

Victorian Aboriginal Palliative Care Project 2007–2010

Evaluation and final report



Palliative Care
VICTORIA
Specialist health care and practical support



VACCHO

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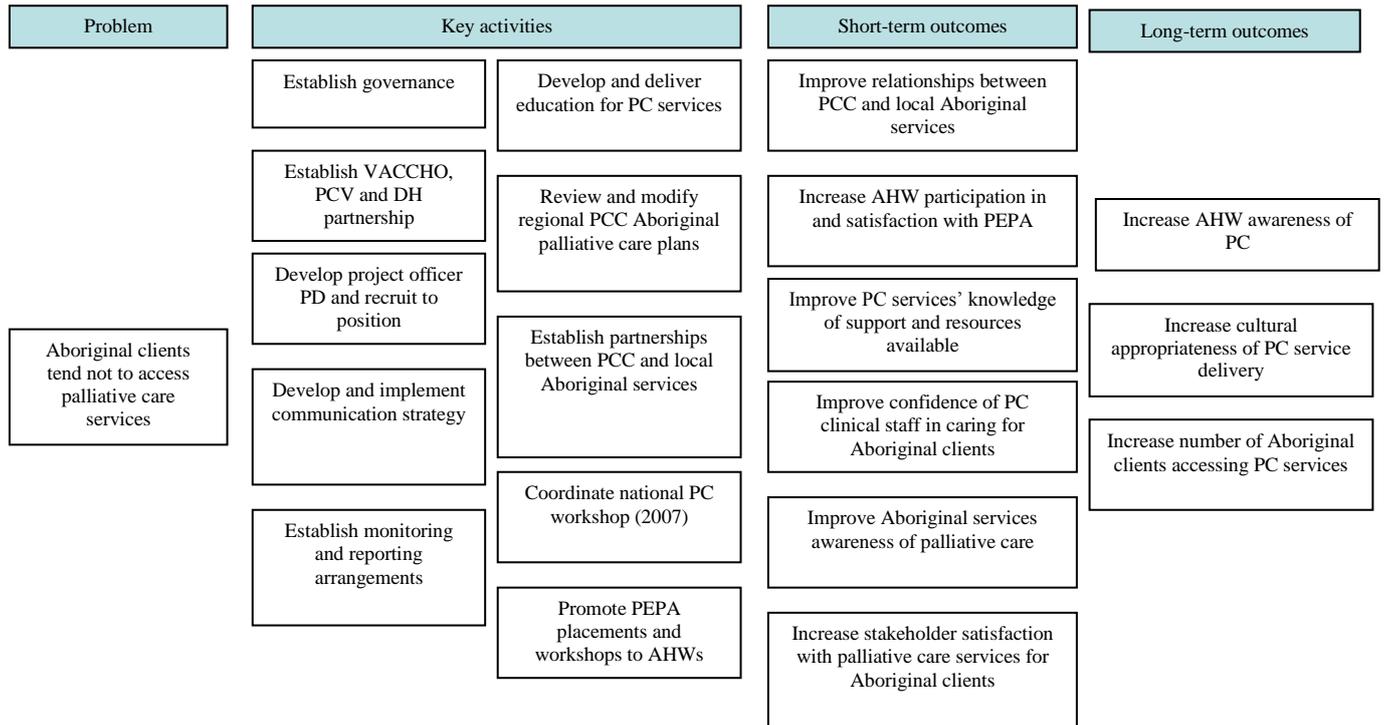
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Acronyms and abbreviations

A&TSI	Aboriginal and Torres Strait Islander
ACCHO	Aboriginal community controlled health organisation
AHLO	Aboriginal health liaison officer
AHPACC	Aboriginal Health Promotion and Chronic Care
AHW	Aboriginal health worker
CALD	culturally and linguistically diverse
CEO	chief executive officer
DH	Department of Health
DVD	digital video disk <i>or</i> digital versatile disk
GP	general practitioner
NACCHO	National Aboriginal Community Controlled Health Organisation
PC	palliative care
PCC	palliative care consortia
PCV	Palliative Care Victoria
PEPA	Program of Experience in the Palliative Approach
SEWB	social and emotional wellbeing
TAFE	tertiary and further education
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VAED	Victorian Admitted Episodes Data Set
VAHS	Victorian Aboriginal Health Service
VAPCP	Victorian Aboriginal Palliative Care Project
VINAH	Victorian Integrated Non-Admitted Health

1 Project background

The Victorian Department of Health (formerly the Department of Human Services) funded the Victorian Aboriginal Palliative Care Project 2007–2010 (VAPCP). The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) undertook this project in partnership with Palliative Care Victoria (PCV) on behalf of the Department of Health. The following figure illustrates the structure of the responses to the issues surrounding Aboriginal clients tending not to access palliative care services.



