

THE AUSTRALIAN CANCER PLAN - CONSULTATION

A Joint Submission from Palliative Care Australia and Palliative Care Nurses Australia







This document is a joint response from Palliative Care Australia (PCA)¹ and Palliative Care Nurses Australia (PCNA)² to the Consultation Draft of the Australian Cancer Plan (ACP).

Summary of key points

- PCNA and PCA commend the Government for a comprehensive consultation draft of the
 Australian Cancer Plan ACP (ACP). We congratulate the Government on the inclusion of
 palliative care in Strategic Objective 3: World Class Health Systems for Optimal Care, in
 particular action 3.1.4 and for referencing the <u>Palliative Care Australia Roadmap 2022- 2027</u>
 and the <u>National Palliative Care Strategy 2018</u>. In addition, we would like to see reference to
 the <u>National Palliative Care Standards for All Health Professionals and Aged Care Services</u>.
- PCNA and PCA are keen to ensure that the World Health Organisation (WHO) definition of
 palliative care is appropriately reflected in the final ACP as per the National Palliative Care
 Strategy 2018. This would clearly and correctly indicate that palliative care goes beyond just
 care at end of life.
- PCNA and PCA strongly advocate for the explicit inclusion of palliative care under the supportive care model presented in Strategic Objective 2: Enhanced Consumer Experience.
- The Paediatric Palliative Care National Action Plan (PPCNAP) will launch in early 2023. PCA and PCNA recommend that the PPCNAP be included in the list of key frameworks, strategies, and plans relevant to children on page 26 of the ACP.
- PCNA and PCA note that advance care planning is defined in the glossary but is missing from
 the strategic objectives. Advance care planning by people with a cancer diagnosis is
 important, particularly for people with life-limiting illness and those receiving palliative care.
 Advance care planning should therefore be included in Strategic Objective 2.

Palliative Care Definition

The ACP glossary defines 'palliative/end-of-life care' on page 147. PCA and PCNA disagree with palliative care being limited to end-of-life care. PCNA and PCA strongly recommend that these two terms be defined separately and that the WHO definition of palliative care – as per the National Palliative Care Strategy 2018 (i.e. not just care at end of life) – is incorporated consistently throughout the document. This definition is also used by the Australian Commission on Safety and Quality in Health Care.

However, under action 3.1.4 on page 75 is the statement "palliative care should be introduced early upon diagnosis of a life-threatening illness to ensure quality of life and prevention or relief of suffering, end-of-life care focuses on the final months before an expected death," which we support. PCA and PCNA would like to see palliative care offered to people living with life-limiting cancer as early in their illness trajectory as possible and for the definition of palliative care used in the glossary of the ACP to reflect this.

¹ Palliative Care Australia (PCA) is the national peak body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it.

² Palliative Care Nurses Australia (PCNA) is a member organisation that gives Australian nurses a voice in the national palliative care conversation.

³ Cancer Australia, 2022. Australian Cancer Plan, Cancer Australia, Surry Hills, NSW pg. 75.

According to the WHO definition:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.⁴

Responses to Consultation Questions

STRATEGIC OBJECTIVE 1: Maximising Cancer Prevention and Early Detection.

Q.4 - Is the ambition statement for Strategic Objective 1: Maximising Cancer Prevention and Early Detection ambitious enough?

PCNA and PCA support this objective. However, we note the need to better integrate genetic
counselling and palliative care so that people who are dying from cancers, where future
screening may be indicated for family members, are identified. We recommend a systematic
approach is adopted to ensure all people are appropriately assessed and linked to further
advice and relevant counselling⁵.

Q.5 - To what extent do you agree that the proposed goals and actions for Strategic Objective 1: Maximising Cancer Prevention and Early Detection collectively ensure the ambition statement is achieved?

• PCNA and PCA support the proposed goals. However, we would like to see an additional goal focused on embedding practices for genetic counselling and screening for family members of people dying from cancers where a known genetic link or risk is identified. This will require support for specialist palliative care, broader cancer services and genetic counselling services to ensure integration and access for all (not just from selected metropolitan centres). We suggest this could be added within 1.1.2 - Strengthen cancer prevention in broader health strategies and public health partnerships or within 1.1.4 - Undertake ongoing assessment of the evidence for risk-based, cost-effective population cancer screening, as an additional dot point to bring focus to this important area.

STRATEGIC OBJECTIVE 2: Enhanced Consumer Experience

Q.6 - Is the ambition statement for Strategic Objective 2: Enhanced Consumer Experience ambitious enough?

PCNA and PCA support Objective 2 but strongly note the need to incorporate palliative care
within this objective. We regard the ACP as an important opportunity to enhance integration
between palliative care services and other services for people with cancer, and while this is
implied it should be more explicit.

