



Culturally Responsive
Palliative Care
Project
2013 - 2015

Final Evaluation Report
EXECUTIVE SUMMARY

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Glossary

BPE	Bilingual Peer Educator
	<i>Bilingual peer educators are trained health educators who conducted the community education sessions in their respective languages</i>
CALD	Culturally and Linguistically Diverse
	<i>For the purpose of this report, a person from a CALD background refers to someone who may or may not have been born in Australia, and identifies as coming from a non-English speaking background</i>
CRG	Community Reference Group
	<i>Community reference groups were convened for each of the 10 community language groups to develop the peer education resource and assist with the media strategy</i>
CRT	Cultural Responsiveness Training
ECCV	Ethnic Communities' Council of Victoria
MCWH	Multicultural Centre for Women's Health
PCS	Palliative Care Services
PCV	Palliative Care Victoria
PEP	Peer Education Participant
	<i>A person who attended a community education session</i>
PER	Peer Education Resource
	<i>The peer education resource developed by MCWH (in collaboration with ECCV, the community reference groups and the project steering group) to be used by the bilingual peer educators to conduct community education sessions. There was a generic resource, and 10 tailored resources, one for each language group.</i>
SG	Steering Group
VAED	The Victorian Admitted Episodes Dataset (VAED)
VINAH	Victorian Integrated Non-Admitted Health (VINAH) minimum dataset

Executive summary

Context

The Culturally Responsive Palliative Care project evolved in recognition of a number of current trends:

- The significant and growing culturally and linguistically diverse (CALD) population in Australia
- The ageing of Australia's population, particularly those from CALD backgrounds
- The growing demand for palliative care services
- The underutilisation of palliative care services by people from a CALD background.

Project Design and Development

The Culturally Responsive Palliative Care Project has two complementary parts (Figure 1). One part is focused on working with culturally and linguistically diverse (CALD) communities to improve their knowledge of (and ultimately increase their uptake of) palliative care. The second part is focused on working with palliative care services to increase their capacity to deliver culturally responsive palliative care.

The first part of the project was delivered in two waves, across two consecutive years. The first wave got underway in July 2013 and included the Chinese, Vietnamese, Italian, Maltese and Turkish communities (see preliminary evaluation report). The second wave was conducted between July 2014 and August 2015 and included the Polish, Greek, Arabic-speaking background, Croatian, and Macedonian communities. Given the learnings from the first year of the project, design and implementation of the second wave varied slightly between the years.

The second part of the project comprised a complementary program of cultural responsiveness education delivered by Judith Miralles and Associates specifically for the palliative care sector. Workshops were conducted between September 2014 and July 2015.

Project Aim

The aim of the project was to raise awareness of palliative care services among culturally and linguistically diverse communities and to improve their access to culturally responsive care services.

The primary project activities included:

- Community education sessions about palliative care services delivered in language to the targeted communities by a trained bilingual peer educator, using a community specific resource developed as a part of this project
- A strong media and communications campaign which utilised ethnic media sources
- Strengthening relationships between the community organisations and palliative care service providers
- Cultural responsiveness training program for palliative care staff, managers and volunteers.