Underlying intentions of the VAPCP

2 Key evaluation questions

The long term outcomes of the VAPCP were to:

- Increase AHW awareness of palliative care
- Increase cultural appropriateness of palliative care service delivery
- Increase number of Aboriginal clients accessing palliative care services.

The evaluation questions that focused on these three key outcomes of the initiative are:

- 1 appropriateness in relation to community need
- 2 operational efficiency and areas of potential improvement
- 3 effectiveness of the initiative in meeting its objectives.

2.1 Appropriateness in relation to community need

What was the rationale for establishing the VAPCP?

Historically, Aboriginal people have not accessed palliative care services to their full extent. In 2005, under the National Palliative Care Program, the Commonwealth Government funded a 12-month pilot project in Victoria that culminated in the report *The Journey: coming together, caring together*. The Victorian Department of Health (then the Department of Human Services) subsequently funded the Victorian Aboriginal Palliative Care Project (VAPCP) for the period July 2007 to June 2010. The VAPCP was designed to build on the success of the original pilot project, which aimed for Aboriginal people to have access to palliative care services, and for palliative care services to provide culturally safe services to Aboriginal people.

The VAPCP's vision was to create a sustainable and culturally safe palliative care service system where Aboriginal people from all over Victoria could access palliative care services in the setting of their preference. The VAPCP also aimed to develop and increase the awareness of, and access to palliative care services, and to develop a long and lasting relationship between palliative care providers and Aboriginal community controlled health organisations (ACCHOs).

The vision also included that:

- Aboriginal people will have access to quality palliative care services that respect their cultural heritage and wishes at every stage of their care
- Palliative care services will be adequately prepared and resourced to provide high quality palliative care to members of Aboriginal communities in a respectful, caring and collaborative manner
- Palliative care workers will feel confident interacting with Aboriginal people, because they are better prepared to deliver culturally appropriate palliative care and have access to resources and experienced clinicians when required
- Aboriginal health workers will have a close working relationship with local palliative care providers, and will jointly assist members of Aboriginal communities with their care needs
- Regional palliative care consortia will have a better understanding of the need for culturally appropriate palliative care to be a core component of service delivery for every provider of palliative care, and will actively assist services to improve the care provided.

2.2 Operational efficiency and areas of potential improvement

What were the key processes involved in implementing, operating and maintaining the VAPCP?

Statewide project officer

Employing a statewide project officer, Cherie Waight, was integral to the success of the project. Professional and personal commitment facilitated connections across the Aboriginal and palliative care sectors. An ability to explain the project to different audiences (including use of appropriate language, for example, 'journey of the end of life', rather than 'palliative care' when speaking with Aboriginal people) and provide practical examples of how the project could benefit communities and services also facilitated acceptance.

Cherie had a good understanding of her role, the VAPCP's history and purpose, and how to introduce the program to community and other services. Through working at VACCHO, she was well connected with Aboriginal communities and ACCHOs as well as other Aboriginal organisations and experts. She also knew when it was *inappropriate* to work with community (for example, when sorry business took place). Cherie could identify champions in the community who took a lead role in supporting and promoting the project (for example, Karen Bryant, Rod Jackson, Vicky Clarke, Karen Bryant and Kevin Larkins). She drove the project and kept it on the agenda.

In managing the project, Cherie faced several challenges. The changeover between the two project officers, who had different business styles, created some initial challenges, particularly related to furthering the relationship with palliative care consortia managers. However, over time, these relationships have strengthened. Also, being a sole worker responsible for the whole state produced a need to prioritise multiple demands, and sometimes this disappointed those regions that had to wait for action to occur. Limited administrative support meant that she was required to spend significant periods of time doing these activities, rather than focusing on building relationships between the sectors.

