development

The complexity of developing new resources in other languages requires significant investment.

The process of resource development in other languages requires:

- agreeing on the priority resources, specific minimum content / messages and priority languages
- revising the content of any current resources for cultural sensitivity and ease of translation
- identifying and commissioning the translations
- checking the translations which can be very challenging and time-consuming
- identifying and developing the visual images
- coordinating design or production including voice over.

While the overall resource development costs would require as significant investment, if done well this investment will provide⁶:

- a range of resources in priority languages
- pictorial resources for other language groups
- a series of other templates that may only require a small amount of resources for developing additional resources in other languages
- a range of resources that will last a significant period of time
- a good understanding of the processes required to develop audiovisual and written resources in other languages.

It will also position PICS well in meeting the challenge of supporting diverse communities within its own host organisations and within the wider children's cancer field.

8.4 Moving forward - recommendations

The following recommendations are made to support the implementation of the PICS strategy for strengthening services to children with cancer and their families from a CALD background.

⁶ It should be noted that without adequate time and resource investment, significant errors can occur which result in developed resources not being able to be used or requiring additional resources to correct.

1. That the PICS Steering Group endorses the overall directions for the development, implementation and monitoring of the CALD strategy over a three year period.
2. That funding is allocated or a strategy developed to attract funding to support the full implementation of the CALD strategy.
3. That mechanisms are developed to ensure effective leadership and coordination of the strategy within and across PICS service sites.
4. That priority be given to:
 - participation of staff in formal cultural diversity training programs being offered through the relevant health services
 - the development of a minimum set of information resources in up to five language groups
 - the development of other pictorial resources to aid communication with families from all language groups
 - ensuring that the specific cultural and linguistic needs of CALD families are adequately assessed and the responses to these needs are agreed and integrated into individual care plans
 - developing and implementing strategies to prepare and support interpreters for difficult or distressing consultations
 - ensuring staff adopt pro-active approaches that will better enable families to access the range of services available
 - a range of strategies to facilitate the support and coordination of care for all CALD families.
5. That all PICS service sites implement mechanisms to create a more culturally aware and welcoming environment for CALD children and their families.
6. That PICS services further strengthen their relationships with interpreter services and those responsible for the organisation's overall cultural diversity policies and procedures for mutual benefit and to reduce duplication of effort.
7. That PICS takes a leadership role in developing partnerships with other children's cancer services / ANZCHOG to address the needs of CALD families affected by cancer to optimise the best use of limited resources.
8. That this plan is reviewed annually and new goals established to ensure that all CALD families have access to resources and services to optimise their active involvement in decision-making, informed consent and care of their child.

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Glossary of terms

Term in English	Other language
<p>Your child's type of cancer</p> <p><input type="checkbox"/> Leukaemia</p> <p><input type="checkbox"/> Brain tumour</p> <p><input type="checkbox"/> Kidney cancer</p> <p><input type="checkbox"/> Bone cancer</p> <p><input type="checkbox"/> Cancer of the soft tissue / muscle</p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>
<p>Your child's type of treatments</p> <p><input type="checkbox"/> Surgery</p> <p><input type="checkbox"/> Radiotherapy</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Bone marrow transplant</p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>
<p>Tests / procedures your child will need regularly</p> <p><input type="checkbox"/> Blood test</p> <p><input type="checkbox"/> Chest – Xray</p> <p><input type="checkbox"/> CT / MRI scan</p> <p><input type="checkbox"/> Bone marrow test</p> <p><input type="checkbox"/> Lumbar puncture</p> <p><input type="checkbox"/> Central line catheter</p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>

Term in English	Other language
<p>Other treatments your child might need</p> <p><input type="checkbox"/> Antibiotics</p> <p><input type="checkbox"/> Pain killers</p> <p><input type="checkbox"/> Special diet</p> <p><input type="checkbox"/> Tube feeds</p> <p><input type="checkbox"/></p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>
<p>Side effects your child might develop</p> <p><input type="checkbox"/> Sore mouth</p> <p><input type="checkbox"/> Infection</p> <p><input type="checkbox"/> Pain</p> <p><input type="checkbox"/> Weight loss</p> <p><input type="checkbox"/> Weight gain</p> <p><input type="checkbox"/> Other treatment related words</p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>
<p>Services that can help you and your child</p> <p><input type="checkbox"/> Nurse coordinator</p> <p><input type="checkbox"/> Social worker</p> <p><input type="checkbox"/> Dietitian</p> <p><input type="checkbox"/> Play therapist (Comfort First)</p> <p><input type="checkbox"/> Music or art therapist</p> <p><input type="checkbox"/> Psychologist</p> <p><input type="checkbox"/> Pastoral care</p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>



Paediatric Integrated Cancer Service

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