WESTERN AUSTRALIAN CENTRE FOR RURAL HEALTH, UNIVERSITY OF WESTERN AUSTRALIA

Evaluation of the Aboriginal and Torres Strait component of the Program of Experience in the Palliative Approach (PEPA)

Final Report

Snapshot II - Phases 1 and 2

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List of Abbreviations

ACP	Advanced Care Plan
ACT	Australian Capital Territory
AHW	Aboriginal Health Worker
ALO	Aboriginal Liaison Officer
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
CATSINM	Congress of Aboriginal and Torres Strait Islander Nurses and Midwives
FTE	Full time equivalent
IHEO	Indigenous Health Education Officer
IHW	Indigenous Health Worker
ILO	Indigenous Liaison Officer
IPO	Indigenous Project Officer
NACCHO	National Aboriginal Community Controlled Health Organisation
NSW	New South Wales
NT	Northern Territory
PEPA	Program of Experience in the Palliative Approach
Qld	Queensland
QUT	Queensland University of Technology
RAN	Remote Area Nurse
WA	Western Australia

Note on Terminology:

The original inhabitants of Australia are Aboriginal and Torres Strait Islander people. In most Australian jurisdictions, the number of Torres Strait Islander residents is very low, and the local first nation inhabitants prefer use of the term Aboriginal. As this is a national project and for succinctness, we have generally used the term Indigenous unless we are using the terms that were used in documents or by the participants in interviews. Whether the term Aboriginal, Aboriginal and Torres Strait Islander or Indigenous is used, we respectively acknowledge the diversity of the original first peoples of Australia as well as the different approaches being taken around Australia to meet their needs.

Acknowledgements:

There are many people to thank for their assistance with this project. Firstly, we thank the staff of the National PEPA office for their assistance in many ways, and particularly Stuart Ekberg for acting as our liaison person and for practical assistance. We thank all of the participants in the interviews for their time and their considered reflective input. We are grateful to both Mick Adams and to Gail Garvey who were instrumental in enabling this team to be entrusted to undertake this evaluation. We are indebted to Beatriz Cuesta-Briand for critical reading and editing of a late draft of this report.

Finally, in the course of undertaking this evaluation, we became aware, yet again, of the commitment and professionalism of people who work in this area as they seek to improve people’s end of life experiences.

Executive Summary

Although comprehensive data on rates of Aboriginal and Torres Strait Islander (Indigenous) people accessing palliative care services are not available in Australia, Indigenous Australians are underrepresented in the palliative care patient population., This suggests that services that are needed by other Australians aren't available, accessed or appropriate for Indigenous Australians. Lack of knowledge and understanding about palliative care, poorer access to specialist palliative care services, chronic health issues, the lack of trust of mainstream services that often exists, and taboos around 'death and dying' are all reasons that have limited Indigenous Australians' use of palliative care services.

The Program of Experience in the Palliative Approach (PEPA) project has been working since 2003 to improve the quality, availability and access to palliative care for people with life-limiting illness and their family members at the end stage of life. PEPA provides opportunities for improving the skills, knowledge and confidence of palliative care providers across the continuum to ensure that they are better equipped to provide culturally appropriate end of life care to patients and their families.

The Indigenous PEPA component commenced in 2007 to specifically address the needs of Aboriginal and Torres Strait Islander patients and their families and to equip health staff with the skill to care for Indigenous patients in a culturally sensitive manner. The Indigenous component of PEPA provides a flexible, clinical learning experience that is tailored to meet the needs of Indigenous Health Workers (IHWs), Liaison Officers, Community and Care Workers. To date, no in-depth evaluation had been done to assess the impact and effectiveness of this component. The team at the Western Australian Centre for Rural Health (WACRH), University of Western Australia was contracted to undertake this evaluation.

The study was approved by the Queensland University of Technology Research Ethics Unit (QUT Ethics Approval Number 1200000183). The evaluation of the Indigenous component of PEPA was proposed and occurred in two phases: Phase One aimed at exploring the history and processes of the implementation of Indigenous PEPA from national and jurisdictional PEPA Managers, Indigenous Project Officers, and PEPA Consultants. A total of 19 interviews were conducted in Phase 1.

Phase Two evaluated the impact of PEPA participation on Indigenous Health Workers and the communities within which they work and provide care. A sample aimed at representing states and territories and including both Indigenous and non-Indigenous participants were approached and invited to participate in an interview or in focus groups. Recruitment occurred through the PEPA coordinators, service providers and their networks using purposive and snowballing sampling technique to ensure a mixture of PEPA-trained health and other care workers as participants in metro, rural and remote locations. Content was analysed thematically utilising key focus areas to determine similarities and differences across jurisdictions and whether program objectives were met.

After synthesis of information about the activity occurring in each state/territory, a summary of information pertaining to that state was checked with each person who was interviewed from that state, with changes made as requested. After this, the draft report was circulated to the PEPA national body for their input and corrections before finalization.

While QUT provides national coordination and project management, subcontractors are engaged to deliver the program at the state and territory levels. PEPA is delivered by the State or Territory Department of Health in five states and territories. Elsewhere, it is delivered by the Cancer Council WA, Palliative Care Council SA and Calvary Health Care in ACT. The employed time for the position of the PEPA manager varies between 0.8 FTE and 1.0 FTE and the Indigenous Project Officers positions vary between 0.0 FTE and 1.0 FTE. In some states/territories, the host organisation supplements the PEPA funding to increase the FTE for the Indigenous position in order to strengthen the capacity and engagement of Indigenous palliative care education. In states where an Indigenous Project Officer is not employed, Indigenous consultants provide advice. Management roles were similar across jurisdictions and were primarily administrative. Indigenous Project Officers were the key driving force in consulting and building relationships with Indigenous communities, in assisting and delivering PEPA workshops and in promoting the program to the communities. In most regions, Indigenous and non-Indigenous staff worked well together in a supportive environment. The overall success of the program was adversely affected when this did not occur. Staff turnover remains an issue due to the uncertainty of ongoing funding for the program and lack of provision for long-term staff contracts.

Most state-based PEPA teams maintained good working relationships with local palliative care services. This helped them to refer the participants for PEPA placements. In some jurisdictions, PEPA staff have trustworthy and long-term relationships with the local Indigenous primary care services and residential aged care facilities.

PEPA offers workshops to health professionals who are interested in learning about the palliative approach. They are free of charge. Workshops are generally run by non-Indigenous palliative care professionals with the assistance of PEPA staff. Indigenous workshops are run in a culturally appropriate manner with the assistance of the Indigenous Project Officers; where an Indigenous Project Officer is not employed, Indigenous consultants help with the delivery. In some states, program and workshop materials have been adapted to suit local participants and regions. Workshops worked well when: run in an informal manner; were less structured in content delivery; allowed for more storytelling and sharing; and allowed time for debriefing. Some states offer a two day “Yarning Workshop” and this has proved to be very popular among participants as it allows for an exchange of ideas and thoughts amongst colleagues in a more informal manner. PEPA in the Northern Territory developed a tailored outreach workshop program for Indigenous communities to increase community awareness in caring for people at the end of their lives. This approach proved highly successful.

PEPA provides an opportunity for primary health care providers to develop skills in the palliative approach by undertaking a supervised clinical placement for up to five days within a palliative care specialist service. These placements offer experiential learning and may include visits to an aged care facility, inpatient palliative care facility, community practice, renal or oncology unit. To date 245 Indigenous participants have completed a placement. Although placement uptake is limited in most states and territories, some targets have been fulfilled. Specific barriers that were cited included: resistance from line managers to release staff for three to five days; difficulties with organising flights and accommodation; anxiety by potential participants regarding travel from remote communities to the city; and fear and distrust around going to mainstream health services without someone they know. IHW participants were usually from a facility where the manager was familiar with PEPA and the organisation recognised the value of palliative care training for their staff and the communities they served. Managers recognising the value of the IHW as part of the health team were more likely to encourage participation.

Reverse PEPA placements entail a palliative care specialist travelling to the applicant's place of employment (reverse PEPA site) to mentor and facilitate learning. This provides an opportunity for two-way learning to occur: the local service has an opportunity to learn about the palliative approach and the palliative care provider an opportunity to learn about the different philosophy and ways of caring for patients in Indigenous primary health care services and aged care facilities. The length of reverse PEPA placements varied between two and five days. Reverse PEPA placements could increase participation of IHW from rural and remote regions who were reluctant to travel to the larger towns and cities to take up a placement or when managers were reluctant to release staff to take up a placement at a palliative care service. However, some PEPA managers stated that reverse PEPA was very labour intensive and they had difficulty recruiting specialist palliative care staff to assist with placements. Most participants indicated that the programs were conducted in a culturally sound and appropriate manner. Participants undertaking the reverse PEPA placement felt that they were treated with respect and that the training was appropriate.

Many factors impacted upon program achievements. At the program level, having a dedicated Indigenous Project Officer (IPO) who had a good relationship with the PEPA manager was a key ingredient for success. These positions were particularly effective when IPOs co-delivered educational sessions and workshops and liaised with the Indigenous communities. Placements facilitated the establishment of sound relationships between participants and palliative care service providers. This enabled them to continue working well together even after the placement was completed. The experience of mixed groups of Indigenous and non-Indigenous health professionals in yarning and outreach workshops, proved valuable in building cross cultural understanding and a broader uptake of this approach could be encouraged.

At the service delivery level, excellent outcomes were evident where there was a high level of support for Indigenous workers from their line managers. A successful model was where a registered nurse working as part of a team with IHWs recognised the importance of palliative care and already had an established relationship with, and trust from, their local Indigenous community. When their skills and knowledge were recognised, ALOs played a vital role in improving Indigenous peoples' end of life experience within the hospital setting.

A number of recommendations have been made for how PEPA could improve and better engage Indigenous participants in promoting palliative care. These include:

- Increasing Indigenous staffing as project officers and workshop facilitators;
- Ongoing and regular communication between the national, regional and local teams for knowledge exchange and sharing experiences;
- Continued development of culturally appropriate and context-specific resources involving Indigenous people in a leadership role.
- Reconsidering current approaches to monitoring and evaluation
- Adapting forms and documents for Indigenous participants.

- Increasing support and capacity building activities for Indigenous palliative care placement participants.
- Placing participants in a palliative care setting where Indigenous people were receiving care and where there was significant experience and expertise in providing end of life care to Indigenous people.

Introduction

The palliative approach aims to reduce unnecessary suffering by treating, relieving and reducing adverse symptoms that a person experiences at the end of their life as well as providing the emotional support that the patient and their families may need. Palliative care considers people's physical, emotional, psychological and spiritual needs and aims to achieve better quality of life for individual patients, carers and families who are dealing with terminal illnesses and end-of-life processes.[1, 2] Lack of understanding of the role of palliative care, poor availability of palliative care services, other serious health problems and family issues often means that palliative care is treated as a low-priority issue in Aboriginal and Torres Strait Islander (hereafter Indigenous) families when this type of care could alleviate stressors in caring for a terminally ill family member.[3] With the ageing of the population and the high burden of chronic and terminal diseases among Indigenous populations, the need for end-of-life care services is increasing.[4] Comprehensive data on the rates at which Indigenous people access palliative care services are not yet available in Australia.[5] However, data from AIHW indicates that the rate of palliative care separations[1] for Indigenous Australians is higher than non-Indigenous Australians but that their length of stay is shorter.[6]

Research, mainly conducted in the Northern Territory (NT), details the distinctive requirements, values and priorities of Indigenous people in relation to end of life care and decision-making.[7] A study on palliative care among Indigenous Australians identified needs around socio-economic contexts, communication, traditional issues, access to palliative care services, planning and delivery of care, settings of care, workforce issues, information, training and education.[5, 7-12] Services offered by Indigenous healthcare providers have historically often had few links with mainstream services, with providers often unaware of what local palliative care services could offer with a resulting lack of referral of Indigenous patients to these services. Similarly, mainstream providers have historically had little awareness either of the special needs of Indigenous patients or the services, networks and cultural supports available to them outside of mainstream services. In addition, community members have had little knowledge of palliative care and often associated it only with death and dying.[13]

Due to past negative experiences with the health services and ongoing marginalisation within Australian society, many Indigenous people have fears about using healthcare services,[5] with many feeling uncomfortable and mistrustful of mainstream health care institutions.[9, 14, 15] Many Indigenous people facing an incurable illness prefer to remain in their traditional country or return to their home town (if a patient is from a rural area) to be cared for by their kin and family members at the end of their life as it enables family and community members to visit and say goodbye.[8, 16] These factors contribute to Indigenous people being underrepresented in the palliative care patient population. Sullivan and colleagues (2003) argued for culturally safe palliative care services, declaring that these services will not be taken up by Indigenous people unless supported by cultural advocacy and/ or involvement of Indigenous staff.[5]

Effective palliative care service delivery requires an informed health sector, with health care providers in all areas committed to providing care that focuses on the quality of life for people with a life-limiting illness and their families. Specialist palliative care services need to be available for consultancy and support, particularly in relation to people who have complex needs.

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[1] A separation (discharge, transfer or death) for which the principal clinical intent of the care was palliation during all or some of that separation

Background to the Program of Experience in Palliative Care

Since 2003, the Department of Health has funded Queensland University of Technology (QUT) to deliver the Program of Experience in the Palliative Approach (PEPA) project. The overall aim of PEPA is to improve the quality, availability and access to palliative care for people with life-limiting illness and their family members at the end stage of life by:

- providing opportunities to ensure that palliative care providers across the continuum are aware of care preferences and provide culturally appropriate palliative care and end of life support including spiritual requirements and bereavement expressions; and
- improving the skills, knowledge and confidence of the health professionals who care for them.

When PEPA commenced as a national program in 2003, it focussed on servicing the needs of general nurses and allied health workers. In 2005, PEPA expanded to include placements for GPs, rural and remote medical staff and specialist palliative care staff. A key focus of the program in 2007-2010 was to promote the program to select groups including Indigenous Health Workers (IHW), GPs and health professionals working with people from culturally and linguistically diverse (CALD) backgrounds.

At the end of 2006, in preparing for the next phase of PEPA, a two-day workshop was held for PEPA Managers. The second day of this workshop concentrated on improved engagement with IHWs. Suggestions made included:

- Improving links with Indigenous groups, organisations and communities;
- Involving Indigenous communities in the development and delivering of PEPA;
- Using suitable terminology in resources for Indigenous participants;
- Clarifying expectations of the IHWs during placements; and
- Developing an approach and delivery mechanism that is sensitive to the cultural needs of the participants.

A number of strategies to strengthen IHW engagement were recommended at the inaugural meeting of the PEPA for Aboriginal and Torres Strait Islander Health Workers Reference Group in June 2008. This assisted the PEPA Working Group to initiate a number of activities to continue the implementation of the PEPA for IHWs program. Some of these included:

- Identifying suitable post–placement support activities for IHWs;
- Promoting cultural awareness training amongst PEPA managers, mentors and palliative care staff;
- Investigating and implementing processes whereby PEPA could form part of training programs for IHWs; and
- Promoting innovative models for increasing uptake among IHWs.

Indigenous PEPA commenced in 2007 in order to specifically address the needs of Indigenous patients and their families and to better equip health staff with the skill to care for Indigenous patients in a culturally appropriate manner. The Indigenous component of PEPA provides a flexible, clinical learning experience that is tailored to meet the needs of IHWs, Liaison Officers, Community and Care Workers. This component specifically aims to provide a supportive learning opportunity to enable IHWs to adopt the palliative approach when required within their workplace and or community setting. Indigenous PEPA offers a combination of learning experiences including workshops, clinical placements, reverse PEPA placements and a self-directed learning guide which is available electronically and in hard copy. Clinical placements provide an experiential learning opportunity and are undertaken for up to five days within a specialist palliative care service within a metropolitan or larger service. Other activities include promoting cultural awareness training for palliative care providers and promotion of innovative models for increasing uptake among IHWs.

Due to the initial poor attendance of IHWs, a national reference group was formed to establish specific objectives for this Indigenous component of PEPA. This group was established to offer advice on program content and to ensure that there was cultural representation within the context of the program. The committee meets quarterly. The National PEPA Reference Group initially had representatives from a number of leading Indigenous agencies and organisations including: a representative from The Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINM); a representative from the National Aboriginal Community Controlled Health Organisation (NACCHO); the Indigenous Education Coordinator at the Cancer Council Queensland; two Indigenous Health Worker representatives from Queensland Health; an Indigenous Affairs representative; an Indigenous Liaison Officer; a Community Development Consultant; and two senior PEPA staff members. The group has since expanded to include representatives from the Indigenous Allied Health Association, the National Aboriginal and Torres Strait Islander Health Worker Association, Torres Strait Islander Primary Health Care, the Australian Indigenous Doctors Association (AIDA) and Palliative Care Australia. An Aboriginal and Torres Strait Islander Health Workers Working Group was convened to implement the recommendations of the Reference Group and to work with the National consultant for the Indigenous component of PEPA (now the National Indigenous Coordinator)to develop appropriate resources. This group consists of PEPA managers, PEPA Indigenous Project Officers and consultants from each state and territory. Key outcomes of this Reference and Working Group include finalisation of the National Application Kit, the Communication Guidelines, the Mentor's Guidelines and the Learning Guide for Aboriginal and Torres Strait Islander Health Workers.

