

# Building capacity in those who deliver palliative care services to Aboriginal and Torres Strait Islander peoples

Tina Janamian<sup>1,2</sup>, Paresh Dawda<sup>3,4</sup>, Gregory Crawford<sup>5,6</sup>, Angelene True<sup>3</sup>, Melanie Wentzel<sup>1</sup>, Donald Whaleboat<sup>7</sup>, Tamieka Fraser<sup>8</sup>, Christopher Edwards<sup>8</sup>

**P**alliative care is holistic care that supports people who are facing life-limiting non-curable conditions to live as well as possible, and is broader than end-of-life care.<sup>1</sup> “Good” palliative care requires an integrated approach in a multidisciplinary team environment involving numerous care providers across the health system.<sup>2-4</sup> It is a person-centred, whole-of-person approach and considers the emotional, psychological, spiritual and social aspects of care, which are deeply linked to a person’s cultural identity.<sup>1,5,6</sup>

Most adults in need of palliative care have chronic diseases.<sup>7</sup> Australia faces the challenges of a rapidly growing ageing population that includes Aboriginal and Torres Strait Islander peoples, 19% of whom self-report their health as poor and 20% of whom will be aged over 50 years by 2031.<sup>8</sup> People in this population are significantly more likely than other Australians to experience life-limiting illnesses, including complex, chronic conditions. For example, 35% of older Indigenous Australians are living with diabetes or high blood sugar levels.<sup>8,9</sup>

The role of culture in palliative care for Aboriginal and Torres Strait Islander peoples builds on over 60 000 years of history and includes practices to support a good “finishing up”. Including cultural practice is a key challenge for contemporary health care and a lack of suitable resources is well documented.<sup>6,9,10</sup>

Evidence suggests that Aboriginal and Torres Strait Islander peoples face barriers to these services owing to a lack of awareness of service availability, difficulty accessing culturally trained health professionals, and fear influenced by a history of health service inequality.<sup>11</sup> Aboriginal and Torres Strait Islander peoples, clinicians and academics have consistently identified the need for better and more culturally relevant palliative care services.<sup>11-13</sup> Despite Aboriginal and Torres Strait Islander health workers and practitioners being well placed to act as a cultural connection, they remain under-represented in specialist palliative care settings, and many require further education and training in end-of-life care.<sup>13</sup>

The Gwandalan National Palliative Care Project (NPCP), an initiative of Australian General Practice Accreditation Limited (AGPAL) and Palliative Care South Australia (funded by the Australian Government under the Public Health and Chronic Disease Care Grant, National Palliative Care Projects 2020–2023) addresses these concerns using value co-creation and user-centred design. The aim is being achieved by providing capacity-building education and training to those who deliver palliative care services to Aboriginal and Torres Strait Islander peoples in a range of settings (Box 1).

## Summary

- The role of culture in palliative care for Aboriginal and Torres Strait Islander peoples builds on over 60 000 years of history and includes meaningful practices to support a good “finishing up”.
- The Gwandalan National Palliative Care Project aims to build capacity in those who deliver palliative care to embed culturally responsive care in all end-of-life settings.
- Community consultation, value co-creation and user-centred design ensured that diverse Aboriginal and Torres Strait Islander perspectives informed the Gwandalan curriculum.
- Emerging communities of practice serve as yarnning circles where barriers to and enablers of service delivery can be shared and addressed collaboratively.

## Addressing the gaps in palliative care services for Aboriginal and Torres Strait Islander peoples

A scoping review conducted by AGPAL, including publicly available resources (grey literature) and peer-reviewed publications (black literature) published between 2010 and 2021 explored the evidence of gaps in palliative care for Aboriginal and Torres Strait Islander peoples. Search terms used for the review are provided online ([Supporting Information](#), table 1).<sup>14</sup>

The grey literature search identified 324 educational resources, toolkits and government reports. Application of robust inclusion criteria and a review process reduced this to 42 resources for inclusion ([Supporting Information](#), table 2). The search of black literature identified 563 publications, of which 24 met the inclusion criteria and were selected for data extraction and synthesis ([Supporting Information](#), table 3). After screening for eligibility, AGPAL further assessed each resource that met the inclusion criteria to establish an overall theme. Eight key themes emerged from the literature, and these are shown in [Box 2](#).