⁴ Definition of Palliative Care in <u>The National Palliative Care Strategy 2018</u> | Australian Government Department of Health Based on World Health Organization, 2017.

⁵ The following reference provides useful evidence to support this inclusion: White, S., McErlean, G., Virdun, C., Phillips, J. L., & Jacobs, C. (2022). Integrating genomics into the care of people with palliative needs: A global scoping review of policy recommendations. Public Health Genomics.

- An enhanced consumer experience is only possible if the oncology and palliative care systems are better integrated. Whilst this is clearly articulated within Objective 3, ACP can promote the use of palliative care terminology throughout in an effort to
- demystify palliative care tenets, and to enable both members of the community and clinicians to see palliative care as a central part of optimal cancer care. 'Supportive care' is the focus of this objective, and we acknowledge the decade long debate about terminology that has occurred within Australia in relation to broader aspects of palliative care. We believe that the role of palliative care within the supportive care model ought to be stated within this objective. At present, we have a highly skilled specialist palliative care workforce who currently provide evidence-based care for thousands of Australians living with cancer. Every day this workforce aims to enhance care experience and quality of life and we believe this needs to be explicitly stated in connection with this objective.

Q.7 - To what extent do you agree that the proposed goals and actions for Strategic Objective 2: Enhanced Consumer Experience collectively ensure the ambition statement is achieved?

- PCNA and PCA suggest that the integration of palliative care is tied to enhanced consumer experience, so this could be more overtly stated within the ACP. There are a number of passages under the 2-, 5- and 10-year narratives where references to integration with palliative care could be added.
- The role of carers in consumer experience has been acknowledged in goals for children, adolescents and older Australians however PCNA and PCA believe that all priority population groups would benefit from the inclusion of carers within the goals. Ensuring the role of the carers is valued and supported throughout the care journey.

STRATEGIC OBJECTIVE 3: World Class Health Systems for Optimal Care

Q.8 - Is the ambition statement for Strategic Objective 3: World Class Health Systems for Optimal Care ambitious enough?

- PCNA and PCA agree with noted ambitions within Objective 3. Again, we would like to see greater visibility of palliative care within the narrative used particularly at the 10 year and 5 year levels. We would also note the need to potentially go further with the use of PROMs and PREMs as key indicators for health care administration so we see a true focus on patient experience to guide care provision and models of care. We feel the need to better consider models of care related to nursing scope of practice could be integrated into this objective to enable improved access to optimal, evidence-based care across the nation. Nurse Practitioners (Oncology and Palliative Care) have an important role to play, and it would be helpful to articulate this need and the need to rigorously evaluate their impact over time (from a PROM / PREM perspective and health system efficiency perspective).
- We strongly support the noted actions listed at 3.1.4 but again wonder if a health literacy campaign to demystify concepts about palliative care is needed to enable effective integration both from a patient/carer perspective and clinical perspective.

Q.9 - To what extent do you agree that the proposed goals and actions for Strategic Objective 3: World Class Health Systems for Optimal Care collectively ensure the ambition statement is achieved?

- PCNA and PCA believe these noted goals are well aligned and commend the inclusion of recommendations from the early consultation process. We particularly endorse the proposed approaches listed under action 3.1.4 and the implementation considerations for priority population groups. We would support more detail about scope of practice work for Nurse Practitioners and using PROMs/PREMs to guide health service administration / resourcing.
- PCNA and PCA welcomes the reference to the <u>Palliative Care Australia Roadmap 2022- 2027</u> and the <u>National Palliative Care Strategy 2018</u>. In addition PCA would like to see the <u>National Palliative Care Standards for All Health Professionals and Aged Care Services</u>⁶ referenced as the standards have been developed with the aim of supporting better experiences and outcomes for people receiving palliative care. Cancer patients would benefit significantly from the increase in knowledge and expertise in the principles and practice of palliative care gained by health professionals across health disciplines.

STRATEGIC OBJECTIVE 4: Strong and Dynamic Foundations

Q.10 - Is the ambition statement for Strategic Objective 4: Strong and Dynamic Foundations ambitious enough?

PCNA and PCA support this objective but suggest consideration of what research and data is
needed to support the palliative care needs of people living with cancer, and bereavement
needs for those after a family member/ friend dies from cancer. This is currently implied, but
the language here could be strengthened.

Q.11 - To what extent do you agree that the proposed goals and actions for Strategic Objective 4: Strong and Dynamic Foundations collectively ensure the ambition statement is achieved?

PCNA and PCA advocate for increased focus on the important role of palliative care within
modern, fit-for-purpose cancer control infrastructure. Whilst palliative care is again alluded
to, we believe this could be strengthened.