Since adopting a specific component focussing on palliative care delivery for Indigenous people, this component has been maintained in subsequent funding contracts with QUT from the Australian Government Department of Health. As the current funding period (2011-2014) was drawing to a close, there was agreement that it would be useful to evaluate the achievements of and challenges faced by the Indigenous PEPA component with a view to how it could be celebrated and improved. This is particularly important given the changes that have been occurring in Aboriginal and Torres Strait Islander (ATSI) health service delivery with the Closing the Gap commitment. Differences in the way in which the Indigenous PEPA has been implemented in different jurisdictions provide an opportunity to consider what aspects of the program delivery seem most critical to achieving the intended outcomes.

This evaluation considers the extent to which some of these strategies have been met and how this has impacted on the Indigenous participants and the communities which they serve.

Methods

The study was approved by the Queensland University of Technology Research Ethics Unit (QUT Ethics Approval Number 1200000183). The evaluation of the Indigenous component of PEPA was proposed and occurred as a two-stage process.

Phase One

Phase One examined the history and processes of the implementation of Indigenous PEPA, including the experience of the national PEPA coordination team and the previous and current PEPA team in establishing an Indigenous component of PEPA; the workforce development of health professionals that provide services to Indigenous people; and views on the effectiveness and sustainability of PEPA within both organisations and communities.

Staff at the National PEPA office made the initial contact with potential participants and once consent was received this was passed on to the research team at WACRH. Each participant was contacted and a time was arranged for a telephone interview using an interview guide (Appendix 1). Individual audio-recorded telephone interviews with PEPA staff in each state and territory, including PEPA Managers, Indigenous Project Officers, and PEPA Consultants were conducted between December 2013 and July 2014. In total, 20 people consented to participate and 19 interviews were conducted in Phase One with current and former PEPA staff. The goal of these interviews was to collect detailed information on PEPA initiatives aimed at increasing the capacity of the health care workforce to adopt a palliative approach when working with Indigenous people.

Phase Two

Phase Two evaluated the impact of PEPA participation on Indigenous Health Workers (IHWs) and the communities within which they work with and provide care. In-depth evaluation of sites across different jurisdictions enabled an appreciation of ways in which the different approaches adopted in PEPA ultimately impact on the care of Indigenous people who have life-limiting illnesses.

A sample aimed at representing states and territories and including both Indigenous and non-Indigenous PEPA participants (involved in the Aboriginal and Torres Strait Islander Health) were approached and invited to participate in an interview or in focus groups so that a deeper understanding of their experiences could be obtained. Recruitment occurred through the PEPA coordinators, service providers and their networks with purposive sampling to ensure a mixture of PEPA trained Health Workers and other health care providers as participants in urban, rural and remote locations. The focus was on obtaining high quality rich information rather than on high numbers of participants. Phase Two interviews commenced in April 2014 and continued through to July 2014. Workshop and placement participants' names were obtained from the state and territory PEPA managers and initial contact was made via telephone. This contact was followed up with an email outlining the evaluation process and their proposed role in the evaluation. Once consent was obtained, a time was arranged for a telephone interview. A total of 5 males and 21 females were interviewed. Those interviewed included IHWs, ALOs, Palliative Care Service Providers and Primary Health Care Workers (Table1). Of those interviewed, 15 had completed placements, two of whom also completed workshops with an additional 3 workshop participants. The remaining participants were palliative care or primary health care service providers. Interviews ranged from 15 to 80 minutes, were audiotaped and transcribed verbatim. Content was analysed thematically utilising key focus areas to determine similarities across jurisdictions and whether program objectives were met.

To enable input into the evaluation from a wider group of stakeholders, the following approaches were taken: 1) a letter was sent to the Chief Executive Officer of NACCHO inviting NACCHO, Affiliates and Aboriginal Community Controlled Health Care Organisations to have their input into the evaluation of PEPA from an Indigenous primary health care perspective and attaching the information sheet and consent form;

and 2) the National Indigenous Coordinator on behalf of the Evaluation team e-mailed all members of the Aboriginal and Torres Strait Islander Reference Group inviting them to make comments from their perspective on aspects of the Indigenous PEPA. The information sheet and consent form were also attached with the correspondence.

Documentary Review

In addition to the data gathered through interviews, written materials from or about the program was examined to understand more about the implementation of PEPA including what had occurred historically and the numbers of participants over time. This included the following documents:

- *PEPA National Reports:* The final reports for the period July-Dec 2006; 2007-2010; 2010-2011 and the Progress Reports 1 to 5 for the period 2011-2014 (excluding Dec 2013-June 2014) were provided and reviewed for information on process, accomplishments and outputs over time; and
- *Review of PEPA National and Jurisdictional Newsletters:* The national and jurisdictional newsletters were downloaded from the website and helped provide the historical context.

Findings and Discussion

The findings of the documentary review (2006-2014) and Phase 1 & Phase 2 are presented here. A brief background to the Indigenous component of PEPA followed by the uptake and engagement with PEPA by Indigenous participants is presented first. Information on the uptake of PEPA came primarily from the documentary review. Then, findings from the examination of human resources and staffing issues are reported. Findings regarding the evaluation of the key PEPA activities (Palliative Approach Workshops, Community Outreach Programs, Culture and Diversity Workshops, Placements and Reverse Placements) are discussed next. Finally, PEPA workshop evaluation processes and educational resources are discussed.

Phase I interviews were conducted across all states and territories. Phase II interviews were conducted across 5 states and 1 territory.

Table 1: Indigenous PEPA Snap Shot Study 2 Participants: Phase I

Evaluation Interviewees	**Total**
Past PEPA Managers	3
Current PEPA Manager	10
Indigenous Project Officers	3
Indigenous Consultants	2
Facilitator	1
Total interviewees	**19**

Table 2: Indigenous PEPA Snap Shot Study 2 Participants: Phase II

Evaluation Interviewees	Total Interviewees	Potential Interviewees
Primary Health Centre Managers	2	6
Managers other (Indigenous Health)	2	
Indigenous Health Workers	16	27
Non-Indigenous Nurse	1	5
Palliative Care Service Provider	5	7
Total	26	45

In addition, attempts were made to contact individuals within the following categories of potential participants, but no interviews were able to be arranged despite numerous phone calls made and emails sent in an attempt to secure an interview time. Sometimes contact resulted in referral to a different person. IHWs were particularly challenging as many had left their listed place of employment and those remaining were often busy with work and community commitments.

Mechanisms for Governance, Coordination and Communication

A brief section on governance is included here, primarily to contextualise the way in which information is disseminated, learning shared and the project managed across different jurisdictions. PEPA has been contracted to the Queensland University of Technology since its inception. The program is led by the Project Director, Professor Patsy Yates. She is supported by the national PEPA team. The national PEPA Advisory Group and the PEPA for Aboriginal and Torres Strait Islander Health Workers Reference Group provide guidance and strategic input to ensure the program objectives and outcomes are met. There is excellent expertise in palliative care, education and research and very good corporate memory of changes that have occurred to the program over time. The record keeping and newsletters were essential to gathering the information which provided the background on numbers and changes to PEPA over time. A PEPA manager and an Aboriginal project officer, education officer or consultants are engaged in each state and territory to deliver PEPA at a local level.

PEPA for Aboriginal and Torres Strait Islander Health Workers Reference Group (ATSIHWRG)

The ATSIHWRG guide the development and implementation of the Indigenous component of PEPA. This group includes Indigenous and non-Indigenous members from Indigenous health, policy and education sectors as well as Palliative Care Australia.

During the data collection, a number of issues were identified relating to the National PEPA Reference Group. The membership of this group changed regularly as many members changed positions and/or organisations and others were nominated to attend on their behalf. These frequent changes have required that new members be updated on progress and this often results in time delays, slowing the progression of projects. In its first year of inception, this group met 7 times via teleconference, with one face–to-face meeting. This was due to the need for their input into Indigenous resources. The group now meets quarterly with a varying numbers of attendees. The National Indigenous Coordinator is the Chairperson and an invaluable member of the team. The Reference Group submits quarterly reports to the PEPA Advisory Group.

National PEPA for Aboriginal and Torres Strait Islander Health Workers Working Group

This group was convened to assist the ATSIHWRG with the implementation of their recommendations. This group comprised of PEPA national office staff, PEPA managers and PEPA Aboriginal project officers from around the country. Due to short term contracts resulting from 3 year funding periods, this group's membership is subject to regular changes. The lack of continuity in both the Reference Group and the Working group has resulted in some delays that have hindered the group's efficacy.

PEPA Managers' Group and Indigenous Project Officers and Consultants

The jurisdictional PEPA Managers meet regularly by teleconference (usually bi-monthly) and annually at a face to face meeting. The regular meetings allow managers to report on PEPA progress in their jurisdictions, discuss issues of concern and to share ideas. This group is chaired by the National Coordinator

The jurisdictional Indigenous Project Officers and Consultants' Group was developed in 2011. The group meets regularly (at least quarterly) to share ideas, discuss issues of concern and suggestions for future improvements. This group is chaired by the National Indigenous Coordinator

Uptake and Engagement with PEPA by Indigenous Health Workers

The number of IHWs that have participated in workshops and placements since 2007 is shown in Table 3. These numbers were obtained from documents from the National PEPA Office and do not include participants from other health professions who identified as Aboriginal and Torres Strait Islander.

Table 3: Uptake of PEPA workshops and placements by Indigenous Health Workers

	Indigenous	Non-Indigenous	**Total**	*% Indigenous*
Workshop Participants				
2007 – 2010	345	6,033	6,378	*5.4*
2010 – 2011	99	973	1,072	*9.2*
2011 - 2014*	328	5,272	5,600	*5.9*
Total	**772**	12,278	**13,050**	***5.9***
Placement Participants				
2007 – 2010	104	937	1,041	*10.0*
2010 – 2011	13	142	155	*8.4*
2011 - 2014*	62	512	574	*10.8*
Total	**179**	1,591	**1,770**	***10.1***

*Incomplete data as data for period Jan-Jun 2014 was unavailable

Participation of Indigenous health workers in PEPA was a key focus from 2007. By 31 December 2013, 245 Indigenous health workers out of a total of 3000 participants, had completed a PEPA placement (8% of overall number of participants) and 983 Indigenous health workers out of a total of ±16 000 (7% of overall number of participants) had participated in PEPA workshops.[2] The high proportion of Indigenous participants as a proportion of the Australian population (or health workforce) shows that the uptake by Indigenous participants has been very good.

Human Resources and Staffing

While QUT provides national coordination and project management, subcontractors are engaged to deliver the program at the state and territory levels. PEPA is delivered by the State or Territory Department of Health in five states and territories: NT, Queensland (QLD), New South Wales (NSW), Victoria (VIC) and Tasmania (TAS). Elsewhere, the program is delivered by the Cancer Council WA in Western Australia, Palliative Care Council SA in South Australia and Calvary Health Care in the ACT. The employed time for the position of the PEPA manager varies between 0.8 FTE and 1.0 FTE and the Indigenous Project Officer (IPO) position varies between 0.0 FTE and 1.0 FTE. In some states/territories, the host organisation augments the PEPA funding to provide extra time to increase the FTE for the Indigenous position in order to strengthen the capacity and engagement of Indigenous palliative care education. In states where an IPO is not employed, Indigenous advisors (sometimes referred to as consultants) provide input into how the Indigenous component of PEPA should be delivered locally and provide PEPA Managers with an access path to Indigenous communities. . A summary of how the program is delivered in different jurisdictions at the time of the evaluation is shown in Table 2.

Management roles were similar across jurisdictions and were primarily administrative. The professional background and experiences of managers differed considerably with some having previous clinical and/or palliative care training whilst others had a background in administration. Differing views were expressed regarding the need for managers to have palliative care expertise. However, 8 out of 13 the past and present managers interviewed indicated a background in oncology and/or palliative care either in nursing or program work.

> *I don't think that having a palliative care background is essential.* (PEPA Manager)
>
> *I worked in oncology and palliative care but I don't think that is a requirement* **(PEPA Manager)**

The role of the IPO/Advisor differed depending on whether this was a remunerated position or only functioned as an advisory role. Most project officers had a clinical background (health worker, nursing, liaison officer) and played a vital role in linking PEPA into the communities and building relationships with key stakeholders, health professionals and community members. IPOs in dedicated positions were able to visit Indigenous organisations and communities prior to presenting a workshop or promoting placements. This helped communities to recognise the value of the program.

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[2] http://www.pepaeducation.com/about/outcomes-research.aspx (accessed 2 July 2014)

> *So really, my role has been a facilitation role around cultural facilitation… making sure that Aboriginal workers have a safe spiritual, emotional well-being area that- because you know talking about death and dying is not easy for our people.* (IPO)

In the NT, the role of the Indigenous Health Education Officer (IHEO) has been quite unique and differed from the other states and territories because PEPA NT initiated Community Outreach Workshops. Here this role was responsible for the education of health providers from all disciplines participating in these workshops. Since 2007, a National Indigenous Coordinator for the Indigenous component of PEPA has been employed. Components of this role include improving engagement with Indigenous organisations and personnel, a cultural line to mentor and support IPOs and provide a path for cultural competency and cultural considerations for the managers take into account when organising workshops or placements for the cultural safety of participants and Indigenous co-workers. The National Indigenous Coordinator organises and facilitates teleconferences for IPOs, an annual face-to-face workshop, provides adhoc cultural advice and practical support to managers and IPOs.

Table 4: Indigenous PEPA staffing and delivery by jurisdiction, 2014

PROGRAM DIFFERENCES								
Organisational	ACT	NT	NSW	Queensland	SA	Tasmania	Victoria	WA
PEPA Manager employed	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
FTE	0.8	1.0	1.0	1.0	1.0	0.8	1.0	1.0
PEPA based with	Calvary Health Care	NT Department of Health	New South Wales Health Department	Queensland Health	Palliative Care Council (PCC), SA	Department of Health and Human Services	Department of Health , Victoria	Cancer Council, WA
Indigenous PEPA Project Officer	No	Yes	Yes-on secondment at time of interviews	Yes	Yes (partially supported by PCC,SA	No	Yes- VACCHO employee	No
Aboriginal consultant	Yes- ALO	NA	NA	NA	NA	Yes-	NA	Yes- APO
FTE	0	1	unknown	0.5	1	0	unspecified	0
Program Facilitator/educator	No	No	Yes	No	Yes -PCC SA	No	Yes - contractual	No
Reverse PEPA placements offered	No	Yes	No	Yes(recently)	Yes	No	Yes	No
Indigenous PEPA outreach workshops	N/A	Yes - remote	Yes- remote	Yes- remote	Yes- remote	No	Yes- rural	No

One PEPA Manager commented that many PEPA managers were still on a "learning curve" with respect to engagement with Indigenous people. The IPO was described in various terms: as "the driving force to make that contact [with the Indigenous communities] happen"; "she is the bridge, she is part of the community"; "the conduit to the Indigenous community". Another point made by the PEPA Manager was that "the fact that she is Indigenous herself introduced elements into the program that other people had not thought of."

The working relationship between Managers and IPOs appeared to be most effective when the IPO was a dedicated, remunerated position based within the same organisation. Staff members that were comfortable and competent working in a cross cultural environment worked well together and were more at ease when approaching Indigenous organisations and community leaders. Managers and project officers working within the same organisation commented:.

> *When you do a workshop where you are able to bounce off someone else, it reminds you of what you have to talk about.* (PEPA Manager)
>
> *So between [Aboriginal project Officer] and I, as a good team, we developed this quite innovative new way of delivering education. But it's about getting that right balance I suppose, ideally one Indigenous and non-Indigenous person in each of the two staff would be ideal.* (PEPA Manager)
>
> *I am lucky because I knew the manager……………, we always supported one another.* (IPO)

Those based in different organisation encountered some difficulties:

> *Because they are not based in here, I have no influencing relationship with them apart from the paper work signing that you would deliver this and that with the individual concern and trying to build the relationship.* (PEPA Manager)
>
> *I mean I'm funded - the project is funded but it's not funded gracefully. It's funded bare minimum. So when they're out delivering workshops across the state …….., [organisation] don't get funded for me to travel or any of the administrative costs, the things like they don't put together - the PEPA manager …… she doesn't do any of the administrative work that requires to be done. You can't just run a workshop and have no workbooks.* (Indigenous Consultant)

Whilst in some regions Indigenous and non-Indigenous staff worked well together in a supportive environment, experiences differed in other regions and this is likely to impact on the overall success of the program. These different levels of support and differences in communication styles in some instances resulted in tension between project staff.

> *They have a very different style of working that I don't quite understand yet.* (PEPA Manager)

On the other hand, some Indigenous people expressed discomfort at the communication style of their manager, and even when things had worked well changes of staff could challenge established ways of working.

> *She's the PEPA manager but things have changed since she's been in place. She [the PEPA Manager] only liaises with me through email if something is needed. Before that [the manager] and I worked very closely together………. New people come in; they've got a different way of working.* (IPO)

Where relationships worked well there was appreciation of the value added by working together.

> *Yes I would not be able to function as I do without that [support].* (IPO)

Staff turnover, although fairly regular in all regions (in part due to short term contracts), was seen as more common or problematic in services where the managers were seconded from their substantive position (which was ongoing and secure).