Most of the reviewed literature indicated an overall lack of resources on Aboriginal peoples’ cultural practices during palliative care and at the end of life, such as the dreaming world view, kinship systems, ceremonial business and responsibilities, the use of bush medicine and the impact of intergenerational trauma associated with death and dying. The literature review also identified a lack of resources about Torres Strait Islander peoples’ beliefs and culture, such as the importance of water, the creation stories of Tagai and how the Tagai constellation informs culture and community, and the role of the Marigeth in the western islands. Of the eight key themes identified in this review, the most noteworthy were those relating to barriers and enablers to access (Theme 1), the role of culture (Theme 2) and communication (Theme 8) ([Box 2](#)). The Gwandalan

<sup>1</sup>Client Focused Evaluation Program Surveys, Brisbane, QLD. <sup>2</sup>University of Queensland, Brisbane, QLD. <sup>3</sup>Prestantia Health, Canberra, ACT. <sup>4</sup>University of Canberra, Canberra, ACT. <sup>5</sup>University of Adelaide, Adelaide, SA. <sup>6</sup>Northern Adelaide Local Health Network, Adelaide, SA. <sup>7</sup>James Cook University, Townsville, QLD. <sup>8</sup>Australian General Practice Accreditation Limited, Brisbane, QLD. [✉ tina.janamian@cfepreviews.com.au](mailto:tina.janamian@cfepreviews.com.au) • doi:10.5694/mja2.51528

## 1 Overview of the Gwandalan National Palliative Care Project (NPCP)

### Project aim

Strengthen relationships between frontline staff and Aboriginal and Torres Strait Islander peoples to increase both access to and the quality of palliative care service delivery

### End users

A network of **Indigenous and non-Indigenous frontline staff** who deliver palliative care to Aboriginal and Torres Strait Islander peoples in any setting

### Key cultural and communication topics

- Introduction to Aboriginal and Torres Strait Islander palliative care and cultural practice
- Safe communication
- Supporting choices at end of life
- Strengthening partnerships
- Community engagement

### Co-created deliverables

- Deliverables were co-designed for flexible use, enabling learners to co-create value in their own communities and organisations
- Fifteen interactive microlearning modules
- 'Dillybag' of 150+ digital learning resources
- In-person train-the-trainer workshops
- Digital workshops and webinars
- 'Yaama' quarterly newsletter
- Ongoing engagement platforms, within and between the Gwandalan NPCP network of stakeholders and end users

### Project outcomes

- **Improve the quality of palliative care** for Aboriginal and Torres Strait Islander peoples **by building capacity in frontline staff** to deliver care that is **culturally relevant and safe**
- **Promote access to and uptake of palliative care services** by Aboriginal and Torres Strait Islander peoples through **improved community awareness and understanding** of palliative care, **by building capacity in frontline staff** to share knowledge around palliative care services
- **Support more choice** during palliative care for Aboriginal and Torres Strait Islander peoples through the sharing of knowledge by frontline staff, **to increase uptake of advance care planning**
- **Support the delivery of coordinated, culturally relevant and safe palliative care** for Aboriginal and Torres Strait Islander peoples **across community and acute care settings**

NPCP advisory committee and the content development and review working groups used the literature review findings to design the Gwandalan curriculum.

### Value co-creation and user-centred design to inform a community engagement strategy

A combination of value co-creation and user-centred design approaches put the end user at the centre of design processes and helped engage them from the beginning and throughout the journey to co-create products and services.<sup>15-18</sup> These flexible and systematic approaches brought together trainers, subject matters experts, stakeholders and end users through iterative facilitated interactions and processes to co-create and co-deliver fit-for-purpose education and training.<sup>19</sup> Details regarding the different engagement platforms that were implemented to co-create the Gwandalan NPCP, steps used to co-create the project's education and training suite, and the key and jurisdictional stakeholders identified in the project's communication and engagement strategy are provided online ([Supporting Information](#), table 4, table 5 and table 6, respectively).

Central to the Gwandalan NPCP are the project's advisory committee members and its subject matter experts in academic and clinical fields (including Aboriginal and Torres Strait Islander health, palliative care and policy development). Committee members add invaluable knowledge and raise awareness of any issues that might hamper engagement or communication with stakeholders, communities or Elders. They also promote the project among existing networks, suggest appropriate avenues for promotion, and provide the project team with contacts and

introductions to communities and other contacts. In line with value co-creation and user-centred design methods, the advisory committee represents Aboriginal and Torres Strait Islander peoples, academic and health professionals, palliative care general practitioners and specialists, peak body organisations, and AGPAL and Palliative Care South Australia.

