Public Health Association of Australia submission on the optimal care pathway for Aboriginal and Torres Strait Islander people with cancer

Contact for recipient:
OCP Project Manager
Cancer Council Victoria
A: 615 St Kilda Road, Melbourne VIC 3004
E: optimalcare.pathways@cancervic.org.au
T: (03) 9514 6360

Contact for PHAA:
Michael Moore – Chief Executive Officer
A: 20 Napier Close, Deakin ACT 2600
E: phaa@phaa.net.au T: (02) 6285 2373

31 October 2017
# Contents

- Introduction................................................................................................................................. 3
  - The Public Health Association of Australia.............................................................................. 3
  - Vision for a healthy population ................................................................................................. 3
  - Mission for the Public Health Association of Australia ............................................................ 3
- Preamble ..................................................................................................................................... 3
- PHAA Response to the draft ......................................................................................................... 4
  1. Overall, is the OCP clear and easy to understand? ................................................................. 4
  2. What else is required to communicate consistent, safe, high-quality, evidence-based care for 
     Aboriginal and Torres Strait Islander people affected by cancer? ........................................ 4
  3. Do you have any issues or concerns regarding the content of the OCP? ............................... 4
     - Research and clinical trials ..................................................................................................... 4
     - Evaluation .................................................................................................................................. 4
  4. Please share any other comments that may be useful to support the development of the OCP 
     and its aim to ensure consistent, safe, high-quality and evidence-based care for 
     Aboriginal and Torres Strait Islander people affected by cancer ........................................... 5
- Conclusion ................................................................................................................................... 5
- Appendix A: Specific wording suggestions.................................................................................. 6
Introduction

The Public Health Association of Australia

The Public Health Association of Australia (PHAA) is recognised as the principal non-government organisation for public health in Australia working to promote the health and well-being of all Australians. It is the pre-eminent voice for the public’s health in Australia. The PHAA works to ensure that the public’s health is improved through sustained and determined efforts of the Board, the National Office, the State and Territory Branches, the Special Interest Groups and members.

The efforts of the PHAA are enhanced by our vision for a healthy Australia and by engaging with like-minded stakeholders in order to build coalitions of interest that influence public opinion, the media, political parties and governments.

Health is a human right, a vital resource for everyday life, and key factor in sustainability. Health equity and inequity do not exist in isolation from the conditions that underpin people’s health. The health status of all people is impacted by the social, cultural, political, environmental and economic determinants of health. Specific focus on these determinants is necessary to reduce the unfair and unjust effects of conditions of living that cause poor health and disease. These determinants underpin the strategic direction of the Association.

All members of the Association are committed to better health outcomes based on these principles.

Vision for a healthy population

A healthy region, a healthy nation, healthy people: living in an equitable society underpinned by a well-functioning ecosystem and a healthy environment, improving and promoting health for all.

Mission for the Public Health Association of Australia

As the leading national peak body for public health representation and advocacy, to drive better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.

Preamble

PHAA welcomes the opportunity to provide input to the optimal care pathway for Aboriginal and Torres Strait Islander people with cancer. The reduction of social and health inequities should be an over-arching goal of national policy and recognised as a key measure of our progress as a society. The Australian Government, in collaboration with the States/Territories, should outline a comprehensive national cross-government framework on promoting a healthy ecosystem and reducing social and health inequities. All public health activities and related government policy should be directed towards reducing social and health inequity nationally and, where possible, internationally.
PHAA submission on optimal care pathway for Aboriginal and Torres Strait Islander people with cancer

PHAA Response to the draft

1. Overall, is the OCP clear and easy to understand?

There is a clear optimal care pathway outlined of prevention, presentation, diagnosis, treatment, aftercare, managing recurrence and end of life.

Given the size of the document, it would be helpful to have a table of contents for a quick understanding of the structure and content, and for navigation. Another consideration for the length of the document is how easily clinical staff will be able to find key points. For example, the sentence in 7.1.2 Pain management – “A lack of request for pain relief should not be interpreted as a lack of need” is key to that section. Similarly, in Care Coordination, “Informing all care coordinators in services at key steps of the cancer pathway or when individual health plans change will help provide seamless transition and continuity of care to the patient” is a key statement. It may be helpful to have a key message for each section highlighted in the summary, throughout the document or both.

The diagram on p18 of the seven critical steps in the patient journey should be higher resolution in the final document to improve readability.

2. What else is required to communicate consistent, safe, high-quality, evidence-based care for Aboriginal and Torres Strait Islander people affected by cancer?

Terminology used in the OCP to describe differences should be consistent. There are implicit meanings with the use of the terms inequality, inequalities and disparities – each with subtle but important distinctions. Inequalities describe differences, without description or understanding or social injustices. Inequity implicitly describes social injustice. And disparities is often used as a combination of the two. It is important to note that differences that exist in the incidence, treatment and outcomes of Aboriginal and Torres Strait Islander people are embedded in existing social injustices, which is well documented.

PHAA recommends a review of the OCP for consistency in terminology.