> *Because we are contracted for only one year or three years, mostly three years but we had that one year in between 2010 and 2011, we lost quite a few staff. And now we don't have security of funding past the 30th of June 2014, so I am thinking that is just going to be natural. Nobody has specifically said that they are heading off yet - - No, but people will start looking.* (PEPA Manager)

Recommendation: The Department of Health consider longer term or three-year rolling contracts so that contracts are negotiated well in advance where there is the intention to renew a contract so that it is in place for at least one year at any time.

All PEPA Managers reported that they had a good working relationship with the local palliative care services. It became evident however, that some PEPA managers would benefit from additional cultural safety training and understanding of the beliefs and issues of Indigenous people to improve approaches when dealing with Indigenous organisations, communities and staff.

> *I am really trying to work through the challenge of the Aboriginal and Torres Strait Islander component… and I would like to understand what their needs are so that I can better meet those needs in the future delivery.* (PEPA Manager)

Support for Indigenous PEPA staffing varies from region to region and often depends on direct support and open communication from line manager. When the manager lacked experience in dealing with Indigenous people, this directly impacted on the work satisfaction levels of the Indigenous staff. There was concern expressed by some Indigenous interviewees at the type of institutional racism that existed in organisations that meant Indigenous staff felt unsupported in an environment that was unsafe and difficult for them. PEPA does offer cultural competency training to non-Indigenous staff. However, whilst online competency training offers a sound foundation, interactive cultural competency workshops presented by regional Indigenous leaders and elders could offer additional insight and understanding to PEPA non-Indigenous staff.

Recommendation: PEPA provide all staff with additional cultural competency training on an ongoing basis to increase their confidence and competency when working in a cross-cultural environment.

PEPA staff reported that they found it beneficial to exchange information with their colleagues from different jurisdictions; however, at the time of the interviews this was not happening on a regular basis. Thus, regular quarterly telephone and/or face-to-face meetings would be advantageous. The ideas shared during meetings between PEPA managers and IPOs were seen as likely to increase knowledge and allow staff from all states and territories to discuss ideas to improve workshops and placement experiences.

> *We do have teleconferences with the PEPA Managers, not with the whole team but we do work fairly isolated. I would like to have meetings with the whole team say every 6 months. (*PEPA Manager)

> *I am interested in how other people [IPOs] are doing in their communities….There are regular meetings but I do this additionally too.* (IPO)

Recommendation: Opportunities to increase sharing between jurisdictions should be encouraged. Potential approaches could be more regular meetings and opportunities for PEPA teams to visit other teams to share information on strategies and programs.

Palliative Approach Workshops

PEPA offers workshops to Indigenous and other health professionals who are interested in learning about the palliative approach. These workshops can be attended before, after or without commitment to a placement, and they incorporate activities that are consistent with the aims of PEPA. The workshops are delivered free of charge.

Whilst some PEPA teams rely on the local Palliative Care Services to assist with workshop delivery, others have a facilitator who is specifically assigned within their own or an outside organisation to run these workshops.

Workshops were generally run by a non-Indigenous palliative care professional with the assistance from PEPA staff. Most managers and IPOs indicated that the Indigenous workshops were run in a culturally appropriate manner. In general there were identified roles for the IPOs and their assistance was well regarded.

> *I do the program delivery; help with setting up the workshops; post and pre workshop stuff.* (IPO)

> *As an Aboriginal Project Officer I run education sessions and co-facilitate the sessions with PC clinical educators.* (IPO)

> *We have always had someone who is there to co-facilitate who is usually the [Aboriginal] Project Officer. We have always worked well together. I find working with her very helpful.* (Workshop facilitator)

Most workshop participants felt that the delivery and approach of the workshops was culturally appropriate and they felt comfortable, relaxed and were able to ask questions when necessary.

> *Yes (I did feel comfortable) there were a lot of people like me* (Workshop participant)

Managers indicated that program and workshop materials needed to be adapted to suit participants and regions. Some managers suggested that the workshop content could be split over two days to allow for more “yarning” or discussion time and enable participants to engage more effectively.

> *When we go to the remote regions it is very hard to do a four hour workshop. They can’t be there or they won’t concentrate for that amount of time so somehow making them a two part workshop or making them smaller workshops. I don’t think that they claim points for these workshops so making it a smaller workshop or a mini workshop.* (PEPA Manager)

> *So I would see the first one very much as an overview of the palliative approach covering those major headings that are already in the program and the second workshop focused on how the health worker can provide practical support for the people in their community*. (PEPA Manager)

Workshops worked well when run in an informal manner and were less structured in content delivery. This allowed for more storytelling, sharing and support. The higher death rates in Indigenous communities resulted in high levels of stress and grief among Indigenous health staff and as one manager commented, it was important to allow time for debriefing at the end of a workshop.

> *It was a lot less structured than the standard PEPA workshop that we ran*. (PEPA Manager)

One jurisdiction offers a two-day "Yarning Workshop" and this has proved to be popular with participants as it is more informal and allows for an exchange of ideas and thoughts amongst colleagues. These workshops are attended by both Indigenous and non-Indigenous staff working in Indigenous health but they are presented by an Indigenous facilitator and in a format that was considered culturally appropriate for the Indigenous participants. These workshops offer a more relaxed, engaging and diverse approach to learning about end of life care. Additionally, this workshop format allows for excellent networking and provides an environment for two-way learning to occur between IHWs from a primary care setting and mainstream health professionals from palliative care and other health services.

> *……….but we do run a separate Aboriginal targeted workshop that is the 'Yarn up 'that covers Aboriginal health workers and/ or anybody working in the Aboriginal health space. It's more informal. We expect lots of conversation, lot of stories to be shared, sharing challenges and good things and bad things… it's a different kind of format of delivering the workshops. More non-clinical, more hand-on particular things people can do to help people at the end of life.* (PEPA Manager)
>
> *It was open to everyone but it was predominantly Indigenous Health Workers about 80% and other health workers that worked with Indigenous clients. I found it a really useful forum because it's very laidback. It's working with the people and what they want to get out of it. It was very workshop like and groups putting ideas together…* (Non-Indigenous workshop participant)
>
> *We get such a positive feedback when we do get to those workshops.* (PEPA Manager)

Recommendation: Workshop design and formats need to be flexible and workshop materials need to be adapted to meet the needs of the varied education, literacy and language constraints of participants. It is also important to have a skilled facilitator who is responsive to participants needs. Consideration should be given to whether spreading workshop learning over two days would improve learning outcomes and Indigenous engagement and confidence.

Community Outreach Programs

PEPA offers a tailored workshop program for Indigenous communities to increase community awareness in caring for people at the end of the lives. The program structure was originally developed in the NT by an Indigenous Education Officer, is underpinned by the principles of cultural respect and overseen by an Aboriginal and Torres Strait Islander Reference Group and these are the key elements contributing to its success. The programs/workshops are now successfully run in some of the other states and territories too.

The structure of these programs is flexible and differs from state to state. The programs are aimed at Indigenous health workers, community workers, liaison officers and elders but all health staff who work with Indigenous people as well as other community members are able to attend. The programs are run by the IPO or Education Officer who is sometimes assisted by specialist palliative care professionals. This team travels to the communities to offer tailored support and deliver community workshops in a culturally safe and respectful manner. The workshop format and presentation is adapted to best suit the needs of the presenting participants. Non-Indigenous health staff attending these workshops gained invaluable insights about the views and beliefs of their Indigenous colleagues through the informal yarning and sharing sessions.

> *The community outreach programs are for all disciplines but we do have set topics that we cover and when we find out who is attending, we are able to pitch the training to those attending*. (IPO)

> *Because we had such a little engagement with Aboriginal Health Workers and people in that lay capacity as carers, the focus was still really on them. So you would get other health staff attending but the program was still primarily aimed at Aboriginal people.* (PEPA Manager)

> *What we worked on was communication between health professionals, access for clients to cancer and palliative care services… so it was quite an overview at a level that was appropriate to everyone.* (Workshop participant)

Outreach workshops were reported to work really well for rural and remote communities. However, they required flexible arrangements and workshop delivery strategies as circumstances in communities could change suddenly, for example, when a death occurs.

Recommendation: Outreach workshops can be offered to Indigenous communities, remote clinics and Aboriginal Community Controlled Health Services for all health staff and carers working with Indigenous people at the end of life.

Culture and Diversity Workshops

These workshops are aimed at health professionals dealing directly or indirectly with Indigenous and/or CALD people at the end of their life. These are often delivered as two separate workshops, Indigenous Perspectives or CALD perspectives. They aim to explore aspects of end-of-life care in communities and to increase awareness of the importance of knowledge and understanding of culture and or religion when attending patients and their families. These workshops are open to all health professionals and are also attended by IHWs at times.

> *Non–Indigenous people need to overcome their fear and their fear of doing the wrong thing which meant they did nothing…well the way to overcome that is start developing a relationship with that fear. And in learning, many got to talk with local Health Workers and develop a relationship.* (PEPA Manager)

There seemed to be a good understanding among PEPA managers of the importance of engaging with Indigenous people in the delivery of these workshops.

> *I organise these workshops and I always use an Aboriginal mentor (to assist with presenting the workshop).* (PEPA Manager)

> *When we go out into the regional areas, I always make sure that we have a person from that region to present the history and culture as this changes from region to region.* (PEPA Manager)

Recommendation: Culture and diversity workshops offered by PEPA should cover Indigenous people's palliative care needs and sensitivities including differences they may encounter when dealing with end-of-life beliefs and wishes.

Comments were made that this training would be more useful if it was tailored to the needs and experiences of participants. Some participants work in an environment that accommodates Indigenous people from a number of regions each with their own specific traditions and cultural practices. These participants would find it useful to know some of the differences they may encounter when dealing with end of life beliefs and wishes.

> *We don't have clients all from that one tribe. We have clients from Western Australia, we have clients from Queensland, and we've had clients from New South Wales, Northern Territory, Victoria and South Australia. Can you please tell us that all their cultures are not the same? We need to know what the guy from Queensland might want have done, or from New South Wales.* (Workshop participant)

This would be useful for both urban and rural/remote non-Indigenous staff dealing with Indigenous patients, their families and other community members.

PEPA Placements

PEPA provides an opportunity for primary health care providers to develop skills in the palliative approach by undertaking a supervised clinical placement of up to five days within a palliative care specialist service. These placements may include visits to a number of different environments such as an aged care facility, an inpatient palliative care facility, a community practice, or a renal or oncology unit. This placement is usually between three and five days in duration and offers experiential learning in a palliative care specialist service. To date 245 Indigenous participants have completed a placement. [3]

Barriers to engagement

Placement uptake is limited in most states and territories although some targets have been reached. Increased effort around engaging participants appears to have improved interest. Specific barriers that were cited by PEPA managers and IPOs included:

- Resistance from line managers to release staff

> *A number of people would take a day off to attend these workshops or take annual leave to do it because they didn't get the approval. (PEPA Manager)*

- Difficulties with organising flights and accommodation in some jurisdictions.

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[3] http://www.pepaeducation.com/about/outcomes-research.aspx (accessed 2 July 2014)

> *Health Workers have to organize their own flights and accommodation and that sort of thing so that is a difficult thing. We refund the money but it does initially have to go through that person's health service and this sometimes makes it difficult.* (PEPA Manager)

- Anxiety by potential participants regarding travel from remote communities to the city. Some Indigenous people who have not undertaken much air travel or spent time in metropolitan settings, may be fearful of travelling by plane to a large city by themselves or going to mainstream health services and palliative care services without someone they know.

> *I think that people would opt out anyway because they were scared of going to placements by themselves* (PEPA Manager)

> *I think travelling so far to deliver workshops is difficult but it does not work to come into the city.* (IPO)

Participants' managers were often cited as a barrier to health staff taking up placements. Managers felt that IHWs and ALOs fulfil a vital role within the community clinics and hospitals, and they found it challenging to replace staff when they are away from work. This meant that at times, workers who were keen to take up placements were not supported by their managers to do so. One IPO felt that this may be because of the length of absence from work:

> *The staff sign the application form, when it goes to the boss they will say "NO". They may say they cannot release them (their staff) for 4 days, thus they are unable to do the placements.* (IPO)

Another IPO felt that as AHWs worked across a range of services in their communities their workload was high and it was difficult to get time off particularly when staff had to travel some distance from a remote community. Also, organisations were often reluctant to let health staff participate in palliative care course such as PEPA because they did not see this as their core focus.

> *The reality is if they didn't have the staff they couldn't let them go, they couldn't release them. That was a big obstacle to them doing the complete PEPA.* (Former PEPA Manager)

> *But the time…taking time to attend those workshops or a couple of days for a placement is a big challenge. This can be a barrier.* (PEPA Manager)

One PEPA manager commented that the information about upcoming workshops or placement opportunities was sent to relevant managers within services, but she thought that if the managers felt that the training was not relevant to their staff or they did not support staff attendance they didn't distribute it to the staff.

> *..they [Indigenous Health Workers] would really like to attend and so on but when it comes down to actual registration of it, it can be very hard and I don't think that it is necessarily the person themselves, I think they have a lot of line managers to go through and I think that stops them a lot.* (PEPA Manager)

Recommendation: Direct engagement with clinic and hospital managers may help them understand the value of PEPA and the importance of addressing specific cultural needs in palliative care for Indigenous patients, increasing their support for IHWs and ALOs to take up placements.

IHW participants were typically employed at a facility where the manager was familiar with PEPA and what the placement had to offer or where they recognised the value of palliative care training for their staff and the communities they served. Managers who recognised the value of the IHW as part of the health team were also more likely to encourage participation. Line managers were more supportive of staff attendance when there were patients in their care requiring end of life care and they therefore perceived a need for further training in this field.

> *When end of life care is really done well it can make the difference between a good death and a bad experience.* (Primary Health Centre Manager who supported her IHW to attend a two-day workshop)

Recommendation: Trial solutions to overcoming barriers to take up of placements. Approaches could include educating line managers about the benefits of PEPA for their staff and improving engagement with hospital and primary health care centre management. Reverse PEPA placement opportunities and Community Outreach Workshops may be suitable in some cases.

Placement sites

Placement sites are pre-selected and are specialist palliative care sites. In recent times, care has been taken not to overburden any particular service as at one time at least one placement site was feeling quite overburdened with supporting people undertaking PEPA placements. That is because some sites are seen a particularly valuable experience for Indigenous PEPA participants. Hence, numbers with placement sites are generally negotiated in advance.

PEPA managers take care when placing participants to ensure they are suited to the site they are sent to and that the site is able to accommodate their needs. This was reported to be difficult at times as last minute changes could occur if patient numbers changed or palliative care staffing was reduced. Good participant preparation beforehand, mentorship during, and debriefing post placement helped ensure the health worker to have an effective placement. It was apparent from the interviews that palliative care services that treated Indigenous people and employed Indigenous staff were able to offer participants a meaningful and rewarding experience. Having Indigenous patients under care by the palliative care team at the time of their placement was considered necessary by some Indigenous placement participants. While placement times varied, feedback indicated that five days was optimal as it allowed participants time to participate in a wide range of activities such as attending meetings, accompanying palliative care workers on home visits, visiting the oncology and radiology units and assisting with patient care. This also allowed adequate time to consolidate their learning experience.

> *Maybe a little bit longer and a little more people involved, like staff coming into the training session, instead of three [days]. That would have been - I think that would have been beneficial for everyone*. (IHW participant)

> *I met one of the consultants and from Day One I spent about an hour or so talking to her about things, my feelings and my experience and how I felt about working in this specific area. It was very helpful….* (IHW participant)

> *I talk to participants about the logistics of their placement….I try to get a key person who can organise directly with the participants on the ground especially with rural participants.* (PEPA Manager)

IHWs felt that dealing directly with Indigenous palliative care patients would improve the effectiveness of the placement and training for them. However some palliative care services with higher levels of Indigenous patients were in demand and providers at times have felt overburdened.

> *So at one stage we felt as though we were virtually having someone there all the time… but it's not like that these days.* (PEPA Manager)

Recommendation: When possible, IHW placements should be arranged at a palliative care facility that caters for Indigenous patients. This enables the IHW to obtain firsthand experience in dealing with these patients. Adequate consultation with palliative care service providers should avoid the risk of overburdening any one service.

One participant emphasised the importance of having an Indigenous mentor at the palliative care placement facility as it enabled more open communication. Another participant noted that although there was an Indigenous staff member at the placement facility, they were not allocated any time with them and this was a disappointment.

> *I think having those Indigenous supervisors it was pretty interesting. I think if it was a non-Indigenous person, then there's less openness and even between workers.*
>
> *I still think you've got to have Indigenous supervisor…. being in that other environment, and that's a supportive environment, the best support will be for there to be Indigenous doctors or nurses involved in training that person, if there isn't already.*(IHW participant)

Recommendation: The PEPA local team should ensure that participants have an Indigenous support person/mentor when they undertake a placement and/or where possible, link Indigenous placements with and Indigenous mentor at the host site

Post-placement support

Post-placement support was limited in most regions and mostly seemed to occur on an ad hoc basis, with many managers relying on participants to contact them or the palliative care service with any issues as they occurred. However, some PEPA managers were proactive in following up after a PEPA placement.