Following cultural protocol

A key feature of the project was the importance of following cultural protocol when introducing the project to Aboriginal community controlled health organisations (ACCHOs) and seeking their support. Having a strong understanding of cultural protocol, community business and local politics enabled the project officer to do this in a culturally appropriate and respectful way. The project officer would introduce the project to the ACCHO CEO, meet with the nominated ACCHO worker to discuss the project further, introduce the palliative care consortia manager to the ACCHO, assist with arranging a community forum and identifying people able to 'tell their story', provide a summary of the key points discussed and prioritised actions, and then encourage the local services to continue working together in a sustainable way.

Establishment of the advisory group

An advisory group was established at the beginning of the project to provide expert advice and endorse activities. Representatives were invited from VACCHO, Palliative Care Victoria (PCV), metropolitan ACCHO, rural ACCHO, metropolitan palliative care consortia, rural palliative care consortia, the Department of Health and an Aboriginal hospital liaison officer. Terms of reference were established, and the advisory group agreed to meet biannually and at other times as required.

All advisory group members were committed to the goals of the project. They contributed ideas, provided feedback on actions, assisted with presentations/activities and so on as required. They also endorsed progress reports and had ongoing contact with the project officer via phone calls, emails and face-to-face contact. A challenge faced by the advisory group was that several members had to travel significant distances (teleconferences were an option), and other urgent commitments sometimes took priority.

Relationships/partnerships

Strong relationships and partnerships were established during the project. Trust and respect for professional expertise was integral to developing sustainable, productive partnerships with Aboriginal communities. Without strong community connections, this initiative would not have worked. Another aspect was the development of personal relationships/connections in addition to professional relationships—this supports the 'walk beside us' goal of the project. The following partnerships were particularly beneficial to the success of the project:

Partnerships	Activities
PCV, VACCHO, Department of Health	Collaboration between state government and two peak bodies.
VACCHO and the Department of Health project officers	Regular catch-up meetings, joint presentations and a collaborative working relationship has strengthened this relationship. The relationship is a best practice example of how government and peak bodies can work together respectfully and constructively.
VACCHO and PCV	These peak bodies re-signed a memorandum of understanding in October 2009. The project officer spends one day per week at PCV, which has strengthened the relationship between these organisations and the links with palliative care consortia/services across Victoria. This partnership has also resulted in 'new doors being opened' to other services provided in palliative care.
ACCHOs and palliative care services/consortia	Palliative care consortia have learned that relationships take time to establish—and this is a 'good thing'. History impacts on current social determinants and attitudes, local Aboriginal protocols must be followed (for example, ceremony, kinship) and Aboriginal culture is unique and does not fit under the CALD banner. ACCHOs have learned about palliative care and how it can benefit Aboriginal people with life-limiting illnesses. Both sectors are learning how to work with each other.

National input	Involvement through PEPA and NACCHO has demonstrated Victoria's work with urban/regional Aboriginal people about palliative care—it has put Victoria on the map.
Other relationships	Relationships and partnerships have been developed outside the project, but they all affect the holistic approach to Aboriginal palliative care.

Consultations

The ability to consult with the Aboriginal and palliative care sectors was integral to the project's success. As the peak Aboriginal health body, VACCHO functioned as the entry point for accessing the ACCHOs and Aboriginal communities; while PCV, as the peak palliative care body, was the entry point for accessing palliative care consortia/services.

The regional forums built links at a local level and improved relationships between local ACCHOs/Aboriginal communities and palliative care consortia/services. The project officer assisted with coordinating the forums and provided advice on which local members should be invited to present and share their personal stories. At the end of the forums the project officer facilitated discussions about recommendations for future activities and next steps. Feedback from forum participants included:

I was very proud and inspired by the whole day... guest speaker Debbie Walsh was an inspiration, with her delivery of her families dillybags story... 'The Journey'. I hope the positive feedback and the development towards strong working partnerships continues throughout the project (Hume—Rumbalara forum, 2010).

We need more information forums like this for all communities... I never knew about palliative care. If these information sessions could be put into nursing and doctors courses it would be good, as well to help them understand Indigenous culture and close the gap (Hume—Mungabareena forum, 2010).