3. Do you have any issues or concerns regarding the content of the OCP?

Research and clinical trials

PHAA supports the inclusion of research and clinical trials as one of the seven principles for the OCP, however, we note concerns with the implementation of this principle. While research and clinical trials are extremely important, particularly in the cancer treatment setting, there are particular considerations to be discussed in the context of Aboriginal and Torres Strait Islander cancer treatment. While it is important to note the need for parity in engagement in research, it should also be acknowledged that the legacy of historical research practices can contribute to this. Considerations regarding the impact that promoting research and clinical trials to Aboriginal and Torres Strait Islander people with cancer within the systems providing treatment and how this may impact treatment uptake should be discussed. This is particularly important for those who have had negative experiences with research and researchers in the past.

Evaluation

The draft OCP does not appear to provide a clear outline of how evaluation of the OCP will occur. This will be vital in ensuring that the pathways identified do provide optimal cancer care for this group.
PHAA submission on optimal care pathway for Aboriginal and Torres Strait Islander people with cancer

Trauma informed care

The draft OCP does not mention trauma informed care. With cancer diagnosis, procedures and treatment sometimes invoking memories of past abuse and trauma, this issue is of great importance to culturally appropriate care for Aboriginal and Torres Strait Islander people. PHAA recommends that the inclusion of trauma informed care be specified in the OCP.

4. Please share any other comments that may be useful to support the development of the OCP and its aim to ensure consistent, safe, high-quality and evidence-based care for Aboriginal and Torres Strait Islander people affected by cancer

Please see Appendix A to this submission for a list of specific wording suggestions.

Conclusion

PHAA supports the broad directions of the draft Optimal Care Pathway for Aboriginal and Torres Strait Islander people with cancer. However, we are keen to ensure culturally appropriate care in line with this submission. We are particularly keen that the following points are highlighted:

- Terminology within the document should be consistent, particularly in relation to differences between inequalities and inequities
- The OCP will need to be evaluated, but it is not clear from the draft how that will occur
- Research and clinical trials are an important element of the OCP, but implementation should consider the legacy of historical research practices and the implications of aligning research with treatment.

The PHAA appreciates the opportunity to make this submission and the opportunity to ensure culturally appropriate care for Aboriginal and Torres Strait Islander people with cancer.

Please do not hesitate to contact us should you require additional information or have any queries in relation to this submission.

Michael Moore BA, Dip Ed, MPH
Chief Executive Officer
Public Health Association of Australia

31 October 2017
## Appendix A: Specific wording suggestions

<table>
<thead>
<tr>
<th>Page</th>
<th>Topic</th>
<th>Comments</th>
</tr>
</thead>
</table>
| 3-4   | Context (Culturally Competent Healthcare)                               | Generally very useful and comprehensive summary, particularly the preamble; inclusion of social and cultural determinants of health; unfair treatment; recognition of disparity in cancer outcomes, especially preventable fatal cancers; and the burden on families, elders and carers as well as those diagnosed:  
  - Disadvantage by rurality (para 6) – needs to be earlier where the identification of differences in urban vs remote first appears. Are there different cancer pathways required for urban vs rural vs remote (in particular remote communities)? |
| p.3   | Modifiable risk factors – include smoking, obesity, lack of exercise, risky alcohol use, Hep B & C. (final para) | Recommend ‘physical activity’ rather than ‘exercise’ – since physical activity is broader/more inclusive of everyday activities, more appropriate for rural and remote areas (where there are e.g. no gyms), and more consistent with Heart Foundation terminology.                                                                                                                   |
| p.4   | Screening participation, cancer stage at diagnosis, inadequate treatment or hospitalisation. (para 1)       | This is where differences in regional, rural, remote vs urban should first be made to more clearly link to screening, participation, treatment. Consider an extra paragraph on this (NOT just reposition para 6)                                                                                                               |
| p.4   | Variation between remote vs metropolitan populations (para 7)          | The reason for the change in terminology from ‘urban’ to ‘metropolitan’ here is not clear. Also, with the reference to limited evidence being available, it is not clear whether grey literature has been considered.                                                                                                                     |
| 5-11  | Intent and key principles                                              | PHAA generally supports the intent and key principles, especially the map of pathways for specific tumour types and evaluation templates for cancer care; the intent for the OCP to complement best practice to facilitate culturally safe and competent care; the focus on aspects of cancer care that are responsive to the needs of Aboriginal and Torres Strait Islander people; key concepts fundamental to Indigenous health; and the 7 evidence-based principles:  
  - This section should note that often, hospitals are places of fear for Aboriginal people, not places of safety  
  - Documentation for identification as Aboriginal or Torres Strait Islander – tribal association may have relevance for cancer pathways, and should be noted where possible. Use of data for evaluation requires improving identification (Cancer Aust 2015) |
| 12-17 | Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer | Health literacy (p15)  
  - Suggest that fear of cancer is incorporated into the issues which may affect participation in care.                                                                                                                                                                                                                                                   |
| 19-23 | Step 1: Prevention and early detection                                 | In the 3rd dot point on p19: Should the risk factor of alcohol consumption be ‘risky levels of alcohol consumption’? Also, should higher levels of infection include hepatitis C?                                                                                                               |
In the dot points on cancer risk reduction (p20), suggest using ‘physical activity’ rather than ‘exercise’ (see comment for p3).