> *I give them a call just to have a chat and find out how they are doing (after their placement). I always let them know that they are welcome to give me a call if they need any additional information or resources…* (PEPA Manager)
>
> *Within 3 weeks there is a phone call. I try contacting the participants three times by phone. After the third time, I send an email asking if everything is going ok…. And to remind people about the post placement questionnaire. If I don't get an email back I usually don't chase it up again.* (PEPA Manager)

Many of the participants reported that they received regular feedback from PEPA through their quarterly newsletters. Others noted that subsequent to their completion of a PEPA placement they had been linked into their local palliative care team and met regularly to discuss local palliative patients and their needs.

> *When I came back after I did the PEPA placement I then had the opportunity to work with some of the palliative care staff with a few of our clients in the area*. (IHW participant)

Some services offered additional learning opportunities such as workshops and training seminars for placement participants to enhance their interest and expand their experience in the palliative approach. Others required participants to complete a post placement workplace activity to enable them to embed the palliative approach in their clinical settings. In one jurisdiction, participants are offered free attendance at another workshop of jurisdictional palliative care providers .

> *They are eligible to take part in post placement activities.* (PEPA Manager)

All participants interviewed commented that on completion of their placement they received additional resources such as booklets and pamphlets as well as the contact details of palliative and other supportive services. Many participants commented that they had subsequently contacted these services for support and/or clarity about a patient or problem.

> *It is made very clear that they can call the palliative care service where they have done their placement.* (PEPA Manager)

Some Indigenous placement participants commented that much of the ongoing support they receive is from their direct line manager/senior staff within their workplace. However, overall the level of support varies depending on other work demands and on the manager's awareness and perception of the importance of a palliative approach within the community. It was apparent that IHWs could benefit from regular contact with a mentor who is known to them and whom they trust. This highlights the importance of ensuring that the participants' line managers are aware of and understand the importance of supporting their health workers on completion of a placement. IHW support was evident in clinical areas where a number of other staff had also participated in PEPA training activities, highlighting the importance of targeting a range of health professionals simultaneously rather than specific groups in isolation.

> *Yes, it was two years ago [the placement]. I went with my manager and [named the other Indigenous Health Worker].* (IHW participant)

One study participant provided an example of the sort of support that she got from her manager after undertaking the Indigenous PEPA placement which she had undertaken with the manager and two other Indigenous health workers, and how it changed the way they worked. Here she was talking about the way in which they debrief following a death:

> *… [the manager] is the advisor if we get a palliative patient so yeah, after the passing and everything we come together as a group and handover with every staff that's had connection with that person and looked after them till the end and we support each other. Yeah, like see how we feel, are we doing things that we should have done better or if and how they're feeling – yeah.* (IHW participant)

Recommendation: Post-placement mentoring, regular follow-up and support need to be structured and proactive. Where possible, a participant's workplace manager should also be involved in the process.

Some managers and palliative care service providers indicated that there was a need for more education on Advance Care Planning for Indigenous people. Palliative care service providers thought this was best done at the local primary health service level.

> *….. (the AHW) and I have been asked to do a presentation around Advance Care Planning at the next managers forum because it appears as if we are one of the few or maybe the only community that is doing advance care planning.* (Primary Health Centre Manager who participated in a PEPA placement with her IHWs)

Recommendation: A follow-up workshop should be trialled and could target specific needs such as Advance Care Planning, allow placement participants to consolidate knowledge and discuss issues and concerns they encountered on return to their communities.

Enablers and suggestions for increasing uptake

The uptake of the program relied upon PEPA having adequate resources so that the health service did not have additional out of pocket costs. The funding to support the placements was regarded as an enabler of the programs.

> *When participants come to do a placement, we can pay their employer backfill, or sort of pay them, sorry, a contribution towards, you know, backfilling that position. But it enables them to release their staff often, and they go, 'Yeah, we can do that because, you know, we have got funding for backfill'. And travel and accommodation, so if they are coming from regional, rural, remote. Oh, and workshops and placements are all offered free of charge, so that is fine. And even our specialist palliative care, you know, when we do the reverse PEPA and send them out we will pay the pal care staff member to go out.* (PEPA Manager)

However as alluded to above the level of remuneration for backfill was only a contribution and did not cover all the costs.

> *… we do backfill but it is not a large amount.* (PEPA Manager)

To what extent this influences line managers not approving placements is unclear.

Strategies which were reported as contributing to the uptake and effectiveness of placements included:

- Encouraging participants to come with others from their workplace so that they had peer support and reduced levels of anxiety (although, as one of the quotes below indicates, this strategy alone may not always be sufficient).

> *We really encourage people to come in pairs so that at least they have somebody else there.* (PEPA Manager)

> *I think people would just opt out anyway because they were scared of going on placements by themselves. We would offer to place people together but even with that some people would opt out.* (PEPA Manager)

Recommendation: Encourage workplaces to send more than one staff member together to ensure greater support for the participants and to achieve greater impact within the service

- A well organised placement that offered opportunities to acquire a variety of skills and had specific emphasis on caring for Indigenous people was most rewarding. Participants who reported a positive placement experience were more likely to recommend a placement to others.

  > *I see that program and that placement as essential almost for working with people in this field. I can't imagine working in there and not having done something like PEPA to prepare you. I think I already said that I recommend it to anyone who was looking at working in oncology or palliative care, because it helps you understand about end-of-life care. One of the good things about going to [placement site] too, is we spent time in these meetings, and allied health meetings. Spent time going around with the doctor on the ward, the oncology ward and the cancer care ward, the palliative care ward as well with the Indigenous people.* (IHW participant)

  > *But I think you've got to have that Indigenous component as far as the training and the supervision role if you can, rather than not having it.* (IHW participant)

- Assisting participant with the booking of flights and accommodation

- It was evident that including some palliative care community patient visits when doing a PEPA placement is important as this fits with the role of the IHW in their communities and will better equip them to do palliative home care visits once they return to their place of work.

  > *With our palliative care patients here in this area, they felt probably a little bit more comfortable with us if we actually did a home visit. And let them know that we can come out and speak to them, rather than get them out of bed while they're sick and bring them into the service, really sick people. It just makes it really, really hard.* (IHW participant)

Reverse PEPA Placements

Reverse PEPA placements entail a palliative care specialist working as a PEPA mentor travelling to the applicant's place of employment (reverse PEPA site) to mentor and facilitate learning. Reverse PEPA placements may be appropriate where the goal is to improve practice through tailored support in a specific practice setting such as a rural or remote Indigenous health services or aged care facility. This provides an opportunity for the local service to learn about palliative care, while the palliative care provider learns about the health service, Indigenous people and the different philosophy and ways of caring for patients in Indigenous primary health care services and aged care facilities. The length of reverse PEPA placements varied between two and five days.

> *Reverse PEPA is limited to residential aged care facilities, Aboriginal health services and sometimes rural and remote regions where they sort of go out and they will do a bit of a travelling road show sort of thing. Out somewhere where they can't maybe get backfill to release them to come into a service or something…* (PEPA Manager)

Reverse PEPA placements offer participants an opportunity to participate in a placement that is tailored to their needs, addresses issues and concerns that are relevant and current to them and are delivered in a culturally appropriate manner.

Reverse PEPA placements worked well in some areas and PEPA managers felt this was one solution to address the issue of releasing Indigenous staff from their service for the three-five days PEPA placement. Reverse PEPA placements could increase participation of IHW from rural and remote regions who were reluctant to travel to the larger towns and cities to take up a placement at a palliative care service. However, some PEPA managers felt that this method of placements was very labour intensive and they had difficulty recruiting specialist palliative care staff to assist with reverse PEPA placements.

> *We have a specialist palliative care educator to go out and do the Reverse PEPA…it becomes very person centred and very individual…* (PEPA Manager)

> *When we do Reverse PEPA, it's harder to do in a host site…hard to do the training when you are only there for 2 days.* (IPO)

A reverse PEPA placement, if done appropriately, was considered a rewarding experience for both the facilitator and the participant/s. They offer a two-way learning opportunity and enable the facilitator to gain an in-depth understanding of the work environment and the challenges of the Indigenous participants so they can tailor the learning package to best meet those needs.

> *So it was really interesting to talk with them and to hear what they had to say. Sometimes we were inside, sometimes we were outside, we'd mix it up, we did short blocks of learning with a long coffee break and with a long lunch break. So it wasn't really rigid but at the same time we got through everything.* (Reverse PEPA palliative care service provider)

Participants reported that reverse PEPA was particularly helpful and rewarding when they, either currently or had recently, cared for a person who was palliative as they were able to link the theory learnt into context.

> *We did [learn a lot] but because we had no residents at that stage of life at work, it was a bit disappointing because we could have learned more.* (Reverse PEPA IHW participant)

There was a high level of recognition that when facilitating a reverse PEPA placement it was important for the palliative care service provider to be aware of cultural sensitivities around discussing death and dying and other aspects of palliative care that participants may find difficult to deal with. Participants reported that the mentor for an IHW should ideally be experienced in dealing with Indigenous people and endeavour to obtain cultural guidance from local elders and health staff.

> *So at the beginning I had a conversation with the Registered Nurse and another gentleman who wasn't involved in the course about whether all of the staff coming would be open to discuss all those subjects.* (Reverse PEPA palliative care service provider)

Delivery and approach of PEPA that is sensitive to the cultural needs of the participants

Most participants indicated that the programs were conducted in a culturally sound and appropriate manner. Participants felt comfortable in asking questions which preceptors and PEPA staff were happy and able to answer. Participants undertaking the reverse PEPA placement felt that they were treated with respect and that the training was appropriate, aimed at the right level and enormously beneficial.

> *It was really good to have someone coming here and actually see what we do up here and we don't – didn't have a palliative care room… but now we're doing a palliative care room up, trying to get it up and running in maybe 3 months.* (Reverse PEPA IHW participant)

While some states reported difficulty in recruiting a suitable Indigenous Project Officer, the importance of having the program presented by an Indigenous person and allowing the educator to introduce some individual elements and activities to it was evident. When this occurred there was strong engagement not only with the health staff but also with the communities themselves.

> *I suppose we didn't realise ourselves just how far we'd come in developing a program that really worked and really engaged with the Indigenous people from remote areas.* (PEPA Manager)

An important component of the training focussed on effective culturally appropriate communication with Indigenous people about very sensitive issues.

> *I think when we did the training; that was one of the first things that came up, that everybody who works in the field, whether they're allied health or whatever their position was... around effective communication and talking to someone about really heavy duty issues, private issues.* (IHW participant)

Workshop and Placement Evaluation

There was recognition of the importance of and commitment to evaluation of PEPA, although no specific evaluation of the Indigenous component of the program has been conducted to date.

Workshop Evaluation

Pre-workshop evaluation forms are distributed to participants on arrival and completed as part of the workshop registration. A standard workshop evaluation process is followed and the forms are not specific to the IHW Workshop. Some informants expressed their concerns about the appropriateness of the wording of this standard evaluation forms. Many Indigenous participants whose first language was not English had difficulty in understanding the questions and terminology used and often required assistance with completion. This evaluation process often took up valuable workshop time; concerns were also raised about the interpretation of the responses.

> *We do have the pre and post workshop questionnaires. This is another issue for a lot of the Indigenous participants because often English is not their first language, it may even be their 3rd or 4th language. Even those that may speak English may not read and write it. This takes a bit of time as these participants need help completing the form. This takes up workshop time. What we usually do is that some of the palliative care team may help us with the participant's response. We understand the importance of collecting the data but it's the way its written makes it difficult for aboriginal people to understand. I think they are confusing, I sometimes don't always understand*

> *what the questions mean; I think it would be very scary and very stressful for people who are unfamiliar with some of the big words they use. They are put off with the way the questions are asked and may feel a bit intimidated by the questions.* (IPO)

> *I use the standard questionnaire that PEPA has developed. This is unfortunately not appropriate for everyone. We could probably workshop it a bit.* (IPO)

> *We've got a dummied down version with better language…When you could get people to complete them, you would get good feedback. Some people just didn't do it at all. I'm talking about indigenous people that are quite traditional…* (PEPA Manager)

Most PEPA staff felt that the standard workshop feedback form was not appropriate for use at the Indigenous workshops and would like to see a specific form designed that was more closely aligned with the Indigenous workshop format and structure.

> *The evaluation form we use is for Palliative Approach workshops which have specific sessions and secondly the wording is inappropriate. The Indigenous Health Workers absolutely need their own feedback forms for both the workshops and the placements.* (PEPA Manager)

Post-workshop evaluation forms are completed at the close of the workshop with participants asked to complete these prior to leaving. Many of the PEPA staff commented that generally positive feedback was received. The evaluation forms were all sent on to the National Office where they were analysed and reported on in the annual PEPA report. When local issues were raised in the evaluation, these were addressed by the local PEPA team.

> *We don't do it anymore; we send it off to PEPA National Office. We do have a look through them but they measure the national outcomes.* (PEPA Manager)

Recommendation: An appropriate approach to evaluation needs to be developed for Indigenous participants. A suitable approach to record and document IHW experiences and learning should be introduced. This could be done by either developing a form suitable for IHW participants using appropriate language (including those with low literacy) or by telephone follow up following the workshops.

Placement evaluation

Pre-placement evaluation forms are sent out to all participants one week before the participant attends a placement and another evaluation form is sent out at three months post placement.

> *The three months allows them some time to demonstrate transfer of learning into what they actually do so that they can actually make changes in their practice, and we want to capture that in their evaluation.* (PEPA Manager)

Some participants do not complete either the pre or post placement forms limiting the evaluation completeness and assessment of the program overall.

> *We send them pre placement evaluation forms before the placement and only about half send them back but post evaluation forms go out about 3 months after the placement and we seldom get them back.* (PEPA Manager)

There were suggestions for strategies which could assist with the evaluation.

> *It would be really helpful if they had a reflection page in the learning guide that they could post back to us like all the other participants do, just to have that written down.* (PEPA Manager)

> *I think they should also have the option for placements to do an oral feedback but at this time we can't do that. I have taken an oral report / feedback before and it worked well.* (PEPA Manager)

Recommendation: Trial completion of the post placement evaluation as a telephone interview undertaken with the Indigenous Project Officer.

Effect on Host Services Offering Indigenous PEPA Placements

The effect on host services varied. In a small number of services that were considered to deliver excellent experience in palliative care and that were used regularly, the staff reported there were times when they became fatigued and more burdened by hosting placement participants. However efforts have been made to respond to these issues and to reduce the burden on any one service, so that this has improved.

Services were generally briefed on the profile of the placement participant and usually tried to offer a varied placement that suited the participant's needs. There were however times when participants were not expected by services and this proved challenging for both the host site and the participant

> *When I got there they didn't have anything organised for me because the lady that was supposed to work with me had to go suddenly. So the first day was a bit hectic. I went out on several home visits with her (the community nurse) but nothing was around Aboriginal people.* (ALO)

Recommendation: Placement participants who travel from rural and remote areas to take up a placement in the larger towns or city may require additional support and mentorship. Regular reminders to host sites about those factors known to result in a high quality placement, and placement confirmation a week before participant arrives may be helpful in improving the placement experience.

In some cases the PEPA manager planned the daily activities for the participant on placement at the palliative care service. This reduced the load on the host site and promoted a sound working relationship.

> *The way we work it is part of my role, the PEPA manager role, is to plan out the whole week or however many days schedule for that person. I do that by having to contact virtually every individual person in the team that that person might want to spend time with related to their learning goals, and other activities we plan. So we actually structure the week much more than what I know they do in some other areas. It's mainly to reduce the load on a whole team that are already really busy, so they're assigned to one particular mentor. So again I've got to ensure that I've got the right sort of mentor available.* (PEPA Manager)

There was a greater impact on the palliative care service when they were responsible for planning the participant's activities for the week. This was particularly evident when a specific mentor was allocated to the participant for the duration of their placement.

> *It takes a lot of time out of my day. I always act as the mentor for a PEPA participant, and so I meet with the participant on a daily basis.* (Palliative care service provider)

Educational Resources

In the NT and Victoria some training materials have been adapted regionally with specific art work from that region. However, many states and territories are yet to develop or adapt resources to suit the needs of Indigenous participants taking into account their level of language and literacy skills. Whereas a skilled facilitator was able to adapt materials as required from workshop to workshop, others indicated that it would be useful for this to be done regionally to accommodate the different needs for urban and rural/remote health workers:

> *Some of the content was for people who have a tertiary level qualification in health. So, it was just a matter of adapting to the audience.* (PEPA Facilitator)

Some participants argued that programs developed and delivered by Indigenous people for Indigenous people is the key to effective engagement and education of Indigenous Health staff. One PEPA manager stressed the importance of involving the Indigenous Project Officers in the development and delivery of a program tailored to the needs of the local participants. The overall success of the program seemed to improve when there was evidence of Indigenous involvement and community engagement and in the development and delivery of programs.

> *So when she came on, she developed a lot of that, and I suppose for the first time, that's when we really realised the critical importance of an Indigenous person delivering that education. Whilst we'd had some remote education before that, it wasn't to a level that she was able to take it to with what she developed. So, as a team we developed this quite innovative new way of delivering education.* (PEPA Manager)

Recommendation: Involve Indigenous educators in the structure, content and resource development for the Indigenous component of the program taking into account the different needs of urban, rural and remote Indigenous participants.