Leaving this life is just as important as coming into this life (Loddon Mallee—Mildura, 2009).

New and/or improved linkages were made with other health related projects, such as Cannaet, Cancer Council Australia, Cancer Council Victoria, NACCHO, ACCHOs and other primary health care programs that work to address the Aboriginal health gap.

2.3 Effectiveness of the initiative in meeting its objectives

What outcomes have been achieved by the VAPCP for Aboriginal clients and the palliative care system?

An increase in the number of Aboriginal people accessing palliative care services

The number of Aboriginal people who have accessed palliative care has increased significantly over the life of the project:

	Community	PC beds	Other beds	Total inpatient	TOTAL
2006–07		11	22	33	33
2007–08	82	12	29	41	123
2008–09	99	21	45	66	165
2009–10	Complete data not yet available				

Source: VINAH and VAED databases

Training

The AHW role is wide ranging, and workers have many competing priorities which can make time available for training difficult. AHWs are continually stretched for time, and supply never seems to meet demand.

Many AHWs did not know what palliative care involved. Training in the palliative approach has given AHW a strong understanding of the palliative care framework and available services.

Supervised clinical placements

Twenty-one AHWs completed a supervised clinical placement at specialist palliative care services. One Aboriginal hospital liaison officer commented:

With holistic healing [for] health and spiritual needs, PEPA provides the skills that were once the traditional practice of dealing with sickness, dying and death of family and community members (2009).

Palliative approach workshops

Eighty-one AHWs participated in workshops designed with the project officer to ensure they were culturally appropriate. The day commenced with a welcome to country from a local Aboriginal person, followed by a smoking ceremony conducted by an Aboriginal elder aimed at cleansing participants' spirits in preparation for the day ahead. The workshop topics included the palliative approach, assessment and intervention, psychosocial and spiritual care, and caring for yourself. Substantial time was allowed for discussion and storytelling. When the workshop concluded the non-Indigenous facilitator left and the participants spent time debriefing in a 'yarning circle' about the workshop, including a discussion about the importance of cultural safety.

The non-Indigenous facilitator's manner was culturally respectful, and he demonstrated a good understanding of Aboriginal culture, people and protocols. He understood how to link with the participants so they felt safe to discuss openly some of their fears of palliative care and what it meant for them as AHWs, community members and family. Comments from participants include:

I learned how to connect with a client (2009).

I would recommend this workshop, because everyone should know the process of dying (2009).

It has made me feel more confident in providing information to clients (2010).

I learned that palliative care is not about the end of the line, but the essential care given to the end of the journey (2010).

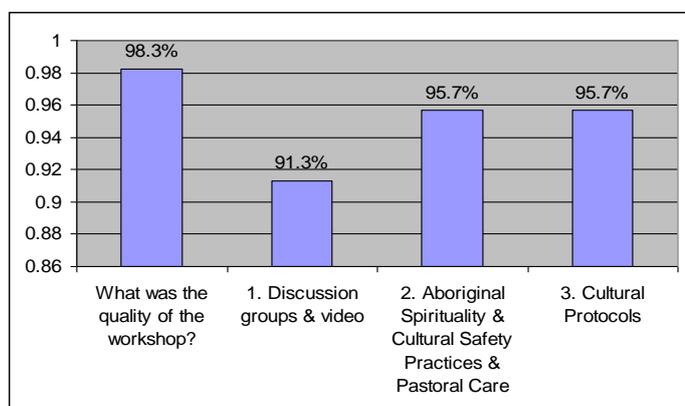
Cultural safety awareness

The level of understanding around Aboriginal cultural dignity and what it means to Aboriginal people to take part in ceremonial events and to be part of a wider kinship network varied between palliative care services and consortia. The training offered an opportunity to improve palliative care services workers' awareness of support and resources available for Aboriginal clients and improve palliative care participants' confidence in caring for Aboriginal clients.

Feedback included that the workshops were successful, primarily because the trainer, an Aboriginal woman, was very experienced and knowledgeable in the area of 'spiritual journey of life ending'. The facilitator used plain English and presented, in a respectful manner, to the non-Indigenous participants, which their attention to other important related areas such as reconciliation and cultural dignity. In 2008 participants at the Swan Hill workshop noted that the facilitator:

...used language that made the impact of history and culture real for non-Indigenous participants

...understood participants' fears of working with Aboriginal people and the importance of reconciliation and cultural dignity for Aboriginal people.