The Gwandalan NPCP has a robust communication and engagement strategy which ensures that culturally safe and responsive protocols are observed across all engagement platforms and project deliverables. The strategy guides the project team in planning and executing effective community engagement strategies to achieve the project aim and objectives. Strategy implementation includes collaborating with organisations that have existing active engagement in Indigenous health and palliative care settings to co-create resources, workshops and community engagement events.

Various principles and considerations are accounted for when co-designing engagement and communication protocols, including respect for Aboriginal and Torres Strait Islander cultures, informed consent for sharing knowledge with Elders and consumers, building trust and working collaboratively with communities, developing and delivering feasible engagement and communications, applying learnings, and ensuring overarching cultural respect.

The project team worked with the Gwandalan NPCP advisory committee to identify in the communication and engagement strategy the jurisdictional stakeholders that deliver services relevant to the Gwandalan NPCP ([Supporting Information](#), table 6). Identifying key stakeholders means that the project

2 Description of key themes identified in the Gwandalan National Palliative Care Project literature review

<b>Primary theme</b> (Number of black literatures found, number of grey literatures found)	<b>Description</b>
<b>Theme 1:</b> Barriers and enablers to high quality palliative care services (9,3)	Any number of factors may limit or assist access to and quality of palliative care services for Aboriginal and Torres Strait Islander peoples. These include: (i) lack of knowledge and understanding around palliative care, (ii) rural and remote regions, (iii) cultural barriers, and (iv) delay in receiving palliative care.
<b>Theme 2:</b> The role of culture in palliative care for Aboriginal and Torres Strait Islander peoples (6,6)	Culture considers all ideas, customs and social behaviour of Aboriginal and Torres Strait Islander peoples which may play a role in end-of-life care.
<b>Theme 3:</b> Models of care for delivering effective and culturally appropriate palliative care (5,7)	A model of care broadly describes the method by which a health service is delivered. In this instance, a model of care describes an innovative and culturally appropriate way of delivering palliative care to Aboriginal and Torres Strait Islander peoples.
<b>Theme 4:</b> The palliative care workforce (4,6)	Workforce refers to any aspect of the health and community workforce that may play a role in delivering palliative care services to Aboriginal and Torres Strait Islander peoples.
<b>Theme 5:</b> Advance care planning and the Aboriginal health worker or health practitioner (3,4)	Advance care planning refers to planning for an individual's future end-of-life care. This theme also emphasises the significant role of the Aboriginal health worker or health practitioner in engaging with and promoting services to Aboriginal and Torres Strait Islander communities.
<b>Theme 6:</b> The knowledge gaps or efforts to increase knowledge in palliative care for Aboriginal and Torres Strait Islander peoples (3,7)	A knowledge gap refers to an area within the peer-reviewed research that has not been explored or is underexplored. Within grey literature, knowledge refers to sources that aim to provide the intended audience with information about palliative care for Aboriginal and Torres Strait Islander peoples.
<b>Theme 7:</b> Children and young people of Aboriginal and/or Torres Strait Islander descent (1,1)	This theme refers to information that is directly relevant to the palliative care of children and young people of Aboriginal and/or Torres Strait Islander descent.
<b>Theme 8:</b> Culturally appropriate communication (0,9)	Communication is fundamentally necessary for health professionals and their patients undergoing care. The literature about palliative care for Aboriginal and Torres Strait Islander peoples emphasises: (i) culturally appropriate communication in healthcare, (ii) appropriate language and behaviours, (iii) principles for staff to engage with Aboriginal and Torres Strait Islander peoples, (iv) communication of choices, and (v) effective and appropriate engagement.

can reach a national audience, and that it can be effectively and meaningfully promoted and delivered to Aboriginal and Torres Strait Islander palliative care audiences for whom ongoing value can be created.