Engagement with Indigenous communities

Enhancing community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services as well as building and enhancing the capacity of all relevant sectors in health and human services to provide quality palliative care are major goals in The National Palliative Care Strategy[17]. The Aboriginal and Torres Strait Islander component of PEPA specifically targets health professionals in primary care and non-palliative settings working primarily with Indigenous patients and their families. Whilst PEPA appears to be successfully addressing these needs, there are insufficient resources for the time and cost of travel to rural and remote communities and the human resources required for meaningful community engagement. The overall success of the program seemed to improve when there was evidence of Indigenous involvement and community engagement and in the development and delivery of programs.

Some PEPA managers found it challenging to engage local Indigenous Medical Services, particularly when they did not have the assistance from a dedicated Indigenous Project Officer. However, experience in this regard was mixed.

> *I have not worked in Indigenous communities before but I have not found it difficult to build those links.* (PEPA Manager)

> *We have been really struggling to engage with them …* (PEPA Manager)

> *…I have also done a lot of work myself building ties and relationships with the local Aboriginal communities and AMSs* (PEPA Manager)

Many Indigenous people find it difficult to talk about death and dying and their understanding of palliative care philosophy and practice is limited [10] and often tainted with myths and misconceptions. This also makes engagement challenging and reflects the need for more community education. Community engagement is the key to improving workshop and placement uptake by participants particularly in remote and rural areas. These Indigenous communities in particular need to build up a level of trust and familiarity with a person for effective engagement to occur.[10] It is often hard for an outsider from the city to make these links. It is important to have an Indigenous champion who is committed to promoting the program and has good connections with the Indigenous communities.

> *If you could get people [PEPA representatives] to spend more time in the community... I know this all costs money but in the ideal world…* (IPO)

> *They may refuse to come in for cancer treatment and then are under palliative treatment but they think this may cure them where in fact this is palliative. Also there are myths about medications too, such as morphine finishing you up early. This can occur when people need treatment for pain and we need to explain this in our workshops.(*IPO)

> *A couple of times many years ago, just after sub cut morphine was given, people finished and that created a lot of blame, unnecessary blame, as well so that's why we then moved to patches but it has taken a long time and even now some people are still suspicious and they say that that's the finishing up patch so we are constantly saying to families that it's not a finishing up patch* (Experienced RAN)

Recommendation: Dedicated Indigenous PEPA project officers be appointed in each state and territory so that they can spend considerable time building community ties, trust and relationships with key community players and partners.

Post placement contact with the participants by the PEPA staff was inconsistent across the states and territories, some participants reported that PEPA staff had visited their region/ community or had subsequently delivered a workshop locally; while others had little or no further contact with PEPA. It is difficult when the IPO is employed on a part-time basis or there is no dedicated IPO to ensure follow-up support occurs. Most participants reported that they maintained contact with the regional and/or urban palliative care centres and that they had no difficulty in accessing services when they had concerns.

Impact of Indigenous PEPA

Impact on the community

PEPA training is particularly valuable in communities that have no visiting palliative care services, as occurs most frequently in remote settlements across Australia's north. A number of Indigenous PEPA participants felt that within their communities, there remained a lack of understanding of palliative care and many Indigenous people remained resistant to engaging services, believing that it remained an end stage intervention and signalled imminent death. Indigenous people may be more accepting of palliative care services when the services work closely with the trusted comprehensive primary health care services to facilitate the patients care at home and assist the family and the patient in planning for the end of life process.

> *Facilitating people dying at home is actually one of our goals* ***(***Palliative Care service provider)

PEPA offers training for the IHW that improves knowledge, enhances confidence and empowers the IHW to care for end-of-life patients and their families. Case Study 1 depicts the experience of this PEPA placement participant:

> *I see that program and that placement as essential almost for working with people in this field. I can't imagine working in there and not having done something like PEPA to prepare you.* (ALO)

CASE STUDY 1: Increasing the Confidence and Capacity in an Aboriginal Worker in a Health Role

Sometimes especially as it got closer towards the end of life care, that I mean more often to emergency again and again more frequently. They'd end up on the ward or - but yeah I'd know at the handover, who was palliative care and who wasn't. Then I'd go and see them or see the doctor, or even go with the doctor on rounds.

So they cut that out over time, but that was part of the idea of having Aboriginal liaison at those meetings, was to be the go between. And there was always flexibility and openness and support there from those allied health units. Allied health palliative care units, because they had them both together, the cancer care ward and the palliative care ward, and they'd just do it on different days. They often deferred to me if they didn't know, so how's it been, have you caught up with so and so.

Because Indigenous people are pretty transient too…they come down to the city then go back up to the community…But one of the things I noticed is that they're more - ***especially when it comes to a home visit, they're more at ease and they're more comfortable when it's another Indigenous person***[4]*. A couple of times the palliative care unit asked me to come over and talk to somebody while they're getting treatment. He was sitting in the chair, he was getting his chemo, but he had an oncology nurse talking to him, a specialist person there talking, a registrar and then myself and then his partner, so all of us standing around a chair talking to him. Asking him questions, and I pretty much said look I'll come and see you later at home aye, or tomorrow or something. Then listen to what they're going to say, but ask your doctor tomorrow about any questions they want to have.*

Then I usually say there's a list of things I want to talk to you about anyway. But asking them, write down anything when you leave here or you get home, write down any questions that you have. Because you've got a lot of people talking to you, talking at you. They all have the best intentions, but it's just a lot to take in, while actually getting your treatment. It was a bit too much for I could see that there were - they were sort of a bit overwhelmed. I said that I'll catch up to him at home, and we did…His partner wasn't far away, but once she realised we were getting into deep personal discussions and she left the room. ***I couldn't have done that without having done the PEPA thing, a bit of confidence to let you know it's okay to ask and talk about dying.*** *Talking about cancer and what the cancer's doing in their body and how they're making you feel and that sort of thing.* ***You're going to get help if you're uncomfortable through the night or during, or something happens. Who to talk to all that sort of stuff.*** (ALO participant)

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[4] The importance of the role of the IHW in caring for palliative patients at home.

Many of the remote communities do not have access to a visiting palliative care service and rely on local health staff for their care. Outreach Workshops such as those offered in the Northern Territory could extend PEPA training to more remote communities throughout Australia. This is seen by some services providers as the key to embedding the palliative approach in the areas that need it most.

> *She's now done her Certificate Three, she's gone down to [the city] and done some PEPA training, and she's come back. But her JDF [Job Definition Format], or the role of the regional Aboriginal health worker in the Palliative Care Service, is supposed to be going out to the remote communities. A bit like the Northern Territory model, doing that outreach stuff, and mentoring, and making sure the people throughout the region and the communities, are actually dying appropriately, or getting advocated properly.* (Palliative care service provider)

It is important for IHWs to feel comfortable and confident explaining the end of life process to patients approaching the end of their life and their families. When IHW's are able to visit patients in their homes they are able to find out what is known and want patients need to know. Many patients are overwhelmed when surrounded by medical staff in a hospital setting and often feel too intimidated to ask questions or are unsure of what to ask. This participant felt that he was able to make a valuable contribution to the patients in his community due to the knowledge and confidence that he had gained through the PEPA placement.

> *I could see that there were - they were sort of a bit overwhelmed. I said that I'll catch up to him at home, and we did, we caught up and talked about one on one, man to man about things. I couldn't have done that without having done the PEPA thing, a bit of confidence to let you know it's okay to ask and talk about dying.* (IHW participant)

Although there is a need to extend the workshops to other Indigenous community members such as carers and other key players to enhance palliative care knowledge and understanding amongst community members, patients and their families, PEPA has been helping and assisting in creating awareness and willingness to use palliative care in the general communities.

> *There is definitely a change [in attitude to palliative care]. People want to look after people.* (IPO)

> *We got to change their mindset that it's not a shame to be engaged with the palliative care services.* (IPO)

There are a number of good news stories about effective palliative care and peaceful passing of patients in communities where staff were PEPA trained and adopted the palliative approach (Case Study 2).

> *…if they are spiritually and culturally-safe and comfortable then their whole wellbeing is better and you can't measure that it is just something that will happen when they are home.* (Remote Clinic Manager)

> *Going to PEPA was good because it showed me that life did not just have to end so quickly. You can take a person home and make him comfortable in the community… (*IHW)

CASE STUDY 2: Making a Difference "A good death"

One of my cousins passed away about two months ago and during her journey, [the health centre manager] and me would go and visit her and at the end of her journey she said a big thank you to [the AHW] and me and [the manager]. And it was really good to hear that from a sick person, thanking us so much and I said 'no it's alright because this is what we do, we help people.' Yes it was very rewarding for us all. It's good to hear from people who are leaving us and the care that they have got and I say to myself at least we are appreciated (IHW participant)

I remember that day well, she was really grey looking and we all thought to ourselves 'Oh the time is getting close' and it was just like she was in such a peaceful place and she had accepted that her journey was coming to an end and she was pain free. She wasn't feeling that great and she was really tired and ready to move on. There was an amazing feeling of peace at that time and in the earlier part of the journey, she was very strong with what she wanted but her sister did not want to follow the plan. It was grieving of course. Sometimes the family doesn't want to accept what is happening and you do cope with some anger and flack and stubbornness (Health Centre Manager)

Many of the smaller remote communities had no access to visiting palliative care services and the patients' only option for a palliative care specialist service was to travel to a city 500-1000 km away. The manager of a small community clinic in one of the remote areas sent a number of their health workers to take up a PEPA placement in order to enhance their palliative care skills. They have now formed their own palliative care team that is now able to serve the community and offer the support to patients and their families at the end of life.

> *We've kind of made up our own palliative care team. You know with a mixture of family, HACC officers, hospital staff and health workers.* (IHW participant)

While it was acknowledged that PEPA has played a role in enlightening Indigenous communities about palliative care, there were still concerns that many services still lacked insight into the cultural requirements for Indigenous people at the end of life.

> *There's still a big gap about getting that cultural safety journey right within a palliative approach.* (IPO)

Whilst most IHW program placement participants found the training useful and enlightening, once they returned to their workplace they were often allocated to or opted to work in a different area and thus the benefit of the training was reduced. Undoubtedly, the impact of the training within the service and the community appeared enhanced when the participant's line manager and fellow health professionals were familiar with the program and understood the importance of the palliative approach for patients nearing the end of their lives. Reverse PEPA Placements and Outreach Programs both worked well in addressing this issue.

> *…there's another lady that I assisted, she has spinal cancer, and she has just come back into the community after having treatment. I said I think she should be followed up for our palliative care program. What do you want me to do for her? She wrote back….she hasn't been referred via…If she*

> *wants to come under the palliative care services she will need to catch up with me for an informal talk…That's what happens, they just get left* (ALO)

Recommendation: Regular post-placement follow-up with participants and their line manager should be trialled to assess whether it enables participants to maintain focus and be PEPA advocates in their communities.

The confidence gained when doing PEPA and the connections with experts in the field of palliative care empowered IHW to help their Indigenous patients understand and cope with the dying process.

> *One of that things about hospital that people don't like, no windows, it's real air, recycled air. You're seeing a lot of strangers who are making decisions about you, and you don't know them. You know that they're doing the right thing or they're doing their job, but it makes a world of difference when you see a black face, another indigenous person working in the area, and prepared to work with you.* (IHW Participant)

Impact on Services Providing End-of-Life care for Indigenous People

There was considerable benefit achieved within some services from their uptake and participation in Indigenous PEPA. This was evident in their ability to work effectively in the multidisciplinary team to prepare the family for the return of the terminally ill family member.

> *We usually get advice or notified by the cancer services and so on when people are ready to come back to us. So usually we will sit down with the doctor and Nurse Manager and decide how it will be best to approach the family and we have a meeting and discuss it. We also tell the family about the illness. We get a call from the hospital and they tell us that a person is due to come back for palliative care and we get the team together. We talk to the whole team, me and the manager. It's a lot of team work.* (IHW participant)

The knowledge gained through participation in the PEPA placement and developing a shared understanding with other health care providers, empowered IHWs and enabled them to identify and develop changes within their facility to improve the end of life care for their patients. An example of this is evident in Case Study 3.

CASE STUDY 3: Working More Effectively Together and Providing Better Care

A manager at one Indigenous aged care facilities commented on the high level of non-attendance amongst IHW. She felt that involving the staff more directly in palliative care service would empower the staff and allow them to take ownership of a project. She arranged for a number of staff to participate in a PEPA placement and this proved to be very successful. Staff are now keen to set up a dedicated palliative care room in the facility that can be accessed by the whole community. Several other staff members have requested a PEPA placement opportunity:

…but that's why I really wanted the palliative care to help, just to empower the workers here and to take ownership of something and really make it theirs because it is so special and the cultural aspect up here is so unique that it's really one of a kind. It really is. (Health Centre Manager)

The palliative care service provider found the experience both enlightening and rewarding. She commented that the experience was not only constructive but that all parties felt excited at what was achieved at the end of the placement.

Yes, so we actually formulated I think it was something like a 16 point action plan out of the four days that we spent together. Some of those things - so what the group was very keen to do was they wanted to set up a palliative care room. They needed a bigger room; they needed a family room, all those things that we would talk about…So really the placement was - not only was it about learning and teaching, it was about real strategies for how do we progress our staff education, how do we progress our palliative care? (Palliative care service provider)

Limitations and data collection issues

There were some time constraints upon this evaluation, particularly given the need to ensure that ethical processes and clearance had been achieved prior to commencing. The evaluation team received excellent support from the national PEPA office at QUT. However, the records of those who had participated in training or attended placements were held at the jurisdictional level, and given the turnover of staff and sometimes of the contracted agencies, there were sometimes limited historical records available. We were fortunate to interview several former program managers and IPOs who had been important in establishing aspects of the program.

Data collection, particularly for Phase 2 proved challenging and time-consuming. Issues encountered were largely related to locating and following up potential participants:

- Indigenous primary health centres are constantly busy and staff were unavailable for an interview;
- IHWs were difficult to locate as many had left their previously listed place of employment;
- IHWs have a busy schedule and were often not available for an interview;
- Scheduling an interview often required multiple follow-up phone calls;
- Interview appointments were cancelled on multiple occasions;
- Host sites were not clearly identified in some jurisdictions;
- There were some language barriers experienced with participants who were not fluent in English; and
- PEPA participants were based in multiple locations; this prevented researchers from visiting key areas to interview or conduct focus group discussions involving several participants as originally planned.

Conclusions and Recommendations

What Approach Works Best?

Inevitably, given the different geographic, administrative, capacity, historical and funding arrangements for the Indigenous PEPA around Australia, there will be diversity in the delivery of the program. The evaluation team do not advocate for a one size fits all approach. However, the opportunity to explore the program from the perspective of national and state PEPA Managers/Coordinators, Indigenous Program Officers and to get input from those who had undergone both the training and the placements allows a picture to emerge of conditions which seemed most favourable to delivery of the successful program. It is acknowledged that many factors impact upon program achievements and some of these are outside of the control of those people employed to work on the delivery of the Indigenous PEPA.

Program Level

- Having a dedicated Indigenous Project Officer (IPO) who had a good relationship with the PEPA manager was a key ingredient for success. These positions seemed most valuable where they had a strong role in co-delivering education as well as liaison with the Indigenous community. The achievements in the Northern Territory when there was both an Indigenous PEPA Manager and an Indigenous Educator demonstrate the real strength of this level of Indigenous ownership and commitment
- Longer PEPA placements worked best as participants who had placements of only 2-3 days reported that this was too short.
- Placements were seen as establishing relationships with palliative care providers which could continue after the placements.
- Reverse PEPA placements appeared to be particularly suitable for Northern Australia. However, completing a reverse PEPA placement should not preclude another placement within a palliative care setting as different knowledge and insights will be gleaned and the relationship begun between IHW and palliative care provider could be enhanced and consolidated by further contact.
- The experience of mixed groups of Indigenous and non-Indigenous people engaged in yarning workshops and outreach together has proved valuable in sharing stories to build cross-cultural knowledge and understanding and broader uptake of this approach could be encouraged.

Service Delivery Level

- Excellent outcomes were evident where there was a high level of support for Indigenous workers to attend training from their line manager and in some cases, managers attended with more than one IHW. This helped all of the team to be on the one page and for planning for how better palliative care could be implemented to begin even during the training.
- A successful model was where a registered nurse working as part of a team with IHWs recognised the importance of palliative care and already had an established relationship with, and trust from, their local Indigenous community.
- There was a very important role for Indigenous Liaison Officers in palliative care delivery. Line managers and broader support to use the skills and knowledge of the ALO to improve Indigenous people's end of life experience was invaluable in creating changes in the physical environment and care provided to affected people at this time.

Improving the Indigenous PEPA into the Future

While recommendations have been made throughout this report, there are additional comments and recommendations made below.

1. **Improve data keeping and record retention**
   Evaluation is a key component for delivery of more effective programs in the future and certainly does not take the place of the monitoring which is already in place though funding contracts. This evaluation was made more difficult because of turnover of staff within the PEPA and difficulty accessing good historical records of PEPA participants, their Indigenous status and contact details. ***Consideration might be given to establishing a (web-based?) database recording details of participants and their contact details, including their place of work and job role, nature of training /placement site attended, number of days, and linking evaluation to individual participants***.

