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Executive Summary

In March 2022, the Palliative Care Curriculum for Undergraduates (PCC4U) project launched the Focus Topic Toolkit: <u>Caring for Australian Indigenous peoples affected by life-limiting illness</u>. Purpose built for Australian entry-to-practice health professional students, the resource is available to support all health professionals to develop the knowledge and skills to provide quality care for Australian Indigenous peoples with life-limiting illness, and their families and communities.

Given the history, trauma and current experience of racism in healthcare, it can be difficult for Australian Indigenous peoples to talk about the kind of care they would like as they age or become seriously ill. As a result, most communities are not receiving the best quality of care while they live with life-limiting illness. This can have a profound effect on both the sick person and their family / community's experience of the end-of-life journey.

Nicole Hewlett, Palawa woman from Lutruwita (Tasmania) and National Indigenous Manager for the IPEPA program supported the development of this resource, stating, "Resources are often written about us, without us - which means our voice is lacking along with true knowledge and education. This toolkit has been decolonised and built again from the ground up, on foundations of the sovereign spirit of our people."

The toolkit supports holistic and culturally-responsive care. It has been designed to educate health professionals about the important role they play in breaking down the access barriers to mainstream healthcare, experienced by Australian Indigenous peoples. They are provided with opportunities to reflect on a living and flexible model of service delivery and consider how their practice can support this.

PCC4U is a QUT-led initiative, funded by the Australian Government Department of Health to support development of graduate capabilities in palliative care. The toolkit and all learning resources are available to educators and students at no cost, and accessible via the PCC4U website.

This report provides details regarding the development of the new toolkit resource, learning outcomes, stakeholder engagement, and peer and student review processes and outcomes.

Background

One of the key deliverables for PCC4U in the 2020-2023 phase is: Targeting inclusion of learning experiences in higher education entry to practice courses to prepare the health workforce to provide culturally appropriate palliative care for Aboriginal and Torres Strait Islander peoples.

The PCC4U project team identified that in order to meet this key deliverable more effectively, the current learning resources for this Focus Topic area required redevelopment. It was identified through user feedback that the existing Focus Topic 2 resource was limited in scope and application, was too generalised and that the case scenario "Tom's Story" was inauthentic and not reflective of best practice in culturally-safe and responsive care.

A plan was made to redevelop this Focus Topic into a toolkit of resources to provide a range of learning opportunities and greater breadth of resources. The intention of a *toolkit* of resources being that educators can select from the various learning activities to best meet the needs of their students in relation to this topic area.



About the Toolkit

To provide culturally-responsive care for people affected by life-limiting illness, health professionals need to be able to identify and respond effectively to individual needs. This Toolkit will support entry-to-practice health professional students to develop the knowledge and skills needed to provide quality care, across various settings, for Australian Indigenous peoples with life-limiting illness, and their families and communities.

Learning outcomes

After completing the relevant sections of the focus topic, students will be able to:

- 1. Critically reflect on power, privilege and the institutional place of health services and professionals and how these impact on provision of palliative care for Australian Indigenous peoples. [Section 1]
- 2. Describe traditional kinship systems, and spiritual connections to Country and culture that influence the views that many Australian Indigenous peoples have of health and wellbeing. [Section 2]
- 3. Identify the key features of the United Nations Declaration of the Rights of Indigenous Peoples (UNDRIP) that relate to provision of palliative care for Australian Indigenous peoples. [Section 3]
- 4. Demonstrate an awareness of the historical and ongoing trauma that contributes to the current barriers that prevent Australian Indigenous peoples accessing palliative care services. [Section 4]
- 5. Demonstrate enhanced capability in communicating with and delivering family-centred care to Australian Indigenous peoples affected by life-limiting illness. [Section 5]
- 6. Recognise the cultural considerations associated with end-of-life care, grief and bereavement for Australian Indigenous peoples. [Section 6]

Learning outcomes align with a number of key strategies and frameworks:

- The <u>National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020-</u> 2025, Australian Health Practitioner Regulation Agency (AHPRA)
- o Indigenous Allied Health Australia's (IAHA) <u>Cultural-responsiveness Framework</u> to incorporate knowledge (knowing), self-knowledge and behaviour (being) and action (doing)
- o Aboriginal and Torres Strait Islander Health Curriculum Framework, Department of Health
- o PCC4U Graduate Capabilities in Palliative Care.