Source: Swan Hill workshop evaluation

The project was instrumental in establishing the first National Aboriginal Palliative Care workshop, which was held in Melbourne in 2007. Attending participants numbered 153 and, as a result of their positive feedback, this workshop will now be held on the day preceding every national palliative care conference.

Resources

The development of culturally appropriate resources formed an important part of the project. Resources include:

- message stick, artwork, calendar, DVD, song, promotional advertisement and interviews on radio 3KND
- *Cultural Safety Tools* fact sheet
- cultural ceremony and history of aboriginal culture
- stories of people's journey of the end of life.

3 Key activities

A range of key activities and output measures were defined to assess the implementation of the VAPCP:

Activities	Outputs
Establishment of governance	Advisory group established Advisory group terms of reference documented
Recruitments to project officer position	Joanne Harrison: July 2007 to September 2007 Cherie Waight: November 07 to current
Establishment of the VACCHO, PCV and Department of Health partnership	Memorandum of understanding between VACCHO and PCV signed in 2007 and re-signed on 14 October 2009
Development and implementation of a communication strategy	Communication activities documented in project officer's work plan and reviewed every six months Communication activities implemented General correspondence (emails, newsletters, letters, flyers, reports) Face-to-face contact (site visits to ACCHOS, palliative care consortia/services) Conference presentation (National Palliative Care Conference, Perth, October 2009) Radio interviews (3KND, May 2009) Music (<i>Going Home</i> by Kutcha Edwards) Artwork (<i>Message Stick</i> by Melissa Brickell, <i>The beginning of our journey</i> by Kahli Luttrell) 2010 calendar Aboriginal advisory directory (in development)
Establishment and implementation of monitoring and reporting arrangements	Key performance indicators developed in July 2007 Twice-yearly progress and financial reports submitted to the Department of Health
Development and delivery of education for PC services/other services	Introduction and ongoing education on the project to 24 ACCHOs 2007: <ul style="list-style-type: none"> ▪ Banksia Palliative Care ▪ Melbourne Citymission ▪ Mt Alexander Hospital ▪ Melbourne University 2008: <ul style="list-style-type: none"> ▪ Swan Hill 'Understanding Aboriginal spirituality in palliative care' workshop for palliative care staff ▪ Northern Hospital study day ▪ Eastern Palliative Care service 2009: <ul style="list-style-type: none"> ▪ Gippsland spirituality workshop ▪ Eastern Metropolitan Region spirituality workshop ▪ Royal Melbourne Hospital 'Aboriginal palliative care'

Activities	Outputs
	<ul style="list-style-type: none"> ▪ La Trobe University ‘ Aboriginal palliative care’ ▪ Tooleybuc Aboriginal SEWB/mental health workers forum ▪ VAHS nurse family partnership program ▪ Southern Health palliative care services ▪ Mildura Aboriginal health service <p>2010:</p> <ul style="list-style-type: none"> ▪ Northern Metropolitan TAFE health care assistants ▪ Loddon Mallee palliative care consortium ▪ St Kevin Paris, Templestowe
Review/modification of regional PCC Aboriginal palliative care regional plans	<p>Regional forums conducted</p> <p>2009:</p> <ul style="list-style-type: none"> ▪ North and West metropolitan, Gippsland, Grampians (2), Eastern metropolitan, Loddon Mallee <p>2010:</p> <ul style="list-style-type: none"> • Hume (2)
Coordination of the national PC workshop	<ul style="list-style-type: none"> ▪ 153 participants attended the inaugural national palliative care workshop held in Melbourne on 28/8/07 before the National Palliative Care Conference
Promotion of PEPA placements and workshops to AHWs	<ul style="list-style-type: none"> ▪ Member of national PEPA A&TSI working group ▪ Twenty-one AHWs attended supervised clinical placements ▪ Eight PEPA workshops held, with 81 AHW participants <p>2008:</p> <ul style="list-style-type: none"> ▪ Melbourne (16 participants) <p>2009:</p> <ul style="list-style-type: none"> ▪ Melbourne (11 participants) ▪ Bendigo (9 participants) ▪ Lake Tyers (9 participants) ▪ Swan Hill (9 participants) <p>2010:</p> <ul style="list-style-type: none"> ▪ Mildura (6 participants) ▪ Shepparton (8 participants) ▪ Melbourne (13 participants)
Evaluation of the initiative	Evaluation framework developed