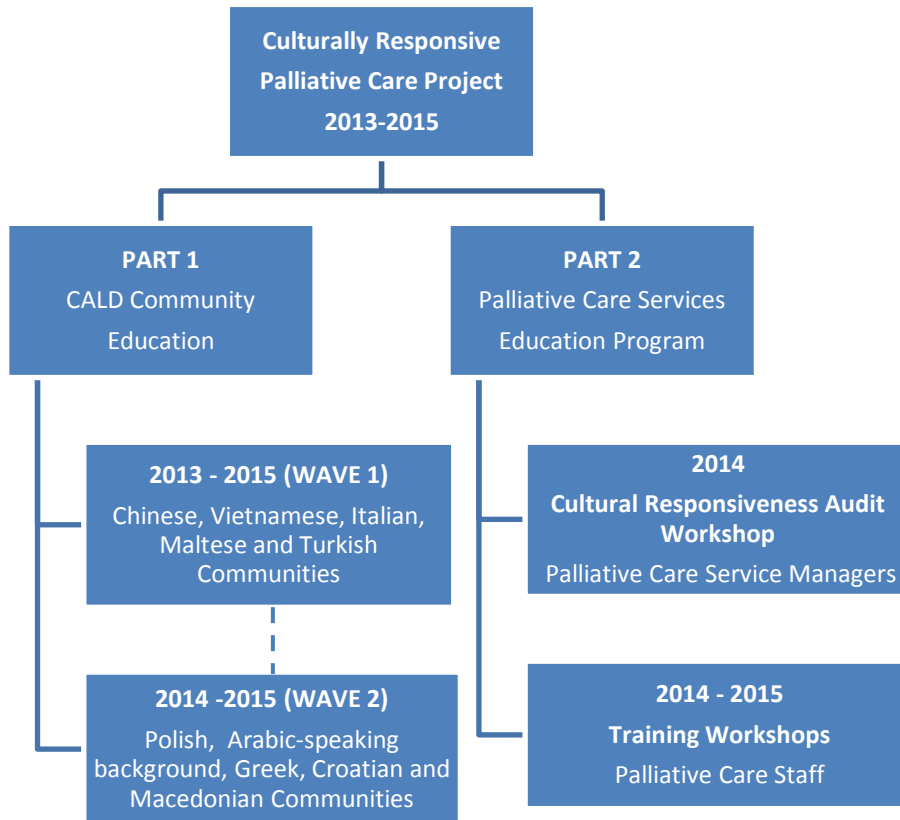


Figure 1. Components of the Culturally Responsive Palliative Care Project

Project Relationships and Roles

This was a collaborative project comprising many different people and organisations (Figure 2).

The four key funding bodies were: Lord Mayor’s Charitable Foundation, Victorian Department of Health, Palliative Care Victoria (PCV) and the Trust Company.

Palliative Care Victoria (PCV) initiated the project, engaging its key partner organisation, Ethnic Communities’ Council of Victoria (ECCV), to drive and deliver the key components of the community education project. Multicultural Centre for Women’s Health (MCWH) was also a key partner in the first year, primarily responsible for the development of the community education resources and training.

Two consultancies also had key roles: Radermacher and Associates, engaged at the project outset, to evaluate the project; and Judith Miralles and Associates to develop and deliver the cultural responsiveness education program.

The steering group provided an opportunity for diverse stakeholders to contribute to the governance of the project and provide feedback across the duration of the project. In addition to the key partner organisations, other stakeholders represented on the steering group included the Victorian Department of Health, palliative care services, palliative care consortia, and two interested organisations.

The other key players included the lead agencies within each of the 10 CALD communities, the bilingual peer educators, and the community reference groups.