Refer to <u>Appendix A</u> for toolkit mapping and alignment. Post-launch, the toolkit learning outcomes have been aligned to cultural safety frameworks (eg, <u>CATSINaM Nursing and Midwifery Health Curriculum Framework</u>) and accreditation standards for individual disciplines / professions. Contact the PCC4U project team for further information regarding this.



Redevelopment timeline and stakeholder engagement

The redevelopment of this learning resource involved a rigorous and consultative process, involving engagement with Australian Indigenous stakeholders, organisational and project partners, educators and students. Feedback was sought at several key stages of development as outlined below:

Timeline	Activity	Stakeholder Engagement	
February - March 2021	Redevelopment plan preparedKey stakeholders identified.	 National Indigenous Manager Indigenous Program of Experience in the Palliative Approach (IPEPA) QUT Carumba Institute - Indigenous research and education 	
April - June 2021	o Proposed learning outcomes developed and mapped to strategic frameworks.	 O QUT Academic Leads - Indigenous Health Indigenous Advisory Group Palliative Care Education and Training Collaborative (PCC4U & PEPA/IPEPA) Palliative Care Australia Yarning Circle 	
July - September 2021	o Development of toolkit content and resources	o National Indigenous Manager IPEPA	
October - November 2021	o Formal peer review process - content and resources	 Indigenous Advisory Group - Palliative Care Education and Training Collaborative (PCC4U & PEPA/IPEPA) Leaders in Indigenous Medical Education (LIME) network Sixteen individual peer reviewers (refer to summary for further details) 	
December 2021	 Revision of content and resources in response to peer reviewer feedback Presentation of content for inclusion in PCC4U website 	 National Indigenous Manager IPEPA National Advisory Group - Palliative Care Education and Training Collaborative (PCC4U & PEPA/IPEPA) Peer reviewer follow up regarding specific questions 	
February 2022	 Formal student review process content and resources Revision based on student reviewer feedback 	o Student reviewers selected in collaboration with PCC4U academic contacts	
March – April 2022	o Official launch of redeveloped toolkit for implementation - 17 March, National Close the Gap Day.	 Communicated through key stakeholder groups, and QUT media release (refer to Appendix B) Educator webinar held on 15 March to introduce those in the PCC4U Educator Community to the new resource and provide support for implementation. Implementation supported by IPEPA, Gwandalan, Australian Indigenous HealthInfoNet, and other National Palliative Care Partners. 	

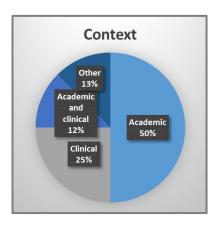


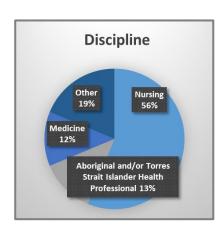
Peer review

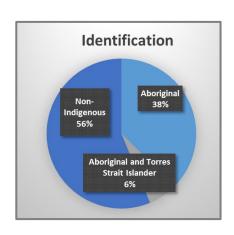
Reviewers from a range of networks and groups were invited to participate in the peer review process. These included, existing PCC4U academic and clinical contacts, PEPA/IPEPA educators, Indigenous Advisory Group for the Palliative Care Education and Training Collaborative (PCC4U & PEPA/IPEPA), and the Leaders in Indigenous Medical Education (LIME) network. An open invitation was also included in the regular PCC4U *eUpdate* newsletter.

