



*Our team would like to acknowledge the Traditional Owners
of the lands on which we are meeting today*

*We would also like to pay respect to the Elders both past and
present and offer our acknowledgment and respect to other
Aboriginal and Torres Strait Islanders who are present.*



Palliative Care

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Program of Experience in the Palliative Approach State and Territory Managers

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Overview of the Presentation

- Aboriginal and Torres Strait Islander people referred to collectively as Indigenous Australians.
 - Understanding the gap in palliative care provision for Indigenous communities in Australia
 - Supporting the Indigenous Health Workforce to address the gap
 - Lessons learnt from the Program of Experience in the Palliative Approach (PEPA)
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Understanding the Gap

- Age-standardised cancer death rate for Indigenous Australians is 1.2 times that of non-Indigenous Australians
- Between 2008 – 2012, cancer death rates:
 - Increased by 16% for Indigenous Australians
 - Decreased by 10% for non-Indigenous Australians

Australian Institute of Health and Welfare 2015. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples: 2015. Cat. no. IHW 147. Canberra: AIHW.

Understanding the gap

- BEACH survey:
 - Data from 97,800 GP encounters from 978 GPs in 2012-2013
 - Weighted to account for national general practice activity
 - 98,564 weighted encounters indicate that:

Indigenous status	Per cent of total palliative care-related encounters
Indigenous Australians	0%
Non-Indigenous Australians	100%

Britt, H., Miller, G. C., Henderson, J., Bayram, C., Valenti, L., Harrison, C., ... & O'Halloran, J. (2013). *A decade of Australian general practice activity 2003-04 to 2012-13: General practice series no. 34 (Vol. 34)*. Sydney University Press.

Understanding the Gap

Palliative care-related separations 2011-2012 (AIHW, 2014)	
Standardised rate (%) per 10,000 population	
Public hospitals	
Indigenous Australians	34.6
Other Australians	19.5
Private hospitals	
Indigenous Australians	1.4
Other Australians	3.6

Australian Institute of Health and Welfare 2014. Palliative care services in Australia 2014. Cat. no. HWI 128. Canberra: AIHW.

Reconciling the Data

- Late or no referral to palliative care

Sullivan K, Johnston L, Colyer C, Beale J, Willis J, Harrison J et al. *National Indigenous palliative care needs study: Final report*. Canberra, ACT: Department of Health and Ageing, 2003.

- More end-of-life care in acute care settings

Hampton M, Baydala A, Bourassa C, McKay-McNabb K, Placsko C, Goodwill K, et al. Completing the circle: elders speak about end-of-life care with aboriginal families in Canada. *Journal of Palliative Care*. 2010;26(1):6-14.

- Remoteness – low service access

McGrath P, Holewa H. (2007). End-of-life care of Aboriginal peoples in remote locations: Language issues. *Australian Journal of Primary Health*, 13(1):18-27.

Characteristics of palliative care for Australia's Indigenous peoples

- Diverse understandings of death and dying so generalisation inappropriate
- Different perspective of death and dying from non-Indigenous
- Racism, inadequate service access and poverty have affected health
- Palliative care services not well known or understood

Anderson, I., & Devitt, J. Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples. Discussion Paper. The National Palliative Care Program

- Clear barriers within healthcare systems and current healthcare provider practices to carrying out Indigenous cultural practices

Duggleby, W., Kuchera, S., MacLeod, R., Holyoke, P., Scott, T., Holtslander, L.,... & Chambers, T. (2015). Indigenous people's experiences at the end of life. *Palliative and Supportive Care*, 13(06), 1721-1733.

The Indigenous Health Workforce in Palliative Care

- Indigenous patients prefer to talk to Indigenous people who understand their culture (Garvey et al., 2012; Valery et al., 2012)
- Able to navigate a highly sensitive topic (Micklem, 2015)
- Able to facilitate communication between Indigenous and non-Indigenous Australians (Micklem, 2015)

Garvey, G., Beesley, V. L., Janda, M., Jacka, C., Green, A. C., O'Rourke, P., & Valery, P. C. (2012). The development of a supportive care needs assessment tool for Indigenous people with cancer. *BMC Cancer*, 12(1), 300.