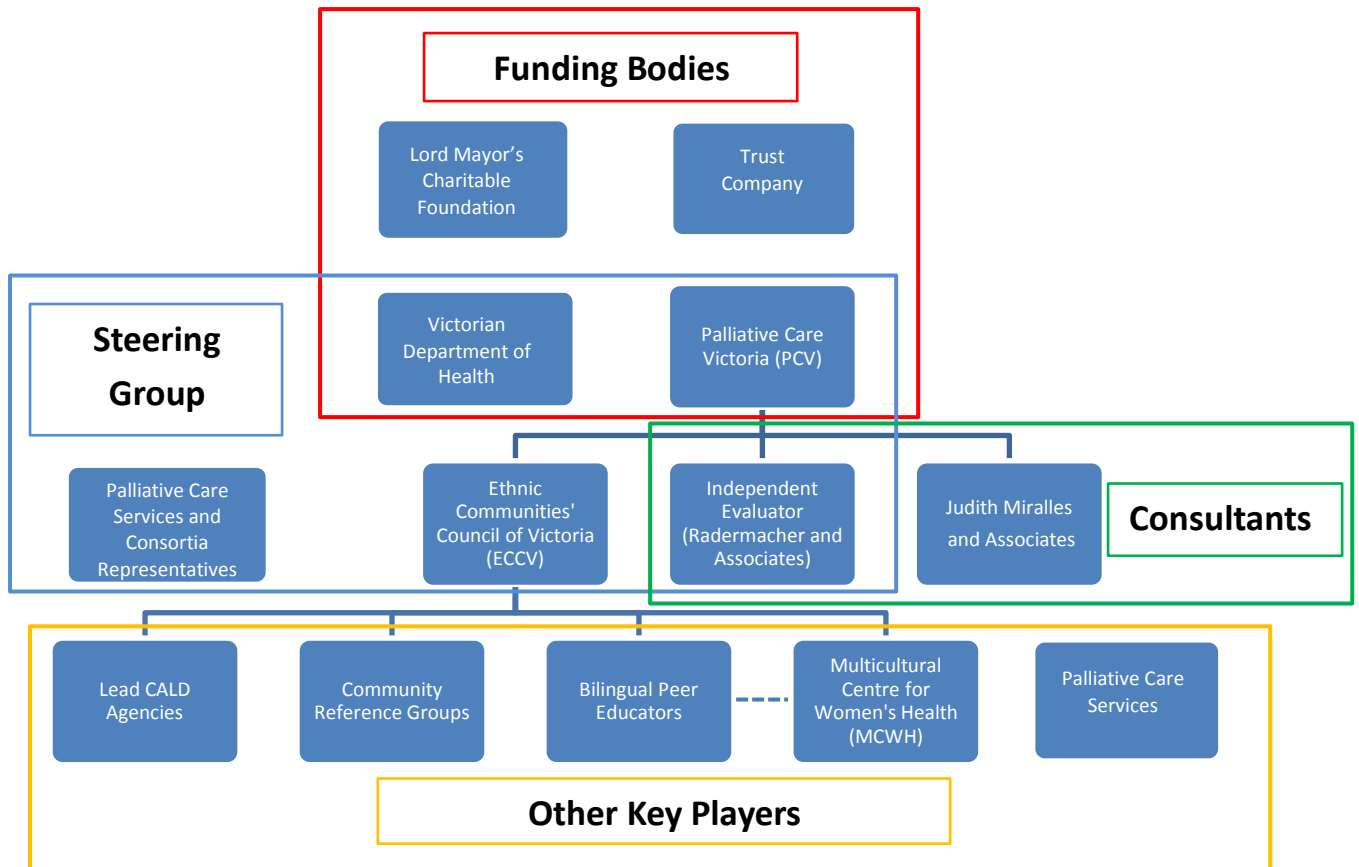


Figure 2. Project relationships and roles

Evaluation Design and Development

A primary aim of the evaluation was to provide information to the funding bodies and other key stakeholders about the value and effectiveness of the project.

Further, on account of key players being part of the evaluation process itself, the aim was to provide key partners and stakeholders immediate feedback about the delivery, implementation and effectiveness of the project. This in turn was used to directly inform project-related decisions going forward. Due to the exploratory nature of the project, the evaluation was primarily process orientated, as opposed to outcome focused. This does not mean that the outcomes were not important, but that it was only within the scope of this evaluation to report on the short-term outcomes.

The evaluation comprised a comprehensive, multi-stage collaborative exercise with all project partners and stakeholders. Key questions were identified to guide the development of an overarching monitoring and evaluation plan.

Data Collection

All the project partners were responsible for the collection of different aspects of the evaluation data. The sets of data generated included:

- 3214 community education participant evaluation forms (66% response rate)
- 135 bilingual peer educator evaluation forms (1 completed for each education session; 90% response rate)
- 394 participant evaluation forms from 26 cultural responsiveness training workshops for palliative care staff and volunteers (85% response rate)
- 26 participant evaluation forms from a cultural responsiveness audit workshop for palliative care service managers (100% response rate)
- 40 face-to-face and telephone interviews, and one focus group (including steering group members, palliative care service representatives, CALD community representatives, and bilingual peer educators)
- PCV website activity and inquiries
- Project documentation materials including media articles, steering group minutes, community reference group minutes, and progress reports.

Project Outputs

High quality and applicable resources were developed, via a rigorous and participatory process, which have utility beyond the project boundaries:

- Peer education resource, tailored by and with each of the 10 communities, which includes specific information about culturally sensitive issues
- Bilingual information about palliative care, endorsed by a reference group from each community, and translated into 11 languages
- Communication toolkit for use by community organisations covering key messages, target audiences, media tactics, templates and FAQs
- Training handbook and video clip used for the culturally responsive education program for the palliative care sector.

Evaluation Overview



The findings of this evaluation are based on data collected from July 2013 to August 2015 inclusive, and are structured according to the evaluation questions devised by the steering group.

During this time frame 10 community reference groups were convened, 9 community launches were held, and 33 bilingual peer educators were trained.

In total, 4846 participants participated in 150 community education sessions. The target of 70 to 90 sessions per year was achieved, and people from all 10 communities heard information about palliative care in their preferred language. Given the scope and available resources, the reach of the project was commendable and there was no evidence to indicate major gaps in the target communities.

