

Western Pacific Palliative Care Advocacy Network

Terms of Reference: Version 1 (20/05/2021)

Preamble

The Western Pacific Palliative Care Advisory Network (WPPCAN) has been formed under the auspices of Australasian Palliative Link International in response to recognition of the challenges that exist for palliative care delivery across Western Pacific nations, and the variability in availability of resources and expertise across countries. WPPCAN aims to support palliative care and other health and social care professionals in advocating for positive change.

We recognise that:

- Advocates most *proximate* to the populations with unmet palliative care needs, know the needs of the populations and the context in which they are operating best.
- Such proximity to suffering is a powerful trigger for empathy.
- Palliative care practitioners, patients, and caregivers make the best advocates, rather than policy “experts”.

The palliative care community is comprised of clinicians across the full spectrum of clinical disciplines including general practitioners and allied health workers who care for people dying or living with a life-limiting illness. They possess a wealth of knowledge and experience in the management of the physical aspects of dying and the emotional, psychological, social, spiritual, and existential care of patients and their families dealing with death.

The members of this Network bring with them extensive networks and skills in organisation, service delivery and provision of specialist palliative care supporting provision of palliative care across the entire region.

The Network will provide a powerful force for positive action by governments, organisations and regulators into the future.

The Network will have an important role to play in the provision of collegiate support to palliative care practitioners and other clinicians at times of natural disaster in the region, including:

- the support and education of the palliative care and broader humanitarian health workforce responding to the disaster who may find themselves needing to provide palliative care when they feel (or are) ill equipped to do so;
- support for the community and clinicians dealing with high levels of death beyond what they had ever expected to deal with, either personally or professionally; and
- support for those dealing with personal loss and bereavement.

Purpose

The Network sees its advocacy role as the processes by which the actions of individuals or groups attempt to bring about social and/or organizational change on behalf of a particular health goal, program, interest, or population. Such action is underpinned by five key principles:

- Rights and obligations
- Hope and vision
- Courage and generosity
- Solidarity and subsidiarity
- Learning and discernment
- Proximity and participation

Katherine Pettus, IAHPC Advocacy Officer, WPPCAN presentation 09122020

WPPCAN seeks to advocate for:

- Meeting the commitments made to the WHA 2014 Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA67.19)
- Ensuring ongoing access to palliative medicines
- Improving equitable access to palliative care services
- Supporting regional partners
- Assisting in the communication and application of new and innovative palliative medicine and care interventions across the region.

Objectives

1. Advocating for increased support and funding by governments, international agencies and national organisations to address specific gaps in palliative care within countries
2. Providing a platform for palliative care advocacy for the WPRO region in regional and international forums
3. Promoting palliative care quality improvement standards through national and regional policy development and change
4. Achieving recognition of palliative medicine/care as a specialty area of healthcare

5. Advocating for better access to professional training in palliative care across the WPRO region
6. Facilitating supportive networks and training across the region to assist palliative care professionals in their advocacy
7. Improving knowledge of evidence-based practice and quality care by sharing knowledge and stories across countries
8. Providing training in advocacy
9. Achieving positive policy and regulatory change in the region, such as measures that deliver reliable and affordable access to essential medicines
10. Developing the recognition of the importance of palliative care in humanitarian crises, and for under-served populations

Activities

The Network will provide a forum, training ground and platform, enabling Network members:

- To assist governments and organisations in understanding the needs of palliative care consumers (patients/carers)
- To assist governments and organisations in understanding the needs of providers of palliative care services
- To connect with development and humanitarian agencies working in health and social care, and to galvanise development and humanitarian agencies and governments to work in tandem to address current and emerging regional palliative care challenges.

The Network will meet virtually on a regular basis:

- To establish and maintain relationships
- To understand the environment in which advocacy is taking place
- To stay abreast of global and particularly region issues
- To share knowledge and support each other across the region.

Intended Participants

Membership is open to all palliative care, health and social care professionals with an interest in advocating for the required support and resources for the delivery of high-quality palliative care across the Western Pacific region.

Governance

The Western Pacific Palliative Care Advocacy Network will be supported by a Reference Group that will be comprised of leading palliative care, health and social care professionals drawn from regional organisations across the region.

The inaugural convenor of the Reference Group will be Assoc. Professor Odette Spruijt (APLI). In future years, members will elect a Convenor and Deputy Convenor for an agreed term via a call for nominations, with an aim to engage a diverse representation across the Western Pacific region in governance.

Details of the governance structure will be developed by a designated working group during 2021.

The Reference Group will determine its own procedures for the conduct of meetings, but must ensure that minutes of meetings are maintained that record decisions and actions from the meetings.

Minutes should be circulated to Reference Group members for comment within 7 business days of the meeting and will be approved by the Convenor. A copy of the minutes will be held with Australian Palliative Link International (APLI).

From time to time the Reference Group may determine a need for a working party to be formed to address particular issues or to make representations to governments.

Organisations facilitating the Network's operations are not responsible for any costs associated with the pursuit of the Network's objectives and activities, unless previously discussed and agreed upon.

Meeting intervals

Network meetings will be held at least three times per annum by video/teleconference. A face-to-facemeeting will be sought where possible during major palliative medicine events taking place in the WP region (eg PCA Oceanic Conference, APHN or other Western Pacific conferences). More frequent meetings can be convened as required during specific work activities.

Reference group meetings will also normally be conducted by video/teleconference and will be held at least four times per annum.

Reporting

The Network is an unincorporated body and as such there are no formal reporting requirements. Within three months of financial year end, the Reference Group Convenor will endeavour to provide supporting organisations with an activity report for the prior financial year including outcomes of meetings, advocacy activities, topics and emerging issues addressed by the Network for inclusion in Annual Reports.

Organisations supporting the Network will endeavour to promote the Network's activities and achievements through their regular communications channels.

Confidentiality

All information nominated as confidential by Network members must remain confidential and not be divulged outside of the Network's proceedings.

Approval and amendment

The Reference Group will review these terms of reference as required and, at least, every two years, presenting any revisions to Network members for consideration and endorsement.

Last reviewed: [20/5/2021]