**Co-created deliverables**

A series of resources released throughout 2021 and 2022, and ongoing engagement platforms, were co-designed to be used in a flexible

manner. They enable learners, and those who would co-create value in their own communities and organisations by extending the training forward, to select those topics and training modalities relevant to their context. One of the main platforms is a set of 15 interactive microlearning modules on an informative and easy-to-navigate e-learning platform; the modules are 15 minutes long, they feature animation, video, images and voiceovers (in English and traditional language), and they invite learners to respond to stimuli and complete onscreen activities as they progress through the curriculum. Another key resource is a digital dillybag of tools and resources to support implementation; this is a highly useful curation of more than 150 existing and newly developed resources designed for use at the frontline of Aboriginal and Torres Strait Islander palliative care, including fact sheets, booklets, conversation starter cards, animations, advance care planning documents, videos and checklists. Other deliverables and ongoing engagement platforms include:

- in-person train-the-trainer workshops;
- digital workshops and webinars;
- *Yaama* — a quarterly newsletter;
- delivery networks led by regional champions; and
- ongoing engagement platforms within and between the Gwandalan NPCP network of stakeholders and end users.

## Targeting strategies to reach end users

To maximise the learner audience, and ensure education and training material can be accessed and implemented across the geographic and cultural diversity of Aboriginal and Torres Strait Islander communities, the Gwandalan NPCP consulted on, co-designed and implemented reach strategies addressing known barriers to uptake:

- in-person reach — workshops and community events in a range of metropolitan, regional, rural and remote locations;
- digital reach — a user-friendly and free digital e-learning platform on which all resources are housed;
- physical reach — hard copy resources available for distribution to services and communities with limited access to technology; and
- temporal reach — capturing the intangible capacity built in for end users throughout the project.

Using this model, we expect lessons, knowledge and practices will be spread throughout respective communities, supporting an even wider and more diverse national audience over time — a viral spread of “win more–win more” value co-creation.<sup>19</sup> Ongoing feedback and evaluation mechanisms continue throughout the project lifespan, informing continual quality improvement and ensuring a culturally responsive approach to project deliverables and implementation. These include the collection of both qualitative and quantitative data through formal and informal feedback, the collation and synthesis of data, action planning for improvement, and ensuring that improvements are reflected in the content and delivery of resources and well communicated to those engaged with the project.

Other engagement, promotional and distribution strategies captured in the community engagement strategy (which were informed by individuals and organisations working in palliative care or with

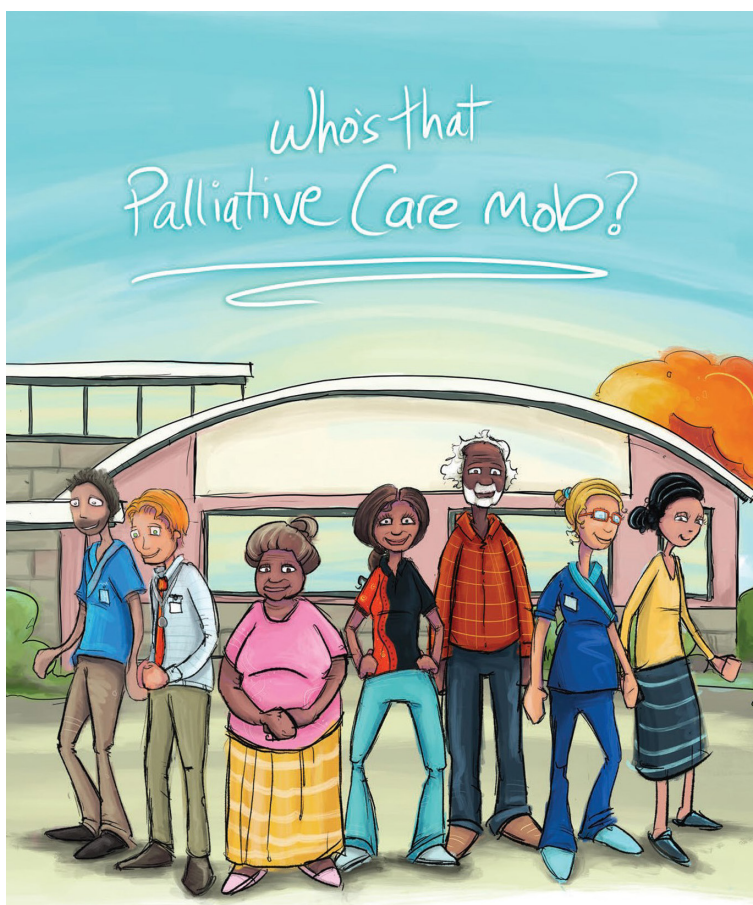
Aboriginal and Torres Strait Islander peoples, Aboriginal Community Controlled Health Organisations, peak bodies and government departments at all levels) include:

- leverage — leveraging primary health centres and Aboriginal medical services to distribute promotional and project material;
- relationships — using existing relationships between AGPAL and Palliative Care South Australia (eg, AGPAL’s extensive network of 31 Primary Health Networks, and Palliative Care South Australia’s links with Aboriginal Community Controlled Health Organisations and palliative care associations nationally); and
- networks — strategically recruiting training participants and reaching an expansive network, so that promotional materials and notifications are sent through appropriate avenues.