Peer review of the toolkit content and resources was undertaken over a six-week period. Reviewers were provided with a complete set of resources and could provide comments on specific aspects of content by adding comments to the document file. They were also asked to provide answers to targeted peer review questions via an online form (see <u>Appendix C</u> for further detail).

Background information was requested regarding the peer reviewer context, discipline and Indigenous identification. This information is summarised in the following images:







Key learnings from peer reviewer feedback

Feedback from peer reviewers was overwhelmingly positive, with many comments regarding the usefulness of the resource, the comprehensiveness of the content, and the value of the resource for entry-to-practice healthcare students. For example,

The video materials

Fantastic document. Really well done, comprehensive and well put together. I can only imagine how much work and collaboration has gone into this. It's fantastic!	were very insightful and value-add to the written content very well. I especially liked the videos used in the communication section - the wrong way to communicate followed by examples of the best way to communicate. This will be a great resource.	The resources are contemporaneous, relevant, and provocative for many students, I expect (which is good - it can elicit deep learning!). This is, in principle, an excellent resource from which I can draw comprehensive and deep information.	The clarity and quality of the writing is excellent. It enables the clear communication of complex and confronting issues, and I am sure will be a great support to educators when using for their teaching. The tone of
Well done on a very high-quality learning resource. I'll certainly be recommending this as an addition to our undergraduate curriculum.	Much more has been provided. Not just a token tick and flick.	The suggested 'thinking points' or activities are achievable and sensible, offering individual or group options to engage.	the entire toolkit is really affirming and encourages people to participate.



The various comments that were made regarding improvements have been summarised here, along with the responses of the PCC4U project team:

	Description	PCC4U Response
Terminology	Clarification regarding use of the terms 'Aboriginal and/or Torres Strait Islander' and 'Australian Indigenous peoples' Use of inclusive language rather than 'othering' language (eg, them/their, definitions of family, use of the term 'loved ones').	 To better acknowledge the cultural diversity within Aboriginal peoples and Torres Strait Islander peoples, the term "Australian Indigenous peoples" was used when referring to as a collective A section on terminology was added to the module introduction to explain the terms used Review of content to improve the inclusivity of language used.
Cultural safety	One non-Indigenous reviewer highlighted that providing information about cultures and specific cultural groups was not in alignment with cultural safety principles. Other Australian Indigenous reviewers valued the information provided on specific aspects of Aboriginal and/or Torres Strait Islander cultures.	Decision made to leave specific cultural information in the content but highlight at each point that intercultural variations and individual preferences should be considered
Trauma- informed practice	Recommendation to include information on trauma-aware, healing-informed practice as an approach to care.	Description added to section on family- centred care and communication
Storytelling	Reviewer comment: "Using narrative as a teaching tool is more than just telling a story - needs to be an element of a morality tale or deeper meaning; and being grounded in your place / Country".	• In collaboration with National Indigenous Manager IPEPA, storytelling relevant to the palliative care context will be explored for inclusion in toolkit resources in the future.
Strengths- based approach	Reviewer comment: "The resource has moved away from a deficit approach but still need to highlight more strengthsbased content - add examples of services / projects with strengths-based approaches".	 Remove statistics highlighting disparity in health outcomes and social disadvantages Focus on current and historical causes of disadvantage and ways to approach care Addition of examples of traditional languages used to refer to palliative care and highlighting services with strength-based approaches to care.