STRATEGIC OBJECTIVE 5: Workforce to Transform the Delivery of Cancer Care

Q.12 - Is the ambition statement for Strategic Objective 5: Workforce to Transform the Delivery of Cancer Care ambitious enough?

PCNA and PCA support the intent and stated goals for Objective 5. We suggest more overt
reference to the need for palliative care skills and capabilities for the multidisciplinary cancer
care workforce, acknowledging that multidisciplinary teams include medical, nursing, and
allied health professionals as well as volunteers who serve specific patient needs. For
example, the idea of dual traineeships is ideal when considering medical specialisation and
training. In addition, embedding palliative care within nursing training at ward and
outpatient levels is crucial for optimal care. We suggest greater emphasis on the potential
for nurse practitioners to build and lead the nursing cancer care workforce – both in cancer

⁶ https://palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services/

roles and palliative care roles. Finally, we suggest specific reference to supporting workforce integration across inpatient and outpatient settings – both in terms of workforce and regarding data infrastructure – to enable shared care and communication models.

Q.13 - Workforce to Transform the Delivery of Cancer Care collectively ensure the ambition statement is achieved?

PCNA and PCA believe the listed actions are highly relevant to achieving the stated objective.
 However, we suggest greater reference to palliative care could be made throughout
 Objective 5, and in particular with regard to innovative models of care and pathways for specialisation within the Nurse Practitioner scope of practice.

STRATEGIC OBJECTIVE 6: Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander People

Q.14 – Is the ambition statement for Strategic Objective 6: Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander People ambitious enough?

PCNA and PCA fully support Objective 6. We believe the strength with this statement is
made positions the ACP well to promote system-level chance. The focus on strength-based
approaches and co-design is particularly positive.

Q.15 – To what extent do you agree that the proposed goals and actions for Strategic Objective 6: Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander People collectively ensure the ambition statement is achieved?

PCNA and PCA believe the proposed goals and actions will support the realisation of
Objective 6. We also note the important work being led about by Professor Gail Garvey and
her team to better articulate quality measures for Aboriginal and Torres Strait Islanders.⁷

Issues not addressed

Q.18 – Is there anything missing from the draft ACP?

• The Paediatric Palliative Care National Action Plan (PPCNAP) is expected to be launched in early 2023. PCA and PCNA recommend that the PPCNAP be included in the list of key frameworks, strategies, and plans relevant to children on page 26:

The PPCNAP provides guidance on key priorities and proposed actions to improve outcomes for children, young people and their families living with a life-limiting condition as informed by input by consumers and other key stakeholders. In acknowledging the sheer diversity of issues and concerns that are often part of the journey for children and young people with a life-limiting condition and their families, ACP aims to promote direct and positive outcomes.

 A critical element that appears to be missing from the draft ACP is advance care planning by people with a cancer diagnosis. Currently advance care planning is only referred to as a term defined in the glossary, but it should be highlighted in the main text of the ACP (e.g. under Objective 2). Advance care planning processes are particularly important for people with

⁷ Butler, T. L., Anderson, K., Garvey, G., Cunningham, J., Ratcliffe, J., Tong, A., ... & Howard, K. (2019). Aboriginal and Torres Strait islander people's domains of wellbeing: a comprehensive literature review. Social Science & Medicine, 233, 138-157.

life-limiting illness and those receiving palliative care. As noted in the National Palliative Care Strategy (2018): 4

Evidence also demonstrates the benefits of individuals, their carers and families discussing their care preferences early in their illness⁸. Advance care plans or other similar documents are becoming more widely used and provide an important mechanism to communicate an individual's preferences regarding their care.⁹

Advance care planning enables the coordination of resources and services to match anticipated care needs and offers individuals the opportunity to take control of decisions which affect their care. PCNA and PCA recommend that the ACP emphasise the importance of advance care planning for any person with cancer. Ensuring that their care preferences during treatment can be documented and understood. Should palliative care and end-of-life care be needed by the person, their wishes and preferences are clear to their families and to those providing care and support to them. Adopting this approach would support the National Palliative Care Strategy's emphasis on advance care planning (2018):

2.2 Clinical and non-clinical service providers can assist individuals, their families and carers to have discussions on palliative care including the development of advance care plans.¹⁰

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⁸ Senate Community Affairs References Committee, 2012 cited in <u>The National Palliative Care Strategy 2018</u> | Australian Government Department of Health page 17.

⁹ The National Palliative Care Strategy 2018 | Australian Government Department of Health page 17.

 $^{^{10}}$ <u>The National Palliative Care Strategy 2018</u> | Australian Government Department of Health page 21.