Awareness about palliative care amongst the community reference group members and the educators also increased and, on account of their role and status in their respective communities, provides a promising avenue for ongoing communication of the project's key messages. This was particularly the case in the second wave of the project when many of the educators were also staff members of ethno-specific organisations.

Also encouraging was the clear applicability of the project model to other areas and communities, as well as the evidence to suggest that the short-term outcomes were directly attributable to the project.

Linkages between palliative care services and ethno-specific organisations were formed as a direct result of the community reference groups and the launches. However, qualitative data indicated that there was room for improvement in terms of the scope and sustainability of the linkages formed.

While there were some indications of a sense of ownership of the project objectives developing amongst some key stakeholders (particularly in the second wave communities), this was identified as a critical focus for longer term evaluation.

The short-term outcomes of the first and second waves of the community education component of the project were consolidated by the cultural responsiveness education program. The training was extremely beneficial for the majority of the 420 palliative care staff, managers and volunteers who took part across the state. Quantitative evidence indicated that participants found it useful and worthwhile, and that they would apply what they had learned to their everyday practice, and this was confirmed by qualitative interviews conducted a few months later.

Given the timeframe of the evaluation (spanning the first two years of the project), it was only possible to report on the immediate, short-term outcomes.

While the findings from this project are positive, ongoing evaluation (particularly via the use of service usage data) in subsequent years will help to determine its true value and effectiveness. And while the project has sown the seeds of sustainability, it will require ongoing maintenance to capitalise on the progress achieved to date.

Assuming the success of the project in raising awareness and increasing access to culturally responsive palliative care services, the evaluation highlighted the importance of considering the capacity of the palliative care sector in the future to service increasing demand and expectations of CALD community members.

Key Outcomes

Raising Awareness of Palliative Care via Community Education Sessions

The majority of community education participants reported to (Figure 6):

- Not know about palliative care before the session (66%)
- Learn new things as a result of the session (92%)
- Have an intention to tell friends and family about palliative care (94%)
- Think that palliative care was a good idea (96%).