2. **Evaluation Forms and Approach**

Reconsider the approach to monitoring and evaluation of the Indigenous component of PEPA. The current approach of using a standardised evaluation form across Indigenous PEPA and the standard PEPA is ineffective, particularly for the evaluation of the impact of the placements once placement participants returned to their host site. ***These forms may benefit from re-design, but a trial of linking either structured questionnaires or using qualitative approaches through phone interviews as part of greater follow up and mentoring is recommended.***

3. **Appoint Indigenous IPOs**
   The important role of an Indigenous project officer or educator in engaging Indigenous people and communities did not seem to be adequately recognised in all settings. In addition, establishing such a role can play an important capacity building function. ***In all jurisdictions there should be provision for at least some FTE from dedicated funding for an IPO/IEO.***

4. **Continue to encourage development of resources appropriate to the local region**
   There are various levels of literacy and health literacy in the Indigenous community and many misunderstandings or myths so different resources are needed in order to be appropriate and meet local needs. Provide ideas and templates so that resources can be adapted for different regions and rural/remote locations. ***One possibility is to bring trainees and facilitators together to discuss, develop and adapt resources.***

5. **Greater Support / Capacity Building for Indigenous Palliative Care Placement "graduates"**
   Support for participants after their initial training and after a placement is important to consolidate learning and to maximise the benefits to trainees and their host organisation and community. ***Additional opportunities for follow-up learning and mentoring of participants are recommended***. This could be one-on-one or through a peer support network to discuss issues they are experiencing and what they are achieving with others. There may also be opportunities for capacity building of skilled and suitable Indigenous people with experience of palliative care through training then as Indigenous educators.

6. **Match Indigenous Placements to Palliative Care services with Indigenous expertise**
   Indigenous people expressed a strong preference for placements to occur in a palliative care setting where Indigenous people were receiving care and there was significant experience and expertise in providing end of life care to Indigenous people. Such sites are also more likely to have Indigenous staff members. While there are challenges in achieving this because of the risk of overburdening some services, further assessment of Indigenous case load in potential placement centres could be useful to assessing sites most suitable for Indigenous patients

7. **Develop accreditation of the PEPA as a Certificate IV unit, potentially through partnerships with Aboriginal Registered Training Organisations**. A unit HLTAHW424B - *Provide information and strategies in palliative care* is registered with the Industry Skills Council as a component of the Diploma of Aboriginal and or Torres Strait Islander Primary Health (Community Care) and the Certificate IV in Aboriginal and/or Torres Strait Islander Primary Health (Community Care). However, only 3 Registered Training Organisations, all based in Western Australia, are currently approved to deliver this unit of competency.

8. **Incorporate a dedicated session on Advance Care Planning.** Palliative care service providers, PEPA managers and primary health care staff all commented on the need for additional education on Advance Care Planning as a timely and well planned approach assisted both patients and their families with end of life preparation.

9. **Trial a longer format for workshops with content delivered over two days to allow for less concentrated information and greater opportunities for discussion and storytelling.**

10. **Explore possibilities of enhancing Indigenous PEPA through being supported for Broader Community Education around Cancer**. Many of those interviewed identified the need for improving the understanding that Indigenous people have regarding cancer. If Reverse PEPA is increased in Northern Australia and remote areas or workshops are reconfigured to run over two days, there may be opportunities for additional funding which could support increased cancer education to occur in Indigenous community settings. Additionally, the role of palliative care for patients with life limiting chronic disease also requires community education.

References

1. Commonwealth of Australia. Supporting Australians to live well at the end of life: National Palliative Care Strategy 2010, 2010
2. Department of Health Western Australia. Rural Palliative Model of Care. Perth: WA Palliative Care and Cancer Network, Department of Health, Western Australia, 2008.
3. Liaw ST, Lau P, Pyett P, et al. Successful chronic disease care for Aboriginal Australians requires cultural competence. *Australian and New Zealand Journal of Public Health* 2011; **35**(3): 238-48.
4. McGrath P. The Living Model: an Australian model for Aboriginal palliative care service delivery with international implications. *Journal of Palliative Care* 2010; **26**(1): 59-64.
5. Sullivan K, Johnston L, Colyer C, et al. National Indigenous Palliative Care Needs Study. Canberra: Commonwealth Department of Health and Ageing, 2003.
6. Australian Institute of Health and Welfare. Trends in palliative care in Australian hospitals. Canberra: AIHW, 2011.
7. McGrath P, Holewa H, McGrath Z. Practical Problems for Aboriginal Palliative Care Service Provision in Rural and Remote Areas: Equipment, Power and Travel Issues. *Collegian*; **14**(3): 21-6.
8. McGrath P, Holewa H. End-of-life Care of Aboriginal Peoples in Remote Locations: Language Issues. *Australian Journal of Primary Health* 2007; **13**(1): 18-27.
9. McGrath P, Holewa H. Seven principles for Indigenous palliative care service delivery: Research findings from Australia. *Austral-Asia Journal of Cancer* 2006; **5**(3): 179-86.
10. McGrath P, Holewa H, Kail-Buckley S. "They should come out here ...": research findings on lack of local palliative care services for Australian aboriginal people. *Am J Hosp Palliat Care* 2007; **Apr-May 24**(2): 105-13.
11. McGrath P, Holewa H, Ogilvie K, Rayner R, Patton MA. Insights on Aboriginal peoples' views of cancer in Australia. *Contemporary Nurse* 2006; **22**(2): 241-54.
12. McGrath P, Ogilvie KF, Rayner RD, Holewa HF, Patton MAS. The "right story" to the "right person": communication issues in end-of-life care for Indigenous people. *Australian Health Review* 2005; **29**(3): 306-16.
13. Prior D. Palliative care in marginalised communities. *Prog Palliat Care* 1999; **7**: 109-15.
14. Shahid S, Finn L, Bessarab D, Thompson SC. Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. *BMC Health Services Research* 2009; **9**(132).
15. Shahid S, Finn L, Thompson ST. Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting. *MJA* 2009; **190**(10): 574-9.
16. McGrath P. Family care giving for Aboriginal peoples during end-of-life: findings from the Northern Territory *Journal of Rural and Tropical Public Health* 2008; **7**: 1-10.
17. Commonwealth of Australia. The National Palliative Care Strategy – Supporting Australians to Live Well at the End of Life: Commonwealth of Australia, 2010.

Appendices

Appendix 1: Approved Ethics materials

Appendix 1a: Information sheet and consent form - Phase 1

Appendix 1b: Question guide for Phase 1

Appendix 1c: Information sheet and consent form - Phase 2

Appendix 1d: Question guide for Phase 2

Appendix 2: Indigenous PEPA structure and delivery by jurisdiction, 2014

Appendix 1.1

QUT ihbi Institute of Health and Biomedical Innovation
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PEPA Program of Experience in the Palliative Approach

Funded by the Australian Government Department of Health and Ageing

Program of Experience in the Palliative Approach (PEPA) 2011-2014

QUT Ethics Approval Number 1200000183

RESEARCH TEAM

Principal Researcher:	**W/Professor Sandra Thompson**	Project Leader, Combined Universities Centre for Rural Health (CUCRH), University of Western Australia (UWA)
	Associate Professor Gail Garvey	Menzies School of Health
Associate Researchers:	**Dr Shaouli Shahid**	Research Fellow, UWA
	Ms Michele Holloway	Research Assistant, UWA

DESCRIPTION

The Program of Experience in the Palliative Approach [PEPA] was established by the Australian Government Department of Health and Ageing under the National Palliative Care Program. PEPA provides primary health care providers with an opportunity to develop skills in the palliative approach.

The staff who developed PEPA are keen to undertake a national evaluation to assess how far the program meets its key objective of increasing capacity of the primary care workforce to provide a palliative approach to care and improving care for people at the end-of-life.

As part of this study we will evaluate the experience of the previous and the present PEPA team in establishing an Aboriginal & Torres Strait Islander component of PEPA; facilitating workforce development of health professionals that provide services to Aboriginal or Torres Strait Islander people; and the effectiveness and sustainability of PEPA within both organisations and communities.

People who will be approached to participate in this evaluation include:

- PEPA Managers;
- Indigenous PEPA Project Officers/ Consultants.

PARTICIPATION

You are invited to take part in this evaluation because we value your ideas and input on how the program can be improved to better meet the needs of Aboriginal Health Workers, Community Workers and Aboriginal palliative patients and their families. If you agree to participate, one of the PEPA evaluation team will talk with you by telephone and ask questions about your experiences with Aboriginal & Torres Strait Islander program of PEPA. You can choose where and when you wish to be interviewed (such as while you are at work or at home, day or night).

Interviews will generally take around 30-60 minutes. With your permission, we will record your answers so that so that your answers can be accurately understood and interpreted later on. You do not have to complete any question(s) that you are uncomfortable answering.

Your participation in this project is entirely voluntary. If you agree to take part, we will send you the list of questions and topics to be covered during the interview before the telephone call. You can withdraw from the study at any time without having to explain why. Your decision to participate, or not participate, will not impact upon your current or future relationship with PEPA.

EXPECTED BENEFITS

Benefits of participating in the evaluation are mostly around you helping to improve the program in the future. It will provide you a chance to provide feedback on the PEPA program for Aboriginal and Torres Strait Islander people. This will benefit others who deliver and undertake the program.

RISKS

There are no anticipated risks beyond normal day-to-day living associated with your participation in this research. Talking about experiences of caring for people with life-limiting illnesses may cause discomfort for some people. If you experience any discomfort from participating in this project, please let us know. We will arrange for you to talk with your local PEPA Manager. He/she can advise you of additional supports if you require them.

PRIVACY AND CONFIDENTIALITY

The Australian Government Department of Health has funded Queensland University of Technology (QUT) to undertake the national coordination (including program evaluation) and program management of PEPA. The PEPA team at QUT has collaborated with the University of Western Australia (UWA) and Menzies School of Health Research to undertake this national evaluation of the Aboriginal and Torres Strait Islander component of PEPA. All comments and responses will be treated confidentially.

We will respect the information you give us and protect your identity so that any information you give is not attributed to you by name. Your answers will be kept safe and stored without your name. Only the primary researchers from UWA will have access to this information. Reports and publications about the research will not use your name, and material will be presented in ways that will prevent anyone from being able to identify you.

Please note that non-identifiable data collected in this project may be used as comparative data in future projects or stored on an open access database for secondary analysis.

CONSENT TO PARTICIPATE

We would like you to sign a written consent form (enclosed with this information sheet) or provide verbal consent at the beginning of the interview to confirm your agreement to participate.

CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

We are committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Unit on (07) 3138 5123 or email ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If have any questions or require any further information please contact one of the research team members below.

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Thank you for helping with this research project. Please keep this sheet for your information.

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PEPA Program of Experience in the Palliative Approach

Funded by the Australian Government Department of Health and Ageing

Program of Experience in the Palliative Approach (PEPA) 2011-2014

QUT Ethics Approval Number 1200000183

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Professor Patsy Yates
School of Nursing-Institute of Health and Biomedical Innovation

patsy.yates@qut.edu.au
(07) 3138 3835 / 6116

STATEMENT OF CONSENT

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the Research Ethics Unit on (07) 3138 5123 or email ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project.
- Agree to participate in the project.

Please tick the relevant box below:

☐ I agree to participate in this study.

☐ I agree to my interview being recorded.

Name ....

Signature ....

Date ....

Please return this sheet to the investigator.

Appendix 1.2

PEPA Program of Experience in the Palliative Approach

Funded by the Australian Government Department of Health and Ageing

PEPA EVALUATION PHASE I

INTERVIEWS WITH PEPA's

ABORIGINAL PROJECT OFFICERS / CONSULTANTS

Thank you for agreeing to participate in this evaluation of the Indigenous component of PEPA. You should have received an information sheet prior to this interview that has outlined some of the background as well as a list of themes that we wish to explore in this interview.

The Australian Government Department of Health and Ageing (DoHA) has funded Queensland University of Technology (QUT) to undertake the national coordination of PEPA, including program evaluation and they have collaborated with the University of Western Australia (UWA) and Menzies Research Institute (MRI) to undertake the evaluation of this component. I work for the University of Western Australia.

This interview will take around 30-60 minutes and with your permission, I will record your answers so that so that they can be accurately understood and interpreted later on. You do not have to answer any question that you are uncomfortable answering and all comments and responses will be treated confidentially. Your name will not be linked to any of your responses.

By participating in this evaluation, you have an opportunity to provide feedback that will help to identify areas for improving the program in the future.

Could you please start by providing a brief description of the Indigenous population in your state territory? (Urban, rural, remote, what language is used, types of available services for Indigenous people, etc.)

Background to Indigenous component of PEPA

1. When did the Indigenous component of the PEPA program commence in your state/territory?
2. What is your understanding of how and why it was set up?
3. What organisation/who is administering the program in your state/territory? Do you know why was it decided to base it with this organisation?

Aboriginal PEPA Project Officers (APOs) responsibilities and support

4. When did you start as the Aboriginal PEPA project officer and have you consistently been employed as APO? Can you please describe your experience during the recruitment phase?
5. What was your experience of palliative care before you commenced in this position?
6. Can you tell us your thoughts on how the Indigenous PEPA project officer position is set up
    - things like how much time you have to work on this,
    - employment conditions,

  - the level of support from the organisation and externally,
  - resourcing and so on
7. Were any Indigenous networks established (with the program or organisation) when you commenced your role?
  - How would you describe the networks now?
  - How valuable has the APO PEPA network been to you in your role?
  - Are there other Indigenous people employed in your organisation and
  - if so, how do you work/ link with them?
8. Has the organisation implemented any specific cultural safety strategies for you or other team members?
9. What sort of support do you get? Have you personally received adequate support in your role?
  - *If yes*, what are the things that make it work? Who are the key people involved in supporting you?
  - *If not*, what did not work? How could this be improved?

Program description

10. Can you tell us about the specific objectives of the PEPA program you are working on and whether you think they are appropriate?
11. Please describe how you promote and advertise the PEPA program to the community and health delivery staff?
  - How would you describe the response from the community?
  - Are you happy with how this is working and/or is there any room for improvement?
  - Do you have any trouble getting people interested?
12. Do you feel the program is appropriate for the target group? Please explain your reason.
  - Do you feel like people who are interested in the course registering to do the training?
  - If not, why do you think this may the case ?
13. What about those who do register – are they appropriate for learning about palliative care?
  - Do you think they are likely to and contribute to delivery of palliative care in their communities and
  - Are they doing that?
14. Can you please describe any gap you have identified in the content and delivery of the course or the placement program?
15. Please tell us about the kind of support that is provided to the participants during and after the training and the placements and who provides this?
16. What kinds of participant feedback processes are in place, and how does the feedback received inform future program delivery?
17. Once participants have completed the training and placement, what kind of follow-up occurs?
  - Can you comment on how adequate and appropriate the post-training seems in practice?

Outcome evaluation and suggestions for improving Indigenous component of PEPA

18. Please describe any specific issue that participants commonly identify that are difficult to address with the community with regards to palliative care. How has the PEPA program worked to address these concerns?
19. What evaluation processes are used for workshops and placements?
  - Is this effective?
  - What makes this evaluation process work or not work?
  - Do you have suggestions about the evaluation process?
20. Can you please describe any examples of where end of life care has worked well for the community where you think an AHWs completing the program contributed to a good outcome?
  - What worked/ works well?
21. Do you have any suggestion on how the program can be delivered in the future to better meet the needs of the participants?

- Do you have any ideas on how to better support participants?

Palliative Care for Aboriginal communities

22. Are you able to describe some of the barriers (real or perceived) and enablers that Indigenous families/communities have to access palliative care?
23. What suggestions do you have for improvements and/or things that would help improve palliative care for Aboriginal people?

Appendix 1.3

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PEPA Program of Experience in the Palliative Approach

Funded by the Australian Government Department of Health and Ageing

Program of Experience in the Palliative Approach (PEPA) 2011-2014

QUT Ethics Approval Number 1200000183

RESEARCH TEAM

Principal Researcher:	**W/Professor Sandra Thompson**	Project Leader, Western Australia Centre for Rural Health (WACRH), University of Western Australia (UWA)
Associate Researchers:	**Dr Shaouli Shahid**	Research Fellow, UWA
	Ms Michele Holloway	Research Assistant, UWA

DESCRIPTION

The Program of Experience in the Palliative Approach [PEPA] was established by the Australian Government Department of Health and Ageing under the National Palliative Care Program. PEPA provides primary health care providers with an opportunity to develop skills in the palliative approach.

The staff who developed PEPA are keen to undertake a national evaluation to assess how far the program meets its key objective of increasing capacity of the primary care workforce to provide a palliative approach to care and improving care for people at the end-of-life.

As part of this study we will evaluate the experience of the previous and the present PEPA team in establishing an Aboriginal & Torres Strait Islander component of PEPA; facilitating workforce development of health professionals that provide services to Aboriginal or Torres Strait Islander people; and the effectiveness and sustainability of PEPA within both organisations and communities.