Learner support	Need for educators to provide social and emotional support to students as this content can be provocative and/or triggering for some Encouragement needed for students to ask if unsure, especially asking Aboriginal and/or Torres Strait Islander people what their needs and preferences are for care.	Student support section added to the toolkit overview - 'Promoting a safe and respectful learning experience' with content warning, information about support services, and encouragement to ask if unsure.
National representation	Acknowledgement that the majority of Australian Indigenous peoples live in NSW and Old, and most in towns/cities. The examples and narratives in the toolkit need to be representative to reflect the lived experience of more people.	PCC4U Project Team will continue to look out for video and other resources that reflect the experiences of Australian Indigenous peoples in urban areas and in these states. Resources will be added as available to provide more options, rather than replacing current resources.
Design of learning resource	Suggest addition of reflection / activity log to enable students to document progress and plan application to practice Add timeline and hours to complete each section to support educators in planning Add in captioning for videos and/or transcripts to support.	Additional resources and information added to the toolkit: • Student activity workbook • Estimation of learning hours for each section / activity (post student review) • PCC4U video resources - to include captioning and update of transcripts • Summary of video resources for each activity with aligned thinking points provided to support educator implementation of the toolkit.
Additional resources suggested	Presentations to be used for lectures Resources specific to residential aged care Project / assessment resources to enable students to plan and apply these learnings into practice.	PCC4U project team will review the need for these resources following feedback received through annual academic survey with specific focus on the toolkit resource.

Student review

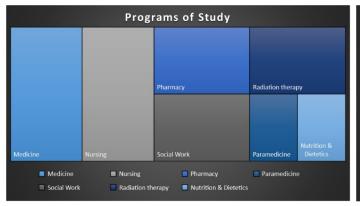
Students from a range of university health programs were invited to participate (via PCC4U academic contacts) in the peer review process. Students who successfully completed the review were offered a gift voucher and a signed record of participation.

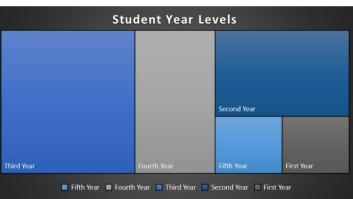
The student review of the toolkit was undertaken over a six-week period. Students were provided with access to the online resources via the PCC4U website as well as print-format document which they could add comments to. For the review, they were asked to provide answers to targeted review questions via an online form (see <u>Appendix D</u> for review questions).

Background information was requested regarding the students' program of study and year level and Australian Indigenous identification. Of the 14 students who participated in the review, 13 were non-Indigenous and one identified as Aboriginal.



Student's program of student and year level information is summarised in the following images:





Key learnings from student reviewer feedback

Feedback from student reviewers was also very positive, with many comments regarding the value of the personal narratives and stories, the comprehensiveness of the resource, and the value of this resource in helping students learn ways to better care for Australian Indigenous peoples. For example,

As an Aboriginal person I found the information provided to be extremely respectful, thorough and safeIt's the truth and it does not fabricate the experiences of Indigenous people.	The content made me reflect quite a bit on my own biases and trying to come up with ways as health professionals that we can improve Indigenous palliative care issues.	The video resources were fantastic and contextualised the learning. The additional resource links were also helpful for further reading on topics I would like to understand in more detail.	This resource answers how to care rather than just telling us about how it is different.
This is the first resource I have seen that actually describes HOW care can be modified to be culturally appropriate	I think all members of society, not just health practitioners, would benefit from undertaking the activities in the section about Trauma, healing and resilience.	A great balance of learning outcomes, from educating students on the history behind Australian Indigenous peoples to integrating this understanding into clinical practise to address life-limiting illness in this population.	Health professionals need to be curious and yarn about 'what the family needs'.
How we handle situations in a palliative care setting have longlasting memories and impacts on the patient's family.	I feelan overwhelming sense of responsibility to become proficient in the factors that affect Australian Indigenous peoples' experience with care for life-limiting illness.	Hearing of physiotherapists, doctors and nurses actively assisting someone in the later stages of their life, return to their country and family really inspired me to get the most out of this toolkit.	Learning more about palliative care sparked my interest in researching places that specialise in Indigenous Australian palliative care.