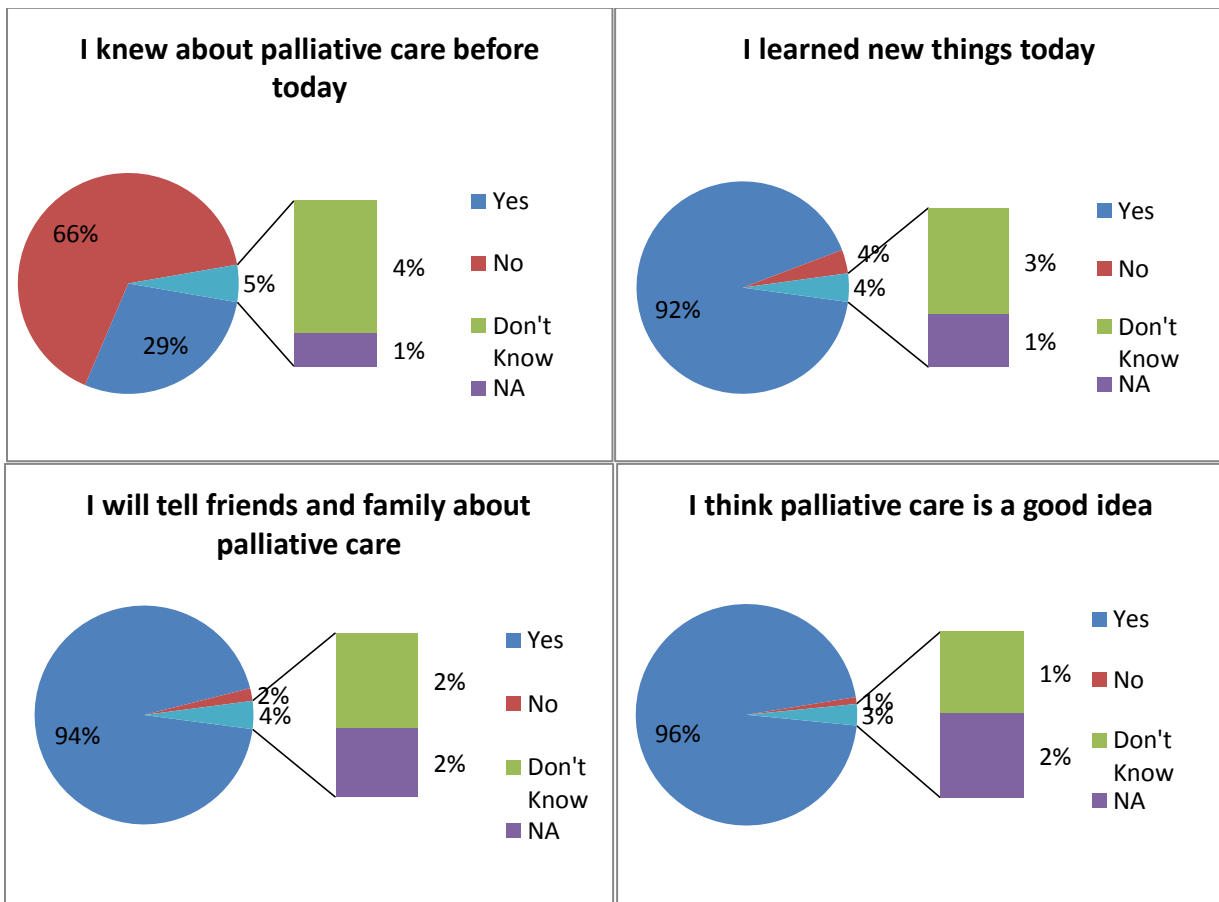


Figure 7. Participants' perspectives about the community education sessions

While an average of 66% of participants reported not to have known about palliative care before they attended the session, the level of awareness ranged dependent on the participant's language. For example, a majority of the Arabic-speaking background (93%), Turkish (80%) and Vietnamese (76%) participants reported not knowing about palliative care, while a minority of the Maltese (41%), Croatian (42%) and Chinese (44%) participants reported not knowing about palliative care.

Overall bilingual peer educators:

- Agreed or strongly agreed that the session was effective at increasing participants' awareness of palliative care (95%)
- Agreed or strongly agreed there was a lot of positive interaction between the participants (86%)
- Agreed or strongly agreed that participants asked a lot of questions (77%).

Qualitative data were also gathered from a range of sources. The following comment by an educator describes the reaction of participants to the material both during a session and afterwards, which not only illustrates how their own awareness was increased, but also potentially of those who did not attend the sessions:

"A lot of the information people didn't know about...a lot of people were uncomfortable with the information that was given, the stories, the scenarios...but overall the majority of people who I spoke to after the session were pretty interested in what was said and you can tell, they asked for more information, information sheets that were done in [community language] and English, not only for themselves but to give to friends and families that weren't there on the day...I spend some time with them after the session, you can tell because, you can even hear them having conversations between, small groups talking about you know...so there was some kind of talk about it, even though the session was over...I've even had phone calls from people who attended, and they spoke to family about the information session, and they asked for more information sheets... the message did get out even to those who didn't, couldn't attend." (BPE Interview, 2014)

Raising Awareness of Palliative Care via Media and Communications

The project did not just raise session participants' awareness about palliative care, but also the wider CALD community via a tailored media strategy.

Between May 2013 and May 2015, there were 120 items of media activity. About a third were 'general' media items (i.e. targeted at the broader community), the rest targeted the 10 participating communities.

Furthermore, a total of 11,002 bilingual handouts were distributed in 11 different languages across the duration of the project.

In summary, the media approach worked reasonably well but was hindered in both waves of the community education project due to unforeseen circumstances and modest resourcing. Furthermore, there was evidence to indicate that the nature of the topic and issues of privacy were likely to have deterred community members from sharing their personal stories – stories that could have been effectively used in the media to demonstrate the value of palliative care.

Those involved in the project implementation and delivery, including community reference group members, steering group members and educators also reported that they learned more about palliative care as a consequence of participating in the project.

Promoting Linkages

The project was launched in August 2013, together with 9 community launches between February 2014 and April 2015. All these events attracted a range of people from the ethnic and palliative care sectors. The project launch and four community launches were also attended by the Victorian Minister for Health.

The August 2013 project launch attracted 41 participants from ethnic communities and the palliative care sector, with data indicating strong agreement from participants about increased awareness of the project, excitement about being involved in the future, and that stronger linkages were fostered.