In the opening sentence on screening (p21), suggest “…as screening can significantly impact on mortality” be amended to “…as screening can significantly reduce mortality”.

| 38-42 | Step 5: Care after initial treatment and recovery | In Survivorship (p38-39) consider including reference to culturally appropriate support groups such as women’s breast cancer support groups and men’s prostate cancer support groups. |
| 46 | Step 7: End-of-life care | PHAA supports the recognition in section 7.1.1 (Return to Country) that Aboriginal and Torres Strait Islander people usually prefer to die on country or in their communities. Therefore, appropriate palliative care needs to be available in regional and remote areas also. |

- The issue of fear of hospitals as places of death should be considered in this section also as it may be a barrier to optimal cancer treatment.
- P47, paragraph 5: “Ensure carers and families receive information, support and guidance regarding their role according to the patient’s needs and wishes”. Suggest that health care workers are added to the list of those receiving information.
- 7.1.1 Return to Country – suggest that the last sentence finishing with “…develop strategies to manage these requests” be changed to “…develop strategies to support these requests”.
- 7.1.2 Pain management – “some patients may be uncomfortable with pain medication administered via injection or through an intravenous drip”. The meaning of “uncomfortable” in this context is unclear.
- 7.1.2 Pain management – suggest that the dot point under effective strategies “fully explaining the options, usage and side effects of pain relief” be changed to “fully explaining the options, usage and side effects of pain relief, in plain English without the use of jargon”.

PHAA recommends that the section on palliative care include more specific details, informed by palliative care experts.

| 50-51 | 7.3 Support and communication | • 7.3.1 Supportive Care - Cognitive dysfunction and personality and behavioural changes: Suggest that “…by a neuro-psychologist/psychiatrist…” be changed to “…by a culturally competent neuro-psychologist/psychiatrist…”
• 7.3.1 Supportive Care – Psychological needs: the term “existential distress” may not be well understood. Suggest a plain English alternative or a glossary definition if a plain English definition is not available.
• 7.3.1 Supportive Care – Social/practical needs: In the third dot point, suggest changing “…particularly for rural patients…” to “…particularly for rural and remote patients…” Also, “…speak of being treated or feeling like an outcast…” should be changed to “…speak of being treated as or feeling like an outcast”.
• 7.3.1 Supportive Care – Information needs: Second dot point “All members of the care team should be notified when the
patient has died” should be changed to “All members of the care team should be notified as soon as possible when the patient has died”.

- 7.3.2 Communication with the patient, carer and family: Last dot point, suggest that “...and provide an opportunity to address any questions...” be changed to “...and provide a culturally appropriate opportunity to address any questions...”.

<table>
<thead>
<tr>
<th>65</th>
<th>Glossary</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The source of the definitions in the Glossary should be noted</td>
</tr>
<tr>
<td></td>
<td>Suggest some additions to the Glossary: carer, discharge destination, existential distress, functional status, teleoncology; support groups, familial cancer service, complementary or alternative medicine (CAM), prognosis, telehealth.</td>
</tr>
<tr>
<td></td>
<td>Suggested definitions for new entries:</td>
</tr>
<tr>
<td></td>
<td>o Adjuvant therapy - From National Cancer Institute (US) Dictionary of Cancer Terms: Additional cancer treatment given after the primary treatment to lower the risk that the cancer will come back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.</td>
</tr>
<tr>
<td></td>
<td>o Neoadjuvant therapy - From National Cancer Institute (US) Dictionary of Cancer Terms: Treatment given as a first step to shrink a tumor before the main treatment .... is given. Examples of neoadjuvant therapy include chemotherapy, radiation therapy, and hormone therapy. It is a type of induction therapy.</td>
</tr>
<tr>
<td></td>
<td>Suggested amendments to definitions:</td>
</tr>
<tr>
<td></td>
<td>o Cancer continuum – should also include end-of-life care including death</td>
</tr>
<tr>
<td></td>
<td>o Care coordinator – the wording of this definition could be improved to make it clear that this refers to a person rather than a position, similar to other definitions in the glossary</td>
</tr>
<tr>
<td></td>
<td>o End-of-life care – consider whether this is just a distinct phase of or separate to palliative care</td>
</tr>
<tr>
<td></td>
<td>o Health professional – review the list of examples provided for completeness</td>
</tr>
<tr>
<td></td>
<td>o Palliative care – review the definition to clarify that it refers to terminal illnesses</td>
</tr>
<tr>
<td></td>
<td>o Practice team – add Royal Flying Doctors Service</td>
</tr>
<tr>
<td></td>
<td>o Risk factor – review the definition for clarity</td>
</tr>
</tbody>
</table>