The various comments that were made regarding improvements have been summarised here, along with the responses of the PCC4U project team:

	Description	PCC4U Response
Technical	 Add text to speech function for webpages to allow students to listen to the content Add transcripts of video links Embedding images and diagrams rather than PDF Reduce text-based content Increase interactivity by adding response/text boxes, games/quizzes Thinking points before/with the videos 	 Where possible, these have been actioned. Limitations with website design meant that the suggestions regarding interactivity and embedding diagrams were not possible. Feedback will be sought from educators who have implemented the toolkit resources and ideas / tools that have been used will be shared through the PCC4U Educator Community Hub.
Content	 More scenarios for communication Clarify links for Section 3 - how is UNDRIP linked to palliative care Add comment about why the toolkit starts with power/privilege/racism rather than starting with info about Australian Indigenous cultures Add summaries of the key resources - "what to look for in this resource" to reduce information overload Add a resource to go with Activity 13 on communication so students can print/take on placement Add in stories from Aboriginal Health Workers and/or interviews with family members Add interviews with different health practitioners (eg, pharmacist, doctor, nurse, OT, social work etc) to show how their role impacts on care of the patient. 	 Where possible, these suggestions have been actioned through adding text to website, adding downloadable / printable resources, and including additional simulation suggestions for communication activities. Further development of video resources will be considered by the PCC4U team following implementation feedback.

Implementation

The toolkit resource was officially launched on 17 March 2022, in acknowledgement of *National Close the Gap Day*. A media release was issued, and key project partners were provided with a communications toolkit to support clear communication regarding the toolkit resource and its implementation (refer to <u>Appendix B</u>).

Ongoing feedback regarding the resource and its implementation will be gained through established curriculum review processes and the annual PCC4U academic survey process, undertaken in November each year.



Summary

This report provides an overview of the process involved in the redevelopment of this PCC4U Focus Topic resource. This involved a rigorous and consultative process, involving engagement with Australian Indigenous stakeholders, organisational and project partners, educators and students. The information gained through stakeholder engagement and review processes was used to inform the development of the resource at various stages, as described in this report.

As project partner, Nicole Hewlett (IPEPA) stated in supporting the toolkit launch "Resources are often written about us, without us - which means our voice is lacking along with true knowledge and education. This toolkit has been decolonised and built again from the ground up, on foundations of the sovereign spirit of our people." Ongoing liaison with key Indigenous stakeholders and PCC4U educators using the resource will continue to inform implementation improvements, and additions to this toolkit resource.

Appendices:

Appendix A: Learning outcome mapping and alignment

Learnir	Learning Outcome: Mapping and alignment				
Section / Time	National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020-2025	IAHA framework	Aboriginal and Torres Strait Islander health curriculum framework	Graduate capabilities in palliative care	
1 30 min	Acknowledge and address individual racism, their own biases, assumptions, stereotypes and prejudices and provide care that is holistic, free of bias and racism.	Knowing	Reflect: Cultural self and healthcare, Racism, White privilege	2, 4	
2 60 min	Acknowledge colonisation and systemic racism, social, cultural, behavioural and economic factors which impact individual and community health.	Knowing	Respect: Cultural knowledge, Diversity, Humility and lifelong learning	2, 3	
3 60 min	Recognise the importance of self- determined decision-making, partnership and collaboration in healthcare which is driven by the individual, family and community.	Knowing	Respect: Historical context Advocate: Equity and human rights	2, 4	

Learnir	Learning Outcome: Mapping and alignment				
Section / Time	National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020-2025	IAHA framework	Aboriginal and Torres Strait Islander health curriculum framework	Graduate capabilities in palliative care	
4 60 min	Acknowledge colonisation and systemic racism, social, cultural, behavioural and economic factors which impact individual and community health	Being	Respect: Historical context Quality and Safety: Population health Reflect: Cultural self and healthcare, Racism	2, 3	
5 60 min	Foster a safe working environment through leadership to support the rights and dignity of Aboriginal and Torres Strait Islander people and colleagues	Doing	Communicate: Culturally safe communication Quality and safety: Clinical presentation Reflect: Cultural self and healthcare	1, 2, 3	
6 60 min	Foster a safe working environment through leadership to support the rights and dignity of Aboriginal and Torres Strait Islander people and colleagues	Doing	Respect: Cultural knowledge, Diversity, Humility and lifelong learning Advocate: Equity and human rights	1, 2, 3	