Each community launch attracted between 50 and 100 participants, and while their effectiveness at promoting linkages was limited, their role in raising awareness and 'buy in' from the respective communities was significantly more important:

"The launch actually made the whole difference. Something acknowledged. There was our consular there... People will remember. There was something, not just information sessions. People you know they can see and meet, our consular, our CEO, people from the Board. Something important for the government, because they've been funded the project, important for them to be there." (CRG-ORG Interview, 2015)

In addition to the launches, the education sessions, community reference groups and the educator training days were also intentionally constructed so as to foster links between palliative care services and the ethnic sector. While there was evidence of positive and valuable linkages forged as a result of this project, it was the scope and sustainability of the linkages that were perceived as a limitation, and subsequently described as a "missed opportunity".

It was not known to what extent community members, as a result of hearing about palliative care, directly contacted services themselves as was anticipated at the project outset. However, there was evidence to indicate that community members were making contact with palliative care services via their respective ethno-specific community organisations.

Increasing Cultural Responsiveness of Palliative Care Services

The main vehicle through which this project sought to increase understanding of cultural perspectives amongst palliative care services was via the delivery of cultural responsiveness education to palliative care staff, managers and volunteers.

One state-wide workshop, held in September 2014, was directed at palliative care service senior managers and quality managers to raise their awareness about how to conduct audits to monitor the cultural responsiveness of their service. In general participants reported the session to be either excellent or very good. This was particularly the case for the relevance of the training program to their work. However, there was slightly less of a positive response in having the confidence to transfer what they had learned to their work.

Between September 2014 and July 2015, 26 training sessions were conducted in 19 metropolitan and seven rural locations, within 35 different palliative care services. The majority of participants reported to find the session either excellent or very good. They particularly liked the facilitator's style, how the facilitator encouraged interaction, and how relevant the program was to their work. Participants had a slightly less positive response in their confidence to transfer what they had learned to their work and in their ability to communicate across cultures.

In summary, the cultural responsiveness education program was very beneficial for the majority of participants who took part. There was evidence that participants found it useful and worthwhile, and that they would apply what they had learned to their everyday practice. The small number of participants who were interviewed a few months after the workshops generally confirmed this finding.

While this education program was generally received well by staff, questions remain about the most effective way in which to enhance culturally responsive care. The training program, as well as palliative care services' involvement in the community education component of the project, should be the subject of a longer-term and more specific evaluation to explore whether participation has improved the capacity of palliative care services to provide culturally inclusive and responsive services to people from CALD backgrounds.

Generating Ownership

There was evidence of some short-term indicators of ownership, and to a lesser degree that this ownership would extend into the future.

Given the revised approach in the second wave of the project (whereby organisational staff took part in the community reference groups and often went on to become trained and deliver education sessions) there was much more potential for sustainability of the project's objectives. The level of engagement and enthusiasm by community members was perceived by project staff to be much higher than the previous year. This was demonstrated by a greater number of sessions being delivered more quickly and more widely (into regional areas). This outcome was partly attributed to the development of stronger relationships with the project staff, with greater opportunities to learn and incentives to run sessions. Regardless of the year of involvement, there was evidence to suggest that the majority of community organisations and educators involved intended to continue to spread the word about palliative care in some form or other.

What was apparent in both the ethnic and palliative care sectors were the structural barriers in place which hindered ongoing progress and adoption of project objectives. Community organisations often don't have the resource capacity to continue education sessions without funding, and palliative care services are often struggling to meet the demand for care so that they have little time to focus on changing how services are delivered.

Key Principles

Five elements were identified as being critical to the successful development, implementation and outcomes achieved to date. As such, they may serve as useful lessons to guide future initiatives.

Solid Foundations and Leadership

This project had solid foundations, in that the groundwork for the project had been laid several years prior. Communities had already been consulted, and relationships formed. This work set the context for the current project, making for a relatively quick roll out and sharing of ownership. It also sent a message to the communities that their previous involvement was not just tokenistic, and that PCV was committed and had credibility.

The significance of this solid foundation, developed over several years, calls into question the value of a project-based approach. Rather, this project may be more aptly referred to as a 'process', particularly given that for many of those involved, they feel the work has just begun and that to stop the momentum now would undo much of the progress that has been made. It also fuels the debate for making culturally responsive palliative care core business.