## Developing networks to ensure adaptable resources respond to local need

The project team consulted with relevant stakeholders to engage appropriate local teams of champions, comprising Indigenous and non-Indigenous members of the health workforce who could

3 Image from *Who’s that palliative care mob?* — a Gwandalan National Palliative Care Project training resource



### Cultural sensitivity warning

Aboriginal and Torres Strait Islander peoples should be aware that this resource contains materials of a sensitive nature and discusses finishing up, Sorry Business and Sad News.

facilitate and deliver Gwandalan workshops and yarning circles in their region. This localised approach, whereby the Gwandalan curriculum and resources are adapted to local context, cultural practice and engagement protocols, is strengthening partnerships (a key project aim). It is also in line with responsive community engagement that is respectful of culture and customs of the local nation. For example, a Bundjalung facilitator (and their non-Indigenous counterpart) would deliver training on Bundjalung Country, creating ongoing value and supporting deep engagement in this region. In addition, diverse visual and audio representations of Aboriginal and Torres Strait Islander people and communities were carefully and respectfully included in the resources. An example is provided in Box 3.

## Conclusion

The importance of reducing health inequity for Aboriginal and Torres Strait Islander peoples, and the complexity of factors contributing to gaps in service provision, cannot be overstated. The Gwandalan NPCP places Aboriginal and Torres Strait Islander peoples, families and communities at the centre of program design. It actively engages diverse co-creation champions to collaboratively co-design fit-for-purpose resources to build capacity in the contemporary Australian health care workforce, with a view to reducing health inequity for Aboriginal and Torres Strait Islander peoples.

By co-designing resources that are culturally safe and flexible, and respond to a diverse and far-reaching audience, the Gwandalan NPCP co-creates value for all frontline workers delivering palliative and end-of-life care (and others working with Aboriginal and Torres Strait Islander peoples in a range of settings). The Gwandalan NPCP contributes a practical and engaging curriculum, and resources that will continue to emerge and evolve as value spreads across the sector when each new health service, community, academic, clinician, student or other person engages with, responds to and shares the resources (freely available at [www.gwandalanpalliativecare.com.au](http://www.gwandalanpalliativecare.com.au)).

The project intends that continually emerging communities of practice between Indigenous and non-Indigenous frontline staff, within and between care teams and broader organisations, will serve as yarning circles, where barriers to and enablers of culturally responsive palliative and end-of-life care will be shared and addressed collaboratively using a strengths-based approach. The goal is that Indigenous palliative care patients, their families and their communities, as well as frontline staff and their own networks, will all “win more–win more” as relationships are strengthened and capacity is continually built for sustained and accumulative effect.

**Acknowledgements:** The Gwandalan National Palliative Care Project is supported by funding from the Australian Government under the Public Health and Chronic Disease Care Grant, National Palliative Care Projects 2020–2023. We acknowledge the Traditional Custodians of the land on which we live and work and recognise the continuing connection to land, waters and culture. We pay our respects to Elders, past, present and emerging, and acknowledge Elders as the holders of knowledge, lore and wisdom. We acknowledge the following key stakeholders for their support in making this project a success: our partner organisation Palliative Care South Australia; Darkinjung Local Aboriginal Land Council; Palliative Care Australia; and Indigenous Program of Experience in the Palliative Approach. We acknowledge the contribution, guidance and support of the Gwandalan National Palliative Care Project Advisory Committee in the co-creation of educational resources. We acknowledge Eliza Munro, the Indigenous Project Coordinator, for her passion and invaluable contribution to the project and in engaging with Aboriginal and Torres Strait Islander communities nationally and other key stakeholders. We also acknowledge the immense contribution of the members of the Gwandalan Project content development and review working groups who guided the co-creation of the suite of educational resources to ensure they were culturally safe and responsive for Aboriginal and Torres Strait Islander communities nationally.

**Open access:** Open access publishing facilitated by The University of Queensland, as part of the Wiley - The University of Queensland agreement via the Council of Australian University Librarians.