People who will be approached to participate in this evaluation include:

- PEPA Managers;
- Indigenous PEPA Project Officers/ Consultants
- Aboriginal and Torres Strait Islander PEPA placement and workshop participants
- Other key stakeholders (Aboriginal primary health care providers, PEPA placement providers, Aboriginal and |Torres Strait Islander Reference Group

PARTICIPATION

You are invited to take part in this evaluation because we value your ideas and input on how the program can be improved to better meet the needs of Aboriginal Health Workers, Community Workers and Aboriginal palliative patients and their families. If you agree to participate, one of the PEPA evaluation team will conduct the one-to-one interview with you by telephone. You can choose where and when you wish to be interviewed (such as while you are at work or at home, day or night). During the interview you will be asked questions about your experiences with Aboriginal & Torres Strait Islander program of PEPA.

Interviews will generally take around 30-60 minutes. With your permission, we will record your answers so that so that your answers can be accurately understood and interpreted later on. You do not have to complete any question(s) that you are uncomfortable answering.

Your participation in this project is entirely voluntary. If you agree to take part, we will send you the list of questions and topics to be covered during the interview before the telephone call. You can withdraw from the study at any time without explanation or penalty but with your permission we would like to use the information that you have already given us. Your decision to participate, or not participate, will in no way impact upon your current or future relationship with PEPA.

EXPECTED BENEFITS

Benefits of participating in the evaluation are mostly around you helping to improve the program in the future. It will provide you a chance to provide feedback on the PEPA program for Aboriginal and Torres Strait Islander people. This will benefit others who deliver and undertake the program.

RISKS

There are no anticipated risks beyond normal day-to-day living associated with your participation in this research. Talking about experiences of caring for people with life-limiting illnesses may cause discomfort for some people. If you experience any discomfort from participating in this project, we encourage you to contact your local PEPA Manager. He/she can advise you of additional supports if you require them.

PRIVACY AND CONFIDENTIALITY

The Australian Government Department of Health and Ageing (DoHA) has funded Queensland University of Technology (QUT) to undertake the national coordination (including program evaluation) and program management of PEPA. The PEPA team at QUT has collaborated with the University of Western Australia (UWA) and Menzies Research Institute (MRI) to undertake this national evaluation of the Aboriginal and Torres Strait Islander component of PEPA. All comments and responses will be treated confidentially.

We understand the need to respect the information you give us and will protect your identity so that any information you give is not attributed to you by name. Your answers will be kept safe and stored without your name. Only the primary researchers from UWA and MRI will have access to this information. Reports and publications about the research will not use your name, and material will be presented in ways that will prevent anyone from being able to identify you.

Please note that non-identifiable data collected in this project may be used as comparative data in future projects or stored on an open access database for secondary analysis.

CONSENT TO PARTICIPATE

We would like you to sign a written consent form (enclosed with this information sheet) or provide verbal consent at the beginning of the interview to confirm your agreement to participate.

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QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If have any questions or require any further information please contact one of the research team members below.

Thank you for helping with this research project. Please keep this sheet for your information.

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PEPA Program of Experience in the Palliative Approach

Funded by the Australian Government Department of Health and Ageing

Program of Experience in the Palliative Approach (PEPA) 2011-2014

QUT Ethics Approval Number 1200000183

RESEARCH TEAM CONTACTS

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	Professor Patsy Yates School of Nursing-Institute of Health and Biomedical Innovation patsy.yates@qut.edu.au (07) 3138 3835 / 6116	

STATEMENT OF CONSENT

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the Research Ethics Unit on (07) 3138 5123 or email ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project.
- Agree to participate in the project.

Please tick the relevant box below:

☐ I agree to participate in this study.

☐ I do not agree to participate in this study.

Name ....

Signature ....

Date ....

Please return this sheet to the investigator.

Appendix 1.4

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PEPA Program of Experience in the Palliative Approach

Funded by the Australian Government Department of Health and Ageing

PEPA EVALUATION PHASE II

INTERVIEWS WITH PEPA's

PARTICIPANTS (Health and Community Workers)

Thank you for agreeing to participate in this evaluation of the Indigenous component of PEPA. You should have received an information sheet prior to this interview that has outlined some of the background as well as a list of themes that we wish to explore in this interview.
The Australian Government Department of Health and Ageing (DoHA) has funded Queensland University of Technology (QUT) to undertake the national coordination of PEPA, including program evaluation and they have collaborated with the University of Western Australia (UWA) and Menzies Research Institute (MRI) to undertake the evaluation of this component. I work for the University of Western Australia.
This interview will take around 30-60 minutes and with your permission, I will record your answers so that so that they can be accurately understood and interpreted later on. You do not have to answer any question that you are uncomfortable answering and all comments and responses will be treated confidentially. Your name will not be linked to any of your responses.
By participating in this evaluation, you have an opportunity to provide feedback that will help to identify areas for improving the program in the future.

Background

- Could you tell us what your role in your community /workplace is and how long you have been in that role?
- Do you care for people in your community who are unwell and not going to get better?
- Could you please provide a brief description of the Indigenous population in your region?
- (Urban, rural, remote, what language is used, types of available services for Indigenous people, etc.)
- How did you hear about PEPA?
- Did you attend both the workshop and the placement component of the program?
- If you did not participate in the placement component can you tell us why?
- What was your experience of palliative care before you participated in PEPA?
- What issues do you find difficult to address with a terminally ill patient and /or their family?

Appendix 1.4

Palliative Care in your community

- What palliative care services, if any, are available in your community/region?
- Do you think that there is a need for culturally respectful support for people in your community who are unwell and not going to get better, people who are getting ready to 'finish up'?
- Has this training changed the way you deal with terminal patients and their families and if so, how?
- Do you feel better equipped to care for terminal patients after completing the training and placement program-if so, how and if not, why?
- How accessible are palliative care services to people who are ill and are not going to get better?
- Have you experienced any situations where end of life care has worked well for the community where you think that your completion of the program contributed to a good outcome?

Support

- What type of support (if any) have you received from your PEPA Aboriginal Project Officer/Consultant?
- Did someone from PEPA contact you after the course to find out how you were managing in the community?
- Do you have any ideas on how you could have been better supported?
- Do you know of any networks or support groups available for participants after completion of the program and would these be beneficial?

Evaluation and suggestions for improving Indigenous component of PEPA

- Were you able to contribute to an evaluation process at the end of the course and what format did this take?
- Can you please describe any gap you have identified in the content and delivery of the course or the placement program?
- You think the training was culturally appropriate and if not, why not?
- Do you have any suggestion on how the program can be delivered in the future to better meet the needs of the participants?
- What suggestions do you have for improvements and/or things that would help improve palliative care for Aboriginal people?
- Would you encourage others to participate in this course and why/why not?

Appendix 2: Indigenous PEPA structure and delivery by Jurisdiction, 2014

Australian Capital Territory (ACT)		
Organisational	**Programs /Policy**	**Issues – Barriers/ Successes/Opportunities**
Administering Agency: Calvary Health Care ACT **PEPA Manager:** (FTE 0.8) ▪ Employed by Calvary health Care ▪ Works from Little Company of Mary ▪ Nurse but not from Palliative care background ▪ Has previously done PEPA as a participant ▪ Role: o Facilitate and coordinate program o Budget o Arranges workshops and placements o Liaise with participants **PEPA Indigenous Consultant** ▪ Indigenous Liaison Officer at the Hospital ▪ Advisory role only ▪ Connection to the Indigenous community	**Program Structure** ▪ Run in a culturally safe format ▪ More informal approach to workshop ▪ Flexible for Indigenous participants ▪ Palliative care specialist runs workshops No Indigenous specific workshops have been run by current manager but Indigenous participant has attended a PEPA workshop No Indigenous placements (at time of interview)	**Barriers:** ▪ Difficulty in engaging the local Indigenous medical service ▪ Main stream hospital patients do not always identify as Indigenous ▪ Small Indigenous population **Successes:** ▪ Following a request from an Indigenous patient who wanted to pass away outdoors, the Hospice has modified a beautiful place outdoors with lights and blinds that overlooks the lake so that in future patients who have a similar request can utilize this facility. **Opportunities:** ▪ Build a relationship with Indigenous Medical service to better understand their needs and meet these needs in future workshop delivery

New South Wales (NSW)

Organisational	Programs /Policy	Issues – Barriers/ Successes/Opportunities
Administering Agency: NSW Health **Manager:** ▪ Admin by background ▪ Situated in Royal Prince Hospital, NSW Health ▪ Work full-time ▪ Long-term in the position ▪ Role: o Covers everything (networking, promoting, organizing the workshops and placement, accommodations, registrations, certificate) **Indigenous Project Officer**: ▪ Position vacant at the moment (has taken up a secondment for 5 weeks) ▪ This position has been running since January 2013 ▪ Role: o Organise workshops and placements o Planning and coordinating roles o Advertise and recruit participants **Workshop facilitator:** ▪ non -Indigenous ▪ Role o Under contract to deliver workshops o Nursing background, adult education and Indigenous Health Worker, Aged Care and Disability worker PEPA training since 2003	**Program structure:** ▪ Indigenous component of PEPA has been available as long as PEPA 2 in NSW ▪ PEPA workshops for Indigenous Health Workers, Liaison officers and Community Workers ▪ PEPA placements (2-3 days) for Indigenous Health Workers (IHW) ▪ Workshop on PC approach (basic PC information) ▪ A 'Yarn up' session (targeted for Indigenous Health Workers: more relaxed, engaging, more cross-learning, diverse in terms of topic although all around end-of-life care) may include non-Indigenous health staff working with Indigenous people ▪ Cultural Awareness workshops for non-Indigenous health staff **Objectives:** ▪ To raise awareness about PC approach across all health professionals ▪ To help establish or re-establish connections between generalist health professionals and specialist PC team **Support to participants:** ▪ No structured support after the workshop ▪ After placements, within three weeks, the participants are contacted three times by phone, followed by emails sent to them ▪ Standard letter sent to the participants about administration type things ▪ Participants are encouraged to keep contact with the host sites (information on education day and other relevant information sent to them)	**Enablers:** ▪ Engagement and open communication links with the NSW health and other external links ▪ Communication links with people from various programs and organisations (add them to their distribution list) **Barriers/ Challenges:** ▪ Trouble recruiting for IPO position (applicants not meeting selection criteria: basic organization and computer skills and understanding of PC; applicants only wanting to work part-time with limited hours) ▪ Stigma around death and dying (bad luck) ▪ At times program information may not go to the right person ▪ Time off to attend the workshops and/or to do the placements (participants need to take a day off or take annual/ study leave to attend the workshop) [Examples are given] ▪ Engaging Indigenous providers to participate is challenging. They are enthusiastic but that does not translate into actual registration, "that is hard"] ▪ Line managers may not grant permission ▪ There are only two dedicated Indigenous roles within specialist teams in NSW ▪ No health worker who is a palliative care champion to help promote PC within the Indigenous communities **Opportunities:** ▪ Well-established link with other NSW health organisations and Indigenous programs within NSW ▪ People acknowledging that PC is trying to do the same things as Indigenous community members do (non-

	Feedback: ▪ Standard pre and post evaluation forms used ▪ All evaluation forms are sent directly to PEPA national **Program delivery:** ▪ Placements are allocated within the local PC networks which helps PEPA to develop local network ▪ Educational session is provided by a local PC person/ local PC specialist team to make sure the participants are learning from local perspectives, and also to build up their networks ▪ The content PEPA national has approved is shared with them and given to deliver those workshops [usually a couple of people are responsible] ▪ Workshop is not a prerequisite for placement ▪ Program is promoted through emails, mail outs, face-to-face contacts, word of mouth and by attending workshops, conferences, the IHW steering committees they are invited to attend (staggered information sent to different people at different times) ▪ Include everyone who applies for the workshop and for the placements	clinical level) **Successes:** ▪ Changes have been occurring in terms of information on PC is being spread and PEPA is doing it in a nice way (it's not confronting, and is done in a nice, relaxed atmosphere, and at a pace that people are able to absorb and take in the best out of it) ▪ Some participants (not among Indigenous participant) had acquired further education and have been working as a specialist PC provider ▪ PEPA participants advocate in the community ▪ Within central NSW, the IHWs are contacting the specialist PC services ▪ An IHW is now employed in Oncology – this position came from the work PEPA is involved in. It has become a permanent position

Northern Territory (NT)

Organisational	Programs /Policy	Issues – Barriers/ Successes/Opportunities
Administering Agency: Department of Health, NT **PEPA Manager**(at time of reporting) ▪ Employed by Department of Health, NT ▪ Previously an ALO at the hospital ▪ Commenced as educator for Community Outreach Program prior to taking on the role of manager **PEPA Project Officer/Education Officer** ▪ Employed by Department of Health, NT ▪ Sits within the Palliative Care Unit ▪ Role o Community Outreach Program o Organise and run workshops for all disciplines along with other specialist clinicians o Facilitate workshops o Promote PEPA workshop and placements o Advocate on behalf of Indigenous people about how to deal with their palliative care needs ▪ Previous long term experience in palliative care as the only specialist palliative care IHW in NT ▪ Work well with Palliative Care team and assist with cultural mentoring and development of resources ▪ Assist with culturally appropriate educational material in the Alan Walker Cancer Care Centre and Palliative Care Service ▪ Designed the Northern Territory Indigenous Palliative Care Model (several years previously in IHW role)	**Program structure:** ▪ Community outreach programs are for all disciplines ▪ Program adaptability allows educators to pitch the program to suit the audience ▪ Open discussions and sharing of information ▪ Use of case studies that related to Indigenous patient journeys and way of life at the end of life **Objectives:** ▪ Large Indigenous population so addressing a need ▪ Meet target numbers for workshop and placement participants ▪ Improve referral networks with palliative care service ▪ Enable IHW and other health staff to offer palliative care appropriate to the community in the community **Feedback process:** ▪ Pre and post workshop questionnaires **Program Delivery:** ▪ Flexible and tailored ▪ Palliative care works best in the communities when the whole health team is on board and taking the program out to the communities enables PEPA training to occur across the different disciplines in the remote health centre ▪ Careful consideration of applicants needs prior to placement to ensure needs are met **Participant support:** ▪ Referred to palliative care services for ongoing support ▪ Followed up by PEPA Manager and Educator ▪ Encouraged to join NT network and attend NT Network conferences and meetings	**Barriers** ▪ Limited funding means- time consuming and expensive to visit very remote communities ▪ English is often not the first language and in some communities little or no English is spoken, but several other languages are. ▪ No representation from the Territory on the PEPA Indigenous Reference Group ▪ Some resources are developed elsewhere and need to be adapted for the Territory. Some local resources have been developed when time and funds allow. ▪ Pre and post workshop questionnaires(feedback form) create a problem as many participants do not speak/understand English well enough to understand some of the difficult words and thus creating anxiety among participants ▪ Many participants require assistance with completing the evaluation form due to poor literacy skill and this is time consuming for the educators and causes participants to feel unworthy. ▪ Fragmented Indigenous Health Organisations requiring separate workshops ▪ Follow up is not routine ▪ Lack of understanding of the term “palliative” ▪ Myths around medications used in palliative care e.g. “Morphine makes you finish up early” ▪ Challenges of Indigenous staff employment for PEPA and palliative care services ▪ Recruiting an IHW to either the PEPA Educator role or Palliative Care services is generally difficult

Support: ▪ Great support for PO from direct line manager ▪ Good support from the National team through meetings, teleconferences and Aboriginal and Torres Strait Islander Reference Group *A new manager has been appointed since the initial interview was conducted* ▪ previously with PEPA (2007-2011) ▪ background mental health nursing and health program management ▪ developed the role of Indigenous Health Educator in NT ▪ Plan the activities for the placement participant ▪ Arrange a mentor for the placement participant ▪ Contact the palliative care team to notify each person of their role when participant arrives ▪ Organize and facilitate workshops and Community outreach program		**Successes** ▪ Good mutual support between the Indigenous Project Officer and the Indigenous PEPA Program Manager in NT – strong sense of Indigenous ownership ▪ Well received in the community and improved client support from community staff ▪ All deliverables met - good workshop participation ▪ Adapted resources to better suit needs of the Indigenous Territorians particularly those with language barriers and those living in remote communities ▪ People who have attended the workshops feel more confident and competent when attending to palliative patients within the community ▪ PEPA training enables local staff to advocate more confidently on behalf of patients ▪ NT runs Palliative Care network support meetings in regional centres that PEPA participants can join ▪ Participants are supported to attend annual Palliative Care conference in Darwin/Alice Springs **Enablers** ▪ Good community relationships and networks established prior to PEPA ▪ Take palliative care education out to the communities ▪ Ability to educate all disciplines about palliative care and the Palliative Approach ▪ Both manager and educator are Indigenous with good experience in working with Indigenous people in the Territory (*both subsequently left positions*) ▪ Good management support locally ▪ Regular visits to some communities by palliative care /PEPA team enable follow up with previous participants on an ad hoc basis ▪ NT PEPA staff understand the need for flexibility in

		workshop delivery and arrangements(these may change at the last minute due to death in the community or other cultural issues) **Opportunities** ▪ Include cultural training and awareness around palliative care specifically and not a general cultural awareness training especially when training professionals in the urban areas ▪ Workshops need to flexible to accommodate community needs ▪ Cultural awareness needs to be tailored to suit local needs ▪ Consider audio discussion for follow up evaluation or other forms that would be more accepted ▪ Extend workshops to include community carers and family members caring for people at the end of life