Strong Collaboration and Respectful Relationship Building

The project was built around the expertise and existing networks of three key partner organisations (PCV, ECCV and MCWH). Despite the complexity and time taken to foster relationships, the investment resulted in significant capacity building for each of the partners involved. This was well supported by the creation and maintenance of a steering group and an operational group. Relationships were not just formed between partner organisations, but between all the diverse stakeholders (lead partner agencies, community reference groups, bilingual educators, palliative care services). Underpinning all the relationships was not only a respect for the diversity of expertise and experience, but a great deal of authenticity, passion and good will by all those involved.

Participatory and Organic Approach

From the outset, the project embraced a participatory approach whereby the emphasis was on sharing expertise and decision-making, regardless of who holds the purse strings. While the deliverables and basic project design were known, most of the detail about how the project was going to pan out was unknown. This approach, while time-consuming, generated unique and tailored outputs and outcomes, further fuelling ownership and credibility.

Peer Education Model

The peer education model employed in this project extended far beyond traditional educational approaches that simply disseminate written information. This project has highlighted the value of face-to-face communication in people's preferred language, particularly given the sensitive nature of the topic and the generally low levels of literacy and health literacy. Furthermore, by engaging community leaders, it demonstrated to the community that the concept of palliative care was not only acceptable but endorsed.

Funding and Economy of Scale

The pooling of collaborative funds by government, philanthropic trusts and a community organisation enabled the project to be undertaken at a scale that was not only more cost-effective but more likely to have an impact.

Strengths and Limitations of the Evaluation

The strength of the evaluation was in its comprehensive and collaborative nature, comprising multi-faceted data collection strategies that simultaneously served to inform the ongoing roll out of the project and provide a foundation for ongoing evaluation in subsequent years.

The main limitation was not being able to access qualitative feedback from community members who attended the education sessions. Despite efforts to do so, there was some reluctance to share individual stories. How families manage end-of-life issues is seen as a private matter, regardless of background, and not one for sharing more broadly with others outside the family.

Also, given the short-time frame of the evaluation, it was not possible to assess the long-term impact and effectiveness of the project, particularly given the inevitable delay between finding out about services and the need to use them.

Recommendations for Future Evaluation

From the outset of this project, it was clear that a two-year evaluation could not serve to answer questions about the long-term impact and effectiveness of the project. The following recommendations provide a guide for the future evaluation of the project, with responsibility for doing so lying with government, ethnic and palliative care sectors:

- Ongoing collection, monitoring and analysis of available data on patient utilisation of community and hospital palliative care services by CALD communities. This should include accessing information about the collection and consistency of measures used across the years.
- Implement a system whereby annual data are collected from ethno-specific and multicultural community organisations to monitor activities related to palliative care (e.g. queries about services, referrals, delivery of education sessions).
- Follow up with palliative care sector regarding the impact of the cultural responsiveness training on subsequent activities of palliative care services.
- Given that the Victorian Palliative Care Satisfaction Survey (VPCSS) is not continuing, it would be timely to ensure that its replacement is accessible to people from CALD backgrounds, and gathers feedback from CALD patients, carers and bereaved carers about their satisfaction with palliative care services, including the way services responded to their cultural and spiritual needs.
- Ongoing collection of culturally specific data from local palliative care services to enable the monitoring of access by people from CALD communities over time.
- Ongoing monitoring of PCV website activity of multicultural content, in combination with project-specific and other organisational activities, and analyse as appropriate.

Recommendations for Policy Makers and Funding Bodies

The overarching message for policy makers and funding bodies is the need to maintain the project momentum, and to build on the groundwork that has been achieved to date – not only in relation to the awareness raising that has already occurred, but in the relationships that have been created. Culturally responsive care is not an add-on, but needs to be core business. However, for culturally responsive care to be core business, ongoing support is required for both the ethnic and palliative care sectors which is not just in the form of more funding, but also addresses prevailing structural barriers.

The key recommendations include:

- Consider funding follow-up or refresher sessions with the same groups and communities to maximise the potential impact and embed learning.
- Promote strategies to encourage the ongoing use and leverage of resources developed by this project (peer education resource, bilingual handouts, trained peer educators, education manual and video) by other communities and organisations.
- Consider the co-development, implementation and evaluation of a multi-faceted education strategy, which may include both online and face-to-face training, which will better meet the needs and preferences of the palliative care workforce.
- Assess the level of organisational accountability and ownership over cultural responsive palliative care, and related structural barriers to delivering care and education, to support the development of appropriate and innovative solutions.
- Support structured and formal mechanisms to build confidence and skills in forging links across the ethnic and palliative care sectors.