**Competing interests:** No relevant disclosures.

**Provenance:** Commissioned; externally peer reviewed. ■

© 2022 The Authors. *Medical Journal of Australia* published by John Wiley & Sons Australia, Ltd on behalf of AMPCo Pty Ltd.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

- 1 Australian Government Department of Health. National Palliative Care Strategy 2018. Canberra: Department of Health, 2019. <https://www.health.gov.au/sites/default/files/the-national-palliative-care-strategy-2018-national-palliative-care-strategy-2018.pdf> (viewed Apr 2022).
- 2 Palliative Care Australia. What is palliative care? Canberra: PCA, 2020. <https://palliativecare.org.au/what-is-palliative-care> (viewed Apr 2022).
- 3 Gómez-Batiste X, Murray SA, Thomas K, et al. Comprehensive and integrated palliative care for people with advanced chronic conditions: an update from several European initiatives and recommendations for policy. *J Pain Symptom Manage* 2017; 53: 509–517.
- 4 den Herder-van der Eerden M, van Wijngaarden J, Payne S, et al. Integrated palliative care is about professional networking rather than standardisation of care: a qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries. *Palliat Med* 2018; 32: 1091–1102.
- 5 Health Foundation. Person-centred care made simple: what everyone should know about person-centred care. London: Health Foundation, 2016. <https://www.health.org.uk/publications/person-centred-care-made-simple> (viewed Apr 2022).
- 6 National Palliative Care Program. Providing culturally appropriate palliative care to Indigenous Australians. Canberra: Australian Government Department of Health and Ageing, 2004. <https://healthinfonet.ecu.edu.au/key-resources/resources/15232/?title=Providing+culturally+appropriate+palliative+care+to+Indigenous+Australians> (viewed Apr 2022).
- 7 World Health Organization. Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers. Geneva: WHO, 2018.
- 8 Australian Institute of Health and Welfare. Older Australians (AIHW Cat. No. AGE 87). Canberra: AIHW, 2021. <https://www.aihw.gov.au/reports/older-people/older-australians/contents/about> (viewed Apr 2022).
- 9 Shahid S, Bessarab D, van Schaik KD, et al. Improving palliative care outcomes for Aboriginal Australians: service providers' perspectives. *BMC Palliat Care* 2013; 12: 26.
- 10 Indigenous Program of Experience in the Palliative Approach Project Team. Cultural considerations: providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples. Brisbane: Queensland University of Technology, 2020. [https://pepaeducation.com/wp-content/uploads/2020/12/PEPA\\_CulturalConsiderationsFlipbook\\_Web.pdf](https://pepaeducation.com/wp-content/uploads/2020/12/PEPA_CulturalConsiderationsFlipbook_Web.pdf) (viewed Apr 2022).
- 11 O'Brien AP, Bloomer MJ, McGrath P, et al. Considering Aboriginal palliative care models: the challenges for mainstream services. *Rural Remote Health* 2013; 13: 2339.
- 12 McGrath P. The living model: an Australian model for Aboriginal palliative care service delivery with international implications. *J Palliat Care* 2010; 26: 59–64.
- 13 Shahid S, Ekberg S, Holloway M, et al. Experiential learning to increase palliative care competence among the Indigenous workforce: an Australian experience. *BMJ Support Palliat Care* 2019; 9: 158–163.
- 14 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005; 8: 19–32.
- 15 Ramaswamy V, Ozcan K. The co-creation paradigm. Stanford: Stanford University Press, 2014.
- 16 Galvagno M, Dalli D. Theory of value co-creation: a systematic literature review. *Manag Serv Qual* 2014; 24: 643–683.
- 17 Dopp AR, Parisi KE, Munson SA, et al. Integrating implementation and user-centred design strategies to enhance the impact of health services: protocol from a concept mapping study. *Health Res Policy Syst* 2019; 17: 1.
- 18 Ratwani RM, Fairbanks RJ, Hettlinger AZ, et al. Electronic health record usability: analysis of the user-centered design processes of eleven electronic health record vendors. *J Am Med Inform Assoc* 2015; 22: 1179–1182.
- 19 Janamian T, True A, Dawda P, et al. Co-creating education and training programs to build workforce capacity to support the implementation of integrated health care initiatives. *Med J Aust* 2022; 216 (10 Suppl): S9–S13. ■

## Supporting Information

Additional Supporting Information is included with the online version of this article.