Queensland (QLD)

Organisational	Programs /Policy	Issues – Barriers/ Successes/Opportunities
Administering Agency: Queensland Department of Health **PEPA Manager** (1FTE): (Metro North Hospitals and Health Services) ▪ Non clinical background ▪ Previously involved in advanced care planning and Queensland Health Resuscitation plan. ▪ Has worked in a multidisciplinary team ▪ Role: o Arrange placements and workshops o Assist with workshop facilitation o PEPA promotion o Works across Indigenous and non-Indigenous PEPA o Post placement support as required o Builds links with key person who can communicate directly and offer assistance to the potential participant who resides remotely **Project Officer** (0.5FTE) ▪ In the position for 3 years ▪ Based in Brisbane ▪ Role: o Workshop facilitation and delivery o Pre workshop community visits o Placement support and follow up o Community relationship building ▪ Good community links and relationships ▪ Nursing and pastoral background	**Program structure:** ▪ PEPA workshops for Indigenous Health Workers, Liaison officers and Community Workers ▪ Cultural Awareness/Diversity workshops for non-Indigenous health staff ▪ PEPA placements for Indigenous Health Workers(IHW) ▪ No reverse PEPA program but do Outreach workshops **Objectives:** ▪ Educate non-Indigenous community about the palliative care needs of ATSI people ▪ Educate IHW about palliative care and how to improve community ▪ Increase palliative care access for the community ▪ Reach target numbers for workshops and placements ▪ Promotion of PEPA **Feedback:** ▪ Pre and post evaluation feedback forms same as forms for non-Indigenous participants ▪ Feedback done immediately following workshop ▪ Post placement evaluation forms are sent to participants 3 months after placement completion **Program delivery** ▪ Program delivery flexibly to accommodate participants; delivery style to suit participants ▪ Funding flexibility for very remote participants ▪ Pre workshop community visits to engage and promote PEPA	**Barriers:** ▪ IHW have to organise their own flights and accommodation and this then initially goes through their health service prior to refunding from PEPA ▪ Backfill amount is small and travel costs are limited and may not fully cover participants travel from a very remote area ▪ Community misunderstanding of Palliative Care ▪ No specific feedback form which is more suitable for IHW-some inappropriate and difficult wording especially if English is not first language ▪ Sensitivity of the topic makes it harder for people to go on placements ▪ Lack of support from local managers may impact on the IHW ability to attend placements and/or workshops ▪ Palliative care is not always seen as the core business for IHW who are in high demand any many other areas ▪ Post placement evaluation forms are sent out too long after placement and many are not returned **Enablers:** ▪ Offer backfill for placement participants but this is challenging with IHW ▪ Encourage placements in pairs to enable additional support and security for the participants ▪ Participant flexibility when in communities enables carers to attend workshops ▪ Workshop delivery flexibility to suit the needs of the participants

	Participant support: - Project Officer has more supportive role - Telephone number are given to participants of manager and project officer - Participants are encouraged to come in pairs - Would like to offer more support at time of placement-enabling project officer to remain with participant throughout placement to allow for debrief at the end of the day and be available for queries or concerns	- IPO Officer has good ties with communities and is well respected due to relationships build during previous employment **Suggestions:** - Ability to spend time marketing the concept to the community - Improve placement support – Project Officer to accompany placement participant when placement not in Brisbane - Greater flexibility in workshop delivery e.g. When visiting communities, reduce length of workshop and rather delivery a 2 part workshop. - Ability to spend more time in community to build relationships and better explain PEPA and placement options - Ability to run combined cultural workshops and include Indigenous people to improve understanding and relationships of all health staff - IHW need their own feedback form in order to improve meaningful feedback - Placement participants should have an option for oral feedback - Combined teleconference meetings 6 monthly would enable managers to gain perspective and share ideas from project officers and managers in other states - Improve placement evaluation follow up

South Australia (SA)

Organisational	Programs /Policy	Issues – Barriers/ Successes/Opportunities
Administering Agency: ▪ Palliative Care Council South Australia Inc, a not-for-profit organization, running the program for three years in SA **Manager:** ▪ Chief Executive Officer of the Palliative Care Council South Australia Inc ▪ Role in PEPA Project: o Oversees all PEPA reporting and contractual compliance **Indigenous Project Officer:** ▪ A Enrolled Nurse and Indigenous Health Worker ▪ PCCSA apportioned funds to augment the position enabling it to be full time ▪ Indigenous Project Officer has been well-accepted and is identified as the ‘go to’ person for bicultural information and support ▪ APO has been appointed since April 2013 **Role:** The accountabilities of the project officer include, but are not limited to:- • Liaising and networking with Indigenous health services to promote PEPA • Administration related to PEPA application process • Liaison with and supporting PEPA participants • Ensuring post placement support activities are offered to past participants • Liaising with host sites to ensure that mentors	**Policy:** ▪ Has a policy for bicultural governance ▪ Have a Reconciliation Action Plan ▪ Has an Indigenous Board member **Program structure:** ▪ Commitment to developing an Indigenous PC program as part of the reconciliation action plan Deliver workshop to the IHWs, Allied health workers, Liaison Officer and Community support workers ▪ Placements in selective specialist Palliative Care sites (numbers are pre-negotiated) ▪ Reverse PEPA ▪ Develop Indigenous-specific resources (Palliative Care Council agenda, not specific to PEPA though) ▪ Cultural educational sessions to non-Indigenous people and organisations **Objectives:** ▪ To educate people and to increase their understanding **Support to participants:** ▪ Personal support ▪ Prepare participants for the workshop and placements by informing them about the program expectations and their achievements out of the program activities ▪ Post workshop and post placement support (reimbursement, follow up reminder on update post placement activity, follow up phone calls) **Feedback:** ▪ Information on participants: Name, role, ethnicity, age, where they work, what their learning objective specific to	**Enablers:** ▪ Full-time Indigenous Project Officer (IPO) ▪ IPO has had well-established community links ▪ Good understanding of PEPA program; close working relationship between the IPO and the PEPA Manager ▪ Passionate Indigenous Project Officer ▪ Male co-worker would be great **Opportunities:** ▪ Palliative Care Council is an autonomous, not-for-profit organization that brings flexibility and less bureaucracy in program delivery. ▪ Palliative care was already on this organization’s agenda; so PEPA benefits from that ▪ Palliative Care Council already developed Indigenous-specific palliative care resources and PEPA gets indirect benefit from those resources ▪ Good past and existing relationship with Indigenous Health Councils in the State ▪ A previous PEPA participant champions PEPA in the Indigenous Community ▪ Employing an IPO - an enlightening, welcome experience for the organization and has changed the organization for the better (moving towards achieving cultural safety within the organization) ▪ They appointed a specialist PC nurse who is the educator and who helps facilitate the reverse PEPA and workshops ▪ Interest from the Indigenous community to know more about PC Support provided to IPO: ▪ Staff are treated in fair, transparent, just, dignified

of Indigenous health workers have appropriate experience/training in Cultural Awareness • Networking with PEPA Indigenous Palliative Care Project Officers from other states and territories via bi monthly teleconference and meetings • Review/update/develop resources as required • Assist with facilitation of workshops and other activities as directed • Engage with the PEPA Project Officer on a regular basis to keep up to date with the program deliverables. • Assist Indigenous PEPA participants to understand the requirements and commitment of the PEPA placement in terms of time, placement preparation and evaluation. • Identify other opportunities which would enhance and add value to the PEPA program. • Maintain close liaison, consultation and information exchange between the target audience, the PEPA Project Officer and members of the community.	PC, etc. ▪ National Office collects all evaluation information, and report against them ▪ Standard pre and post (3 months after the placements) evaluation forms used ▪ Prepare 6 months jurisdictional report for the national office **Program delivery:** ▪ Workshop is not a prerequisite for placement	and respectable manner regardless of their heritage ▪ IPO has opportunities for capacity building ▪ Efforts made to make the relationship comfortable for IPO ▪ IPO comfort would benefit if more Indigenous staff were employed within the organization ▪ IPO would like more support and mentoring **Challenges:** ▪ Placements are challenging ▪ Permission for IHWs to be released from their work to do the placements is often a barrier ▪ The enthusiasm and encouragement for placements is not translated into practice ▪ Palliative Care Council SA has not previously employed an Indigenous person, some apparent issues with regard to cultural safety. ▪ Indigenous people tend not to access PC services ▪ Workshop content and clinical language ▪ High staff turnover within the hospitals and health services ▪ ILOs have been challenging to involve in PEPA ▪ IPO experiences some confusion regarding roles and responsibilities **Successes:** ▪ Participants, when they go back, know and consider what shouldn’t be done to a patient (empathetic relationship) ▪ Women’s gathering story (Indigenous elder gathering): They invited the IPO to talk to them about PC and PEPA program and PEPA program presentation was regarded as the only good news story (a solution to the problem/ positive initiative) in their agenda ▪ Hospitals and health services refer patients, families and doctors to IPO who contact her directly for information.

<table>
<tr><th colspan="3">Tasmania (Tas)</th></tr>
<tr><th>Organisational</th><th>Programs /Policy</th><th>Issues – Barriers/ Successes/Opportunities</th></tr>
<tr><td>Administering Agency: Department of Health Tasmania
PEPA Manager (0.8 FTE)
▪ PEPA commenced 2005
▪ First Project Officer for 18 months prior to leaving for 7 years
▪ Current position -12months
▪ Role:
o Reporting
o Funding oversight
o Arrangement of workshops and placements
o Sole person employed in PEPA
▪ 15 years’ experience in Palliative care with nursing background
Indigenous Liaison Consultant:
▪ Role:
o Assists with community engagement
o Advisory
o Accompanies facilitator at workshop
▪ Well respected and well known to communities</td><td>Role
▪ Arranges and runs workshops and placements
▪ 1 workshop and 2 placements per year(for the 3 year funding period)
▪ Workshops tailored to suit target group</td><td>Barriers:
▪ Staff retention-deployed from other positions or given short term contracts
▪ Fragmented Indigenous Health Services requiring separate workshops
▪ Indigenous do not always identify as such
▪ Indigenous Health workers focus more on youth – adolescents and young children
▪ Lack of understanding by Indigenous Health Services about Palliative Care
▪ Small organisations more likely to feel the loss for the week if the IHW is away</td></tr>
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Victoria (Vic)		
Organisational	**Programs /Policy**	**Issues – Barriers/ Successes/Opportunities**
Administering Agency: Department of Health Victoria **Manager:** ▪ *Current manager* commenced 18 months ago (non-Indigenous) ▪ Indigenous PEPA is part of the role as PEPA manager ▪ Role: o Administration o Managers Project officer and workshop facilitator o Workshop preparation o Placement arrangements-matching goals with palliative care services o Budget management o Reporting **Indigenous Project Officer** with VACCHO (Indigenous) works as a consultant to PEPA ▪ Dept. of Health works through VACCHO on a number of programs involving Indigenous people ▪ Role: o Her substantive role within VACCHO is to work on palliative care policy o VACCHO does not receive additional funding for the role but catering and venue are funded o Advocacy and mentorship and cultural facilitation o Workshop and placement promotion, coordination and organisation including catering, study material and administration.	**Program structure:** ▪ PEPA workshops for Indigenous Health Workers, Liaison officers and Community Workers ▪ Cultural Awareness workshops for non-Indigenous health staff ▪ PEPA placements for Indigenous Health Workers (IHW) ▪ Reverse PEPA placements for IHW (specialist sent to community) **Objectives:** ▪ Improve IHW understanding about the Palliative Approach ▪ Improve IHW knowledge of and relationship with local palliative care services ▪ To improve Palliative Care Services understanding of the palliative needs of Indigenous people ▪ Build relationships between main stream palliative care services and Indigenous agencies. **Feedback:** ▪ Standard pre and post evaluation forms used ▪ Participants often require assistance by project officer to complete feedback form **Program delivery:** ▪ Flexible and can be tailored to meet the participants needs ▪ Good content and easily adaptable **Participant support:** ▪ Offered through the Project Officer from VACCHO	**Barriers:** ▪ PEPA Project officer in different organisation ▪ Commitment to work through VACCHO but can be challenging ▪ Material not appropriate as this is focused on rural and remote Indigenous communities and in Victoria many Indigenous people are living in urban areas ▪ Poor ongoing support for workshop and placement participants ▪ Poor uptake of placement opportunities ▪ Poor association with "palliative" and misunderstanding of palliative care ▪ Indigenous Project Officer is not a funded position ▪ No one on one mentorship for Indigenous Health Workers on placement **Enablers:** ▪ Program flexibility ▪ Engagement with peak Indigenous body ▪ Excellent experience and advice from palliative care advocate and mentor in VACCHO **Successes:** ▪ Good community links through VACCHO involvement ▪ Input from Indigenous project officer ensure workshop content is culturally appropriate ▪ Processes in place to ensure cultural security at workshops ▪ Good participant feedback from workshops ▪ Workshops are run in communities ▪ Overall good workshop attendance ▪ Materials adapted by VACCHO to better suit Indigenous Health Workers.

o Deliver cultural safety workshops to non – Indigenous palliative care personnel o Target Indigenous organisations o Advice on Indigenous culture, ensuring at all times a culturally safe environment o Advocates for clinical placements but do not mentor or fund any of the placements-this is the PEPA manager’s role o Will offer additional mentorship to VACCHO members when required **Workshop facilitator** (non -Indigenous) ▪ Role o Under contract to deliver workshops o Nursing background, adult education and Indigenous Health Worker, Aged Care and Disability worker PEPA training since 2003		**Opportunities** ▪ Follow up workshops to focus on more practical ways for IHW to support people in their communities ▪ Expand the program to include carers and other family members ▪ Include some specifically Indigenous targeted materials that would be more appropriate to the Indigenous workforce - having materials that are more culturally specific ▪ Make sure that all policies and procedures within palliative care have a good cultural component to ensure there is change at the clinical level.

Western Australia (WA)

Organisational	Programs /Policy	Issues – Barriers/ Successes/Opportunities
Administering Agency: Cancer Council WA **PEPA manager** (1.0FTE) ▪ Employed through ▪ Program run out of the Palliative Support and Education team ▪ Current manager in PEPA for 2.5 years ▪ Working for Cancer Council for 6 years ▪ No Project Officer employed through PEPA ▪ Use the services of the Cancer Council project officer as required for cultural mentorship who has some ties with the local Indigenous communities ▪ Role: o Manage-PEPA for both Indigenous and non-Indigenous participants o Arrange placements and ensure participant is match with a suitable mentor o Arrange flights and accommodation for placements when required o Arrange and assist in delivery of workshops o Liaise with communities and the Indigenous consultant o Maintain a register of workshop and placement participants **Indigenous Consultant:** ▪ Not employed by PEPA ▪ Employed by Cancer Council WA within a different program area ▪ Offers advice on cultural issues as required	**Programs structure:** ▪ Run workshops in metro and regional areas ▪ Run workshops for IHW, Aged Care Workers, Community and Outreach Workers (have had a social worker on a workshop) ▪ Placement programs ▪ Reverse PEPA placements ▪ Cultural awareness workshops ▪ PEPA workshop and placement promotion ▪ Approximately 2 workshops per year and most participants attend the regional workshops ▪ Run workshops for students at Marr Mooditj Indigenous Training college **Objectives:** ▪ To provide the best possible experience for each Indigenous Health Worker of participant attending a workshop or placement. ▪ Determine a placement site most suited to the participants role and place of work **Feedback/Follow-up:** ▪ Pre and post evaluation form completed immediately after the workshop ▪ Placement follow up 3 months after completion of placement ▪ Follow up phone after placement **Program delivery:** ▪ Participants include IHW, ALO, ACW and Aged Care Workers (have had a Social Worker) ▪ 2 Workshops per year ▪ Placement flexibility- some placements are done in NT	**Barriers:** ▪ Difficult for workshop participants to get time off to take up placement many suggesting that their line managers will not release them ▪ Many Indigenous people do not like to use the palliative and refer to end of life as “finishing up” **Enablers:** ▪ Ability to place IHW in placement regionally such as Broome and Geraldton where there are large number on Indigenous people needing palliative care services ▪ Palliative care services in the regional centers offer great mentorship for IHW doing placement **Successes:** ▪ Placement participants are offered a free palliative workshop offered through cancer Council once they have completed their placement ▪ Some staff from WA request to go to Darwin on placement to gain more Indigenous experience. PEPA is able to accommodate this. ▪ Good workshop participation rate **Opportunities:** ▪ Health service staff participating in workshops have expressed a need for palliative care training within the community ▪ Build relationships with AMS managers directly to encourage them to allow their Indigenous staff to take up placement training ▪ Feedback forms should be tailored to suit the target group ▪ Develop community educational material in language

	where palliative care services see larger numbers of Indigenous clients **Participant support:** ▪ Flights and accommodation arrangements made prior to workshop ▪ Phone call prior to workshop to ensure all materials have been received ▪ Ensure placement participants are linked with a mentor during placements ▪ Telephone follow on final day of placement	about palliative care and the Palliative Approach. ▪ To employ an Indigenous Project officer to assist with relationship building ▪ Add a reflection page in the participant learning guide that could be posted back to the PEPA manager once placements are completed