Micklem, J. (2015). Self-reported health-related quality-of-life issues for Aboriginal and Torres Strait Islander people with experience of cancer: a review of literature. *International Journal of Evidence-Based Healthcare*, 13(4): 233-53.

Valery PC, Beesley VL, Hawkes AL, et al. (2012). Unmet supportive care needs of Aboriginal and Torres Strait Islander cancer patients in Queensland: preliminary results of a prospective, longitudinal study. *Asia Pacific Journal of Clinical Oncology*, 8(Suppl. 3): 215.

Program of Experience in the Palliative Approach (PEPA)

- Commenced in 2004 to build the capacity of the health workforce to provide palliative
- Specific focus on generalist health care providers
- Aim to enhance knowledge, skills and confidence in the palliative approach through clinical experiences and interactive learning activities

Program of Experience in the Palliative Approach (PEPA): Indigenous Focus

- Indigenous PEPA program commenced in 2007:
 - a) developed in consultation with Indigenous people
 - b) overseen by Indigenous people
 - c) underpinned by a cultural respect framework
- Activities include:
 - clinical placements including self-directed pre and post activities and learning guide
 - 'reverse' PEPA placements
 - workshops for Indigenous health workforce
 - workshops on culture-centred care for non-Indigenous health workforce

Indigenous PEPA resources and photos



Program participation

- January 2007 - Dec 2015.
- 320 placement participants were Indigenous
- 1327 workshop participants were Indigenous

Learnings: Qualitative Study

- Interviews with 46 participants, managers and PEPA staff to identify program elements that facilitated optimal learning experiences

PEPA staff	Workshop/placement participants
Past and present Indigenous Program Coordinators (<i>n</i> = 2)	Non-Indigenous Primary Health Centre Managers (<i>n</i> = 2)
Past and present PEPA Managers (<i>n</i> = 10)	Other managers [Indigenous Health] (<i>n</i> = 2)
PEPA Project Officer (<i>n</i> = 1)	Indigenous Health Workers (<i>n</i> = 16)
Indigenous Project Officers (<i>n</i> = 4)	Non-Indigenous nurse (<i>n</i> = 1)
Indigenous consultants (<i>n</i> = 2)	Non-Indigenous palliative care provider (<i>n</i> = 1)
Facilitator (<i>n</i> = 1)	

Shahid, S., Ekberg, S., Holloway, M., Catherine, J., Yates, P., Garvey, G. & Thompson, S.C. (Under review). Experiential learning and increasing palliative care competence among the Indigenous workforce: An Australian experience

Learnings: Qualitative Study

- Analytic framework – Situated learning theory
 - Content and engagement in authentic activities
 - An authentic and unique practical context
 - Community of practice
 - Assessment of transfer of learning, active participation and post-placement support
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Content and engagement in authentic activities

- Attending meetings
- Accompanying palliative care workers on home visits
- Visiting oncology and radiology units
- Observing patient care

“I think it gives people confidence and permission to realise that it’s normal... palliative care is an accepted ways of treating someone in the right situation, obviously and for them to come in here and look at it being done gives them a lot of confidence and validation about maybe what they were already doing” (IHW, Program participant)

An authentic and unique practical context

- Placement in a clinical palliative care setting
- Real-world occurrences (staff absences and admission changes)
- Services delivering palliative care to Indigenous patients used for placements
- Reverse PEPA placements – Palliative care staff come to Indigenous providers' workplaces

Community of Practice

Two-way: both cultural and practice knowledge important:

1. Practice: participants access experts in palliative care practice
2. Indigenous culture: participants access Indigenous mentor/elder at some sites