Appendix B: Communications log - PCC4U Focus Topic 2 Toolkit Launch

17 Mar 2022	QUT media brief to promote FT2 launch	NIRS (Part 2, 1:03) - https://nirs.org.au/news/weekly-news-in-review-news/weekly-news-in-review-march-18-2022/ Mirage News - https://www.miragenews.com/providing-culturally-responsive-palliative-care-744954/ NACCHO Aboriginal Health News Alerts - https://nacchocommunique.com/2022/04/01/naccho-aboriginal-torres-strait-islander-health-news-fri-1-4-22/ https://nacchocommunique.com/category/palliative-care/
12 Apr 2022	CPCRE Centre Online eNews	FW CPCRE Centre Online eNews April 2022.pdf
21 Apr 2022	LIME Newsletter April	https://mailchi.mp/f7a1b476da4c/lime-network-newsletter- 5131901?e=02e57aa1fb



Appendix C: Peer review questions

In addition to the questions relating to background information, peer reviewers had the opportunity to provide information in response to the following questions:

1. Content Review Questions

- O Do the learning outcomes outlined in each section reflect the capabilities that you aim to develop in your entry-to-practice students? If not, please provide additional information or suggestions for improvement.
- o Do the learning outcomes, content and approach align with the Aboriginal and Torres Strait Islander Health Curriculum Framework (2014)?
- o Do the content areas included in the toolkit reflect the key areas required to support the development of palliative care capabilities for your discipline / professional group at an entry-to-practice level? If not, please provide additional information or suggestions for improvement.
- o Do the resources referred to in the toolkit (ie, further reading, videos, website links, etc.) add to and enhance the learning experience? If not, please provide additional information or suggestions for improvement.
- Are the 'thinking points' or prompts for students to engage in personal reflection or learning activities relevant to the content and appropriate for entry-to-practice level students? If not, please provide additional information or suggestions for improvement.

2. Learning and Teaching Review Questions

- o Will this toolkit add to existing learning and teaching resources in this area? If not, please provide additional information or suggestions for improvement.
- o How would you use this resource in your education context?
- o Do the learning and teaching approaches used in this toolkit appropriately reflect Indigenous ways of knowing, being and doing? If not, please provide additional information or suggestions for improvement.
- o What other approaches would enhance the learning experience for your students?
- o Any additional comments

Appendix D: Student review questions

In addition to the questions relating to background information, student reviewers had the opportunity to provide information in response to the following questions:

1. Learning Outcomes

- For each section learning outcome, students could rate on a 5-point Likert scale 'Greatly, Moderately, Somewhat, Not at all, Not sure'
- o How well did the toolkit content, resources and thinking points help you to develop the learning outcomes?
- o Indicate how long it took you to complete each of the toolkit sections
- Any additional comments.

2. Learning Experiences

o For each type of learning experience, students could rate on a 5-point Likert scale - 'Greatly, Moderately, Somewhat, Not at all, Not sure'



- Content presentation reference-based text information
- Content presentation images and diagrams
- Embedded video resources
- Key resource links videos, websites, journal articles
- Thinking points.
- o Any additional comments regarding the toolkit learning experiences

3. Your Opinions and Experiences

- o What are the strengths of this resource?
- o Thinking about the resource as a whole, if you could keep one thing that had the greatest impact on your learning, what would that be?
- o Thinking about the resource as a whole, if you could change or add one thing that had the greatest impact on your learning, what would that be?
- o We're curious about the experiences you had in undertaking this learning. Did anything come up for you when you reviewed this resource? (eg, a story, image, feeling etc)
- o Did you find the content to be triggering? If 'Yes', please outline which aspects, and any suggestions you have for ways to best support students using this resource.
- o If you identify as an Australian Indigenous person, would you recommend this resource to your fellow students who are non-Indigenous? Why or why not?
- o Any final comments you would like to make about the Toolkit?