4 Recommendations

The major considerations are to continue the project under VACCHO, to address the 30-plus year gap for Aboriginal people and communities on palliative care focusing on and to increase Aboriginal peoples' knowledge, skills and awareness across Victoria. This will require recurrent funding.

Other recommendations for consideration regard positions, training, cultural awareness training for palliative care staff, resources, research and data, and other.

Area	Recommendation
Positions	<ul style="list-style-type: none"> ▪ one full-time project officer ▪ one part-time position to assist with administrative business ▪ the pilot of an AHW palliative care case manager position based at a rural and an urban ACCHO to assist in the links required for a person in their palliative care journey (minimum two-year pilot)—this position will seek Commonwealth Government funding
Training	<ul style="list-style-type: none"> ▪ ongoing training for the project officer (for example, PEPA workshop facilitation, formal palliative care education, AHW certification) ▪ further training and skills development for ACCHOs, AHW/AHLO, primary health workers and GPs working in Aboriginal medical services
Cultural awareness training for palliative care staff	<ul style="list-style-type: none"> ▪ a 'road show' to ACCHOs that includes information sessions on the consortia's role and local palliative care services ▪ palliative care services staff undertaking placements at ACCHOs ▪ PEPA workshops and PEPA-supervised clinical placements for AHW ▪ an investigation of the inclusion of the PEPA training in the AHW training (VACCHO education and training unit)
Resources	<ul style="list-style-type: none"> ▪ develop promotional cultural materials, for example, DVDs, pamphlets, posters ▪ develop a palliative care cultural safety training package ▪ develop information kits ▪ record Aboriginal peoples' 'journey' stories
Research and data	<ul style="list-style-type: none"> ▪ increase research activities and data collection with a view to publishing articles
Other	<ul style="list-style-type: none"> ▪ hold a statewide Aboriginal palliative care forum every 2 years ▪ build a national profile to influence and implement at a policy and research level ▪ include Aboriginal palliative care activities during National Palliative Care week ▪ build a broader statewide profile through different media avenues, for example, Koori Mail, newsletter, VACCHO newsletters, podcasts ▪ conduct information sessions to Aboriginal community members on the 'journey at end of life'

5 Conclusion

The VAPCP has proven to be an overall success in the past three years of its operations and has achieved the project's aims, objectives and goals identified at the beginning of the project. One of the most important achievements has been the development of cross-agency relationships that strengthen the knowledge and awareness of what palliative care means to Aboriginal communities and have helped them gain a better understanding of what services exist. Another important component of the project was the expansion of understandings around the journey towards the end of life of Aboriginal people with the ACCHOs, AHLOs, VACCHO and other health-related programs and services (for example, AHPACC and Chronic Care).

At times the VAPCP has been challenging, particularly when discussion occurred around cultural sensitivities, and especially when some crossover ensued with other sensitive areas, such as cultural lore, talking about death and dying in Aboriginal communities. Nevertheless, the project managed to work through many of these concerns by addressing them directly with service providers and the Aboriginal communities.

Having knowledge and understanding of palliative care and what it is about has allowed more AHWs, AHLOs, ACCHOs and other Aboriginal services to be empowered and become more accepting of the process that needs to take place, as well as how they can influence culture to become a part of the care plan. This includes ensuring cultural ways, value and beliefs of the individual and family are included in the overall care and treatment of the Aboriginal person.

This project has also given palliative care services a broader knowledge and awareness of best practices when working with Aboriginal people and communities through respecting the diversity, cultural values and lore of Aboriginal people during experiences such as the journey at the end of life. This includes identifying other important considerations, such as cultural lore in the meaning of ceremonies and requests to go home to country. It has also resulted in local communities and ACCHOs playing a bigger role in the overall treatment and care of Aboriginal people going through palliative care in Victoria.