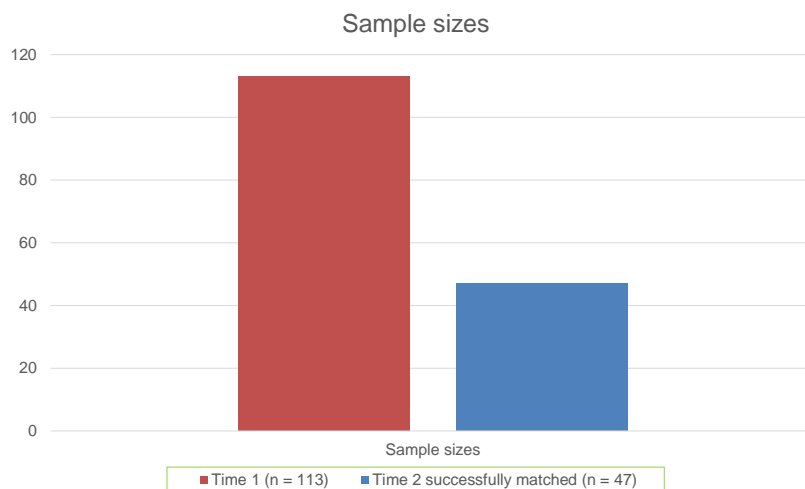
Indigenous doctors or nurses facilitated reflection on clinical and cultural considerations. Allocated Indigenous mentors had an important role in the success of placements:

"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, Program participant)

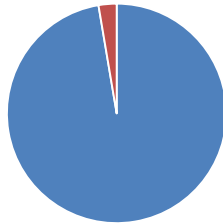
Assessment of transfer of learning, active participation and post-placement support

- Post-placement contact important (newsletters, linkages to local palliative care teams)
- Activities more common and effective when PEPA staff well-connected with local palliative care services
- Post-placement workplace activity sheets
- Free attendance at workshops to network
- Booklets, pamphlets, contact details

Learning: Placement Program Evaluation Data



Population



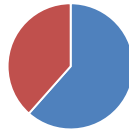
■ Aboriginal (n = 110)
■ Torres Strait Islander (n = 3)

Participant geographical location



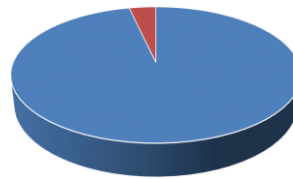
■ Highly accessible/major cities (n = 18)
■ Accessible/inner regional (n = 22)
■ Moderately accessible/outer regional (n = 15)
■ Remote Australia (n = 18)
■ Very Remote Australia (n = 40)

Major participant employment sectors



■ Community (n = 56) ■ Hospital (n = 35)

Placement type



■ Standard (n = 109) ■ Reverse (n = 4)

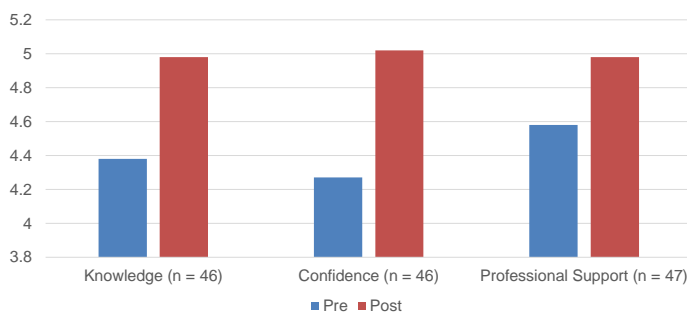
Capability of Adopting a Palliative Approach (CAPA) scale

- 7-point Likert Scale
- Knowledge of palliative care (4 items)
- Confidence of providing palliative care (5 items)
- Professional support for palliative care (4 items)



Inferential Statistics

Variable	T1 M	T2 M	M diff	t	p	Eta sq.
Knowledge	4.38	4.98	0.60	3.67	.001	0.23 (.26 is large)
Confidence	4.27	5.02	0.75	3.72	.001	0.24 (.26 is large)
Professional support	4.58	4.98	0.40	1.71	.093	0.06 (.02 is small, .13 is medium)



Success Factors

- Program activities led and implemented by Indigenous health professionals and community leaders
- Respect for Indigenous cultures and knowledges
- Engagement with Indigenous communication and promotion networks
- Use of culturally appropriate learning activities
 - Activities close to community
 - Learning in groups
 - Story telling and yarning
 - Respect for Indigenous learners
- Support for non-Indigenous health workforce

Future Directions

- Working with managers to develop supportive environments
- Development of resources to support practice
- Development of pathways for ongoing learning for the Indigenous health workforce in palliative care
- Development of culturally appropriate evaluation

Future Directions

- CareSearch Indigenous Hub
 - www.caresearch.com.au
- Advance care planning programs
- Palliative Care Australia Position Statements
- Community engagement and discussions
 - 'tweetchat' 31st March2016