Cancer Council NSW response to the Productivity Commission Draft Report 'Introducing competition and informed user choice into human services: Reforms to human services' June 2017

Note about use of language: Cancer Council NSW generally uses the term Aboriginal in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of NSW. However, to be consistent with terminology in the Productivity Commission's draft report, which covers all states and territories, the term Indigenous will be used in this submission. Cancer Council NSW also recognises that a person's cancer diagnosis, treatment, survivorship care and palliative and end-of-life care can affect their family, and carers. Therefore, we will use the term 'people affected by cancer' in this submission.

Introduction

Cancer Council NSW is pleased to present this submission in response to the Productivity Commission's draft report. Our responses will focus on the Commission's recommendations about end-of-life-care, and human services in remote Indigenous communities.

People with cancer who require palliative and end of life care (PEoLC), and Indigenous people with cancer living in remote communities, deserve high quality, safe, culturally appropriate health care where they need it, when they need it, wherever they live in Australia. When considering human services reforms, governments must ensure that quality and safety, and accessibility with no out-of-pocket costs, are maintained as essential elements in the delivery of cancer care and PEoLC services.

As recognised by the Commission, competition and contestability are means to an end and should only be pursued if proved to increase the effectiveness of service provision. Delivery of PEoLC services by non-government providers, rather than by publicly provided health services, will not automatically ensure a more efficient service. This may be achievable without resorting to the creation of new mechanisms for delivering the services. Governments must ensure that any costs as a result of reforms do not exceed the costs that would have occurred had the services continued to be provided by the public sector.

Cancer Council NSW agrees with the Commission's assessment that PEoLC in Australia needs to improve to avoid tens of thousands of people dying in a way, and in a place, that does not reflect their values or their choices. No one deserves to have an end-of-life journey punctuated with avoidable, or unwanted, admissions to hospital which may result in confusion and the loss of dignity and control. Nor should they be exposed to medical interventions that are not beneficial to them, which is more likely if they die in hospital. States and territory governments need to ensure that people with a preference to die at home are able to access support from community-based palliative care services wherever, and whenever, they need it.

People with cancer are often in a vulnerable situation, particularly those needing PEoLC. They may not be in a position, nor have the knowledge and expertise to appraise the quality of PEoLC services and make an informed judgement about what they, and their family need. Consumer-based information about models of care already being provided by non-government PEoLC providers is not easily accessible. These barriers are likely to be even greater for some people such as those with low health literacy.

The Commission recognises that competition between multiple providers is not possible in relation to PEoLC care, rather suggesting that community-based PEoLC services are ideally suited to a contestable approach. This means that governments would commission non-government organisations to deliver services. Under this process, organisations not currently providing PEoLC services could do so in the future. People needing PEoLC should have access to the best evidence-based care, provided by a high quality service, with no out-of-pocket expenses. They must be protected from exploitive, substandard or inappropriate service relationships. Any reforms require careful stewardship from governments and input from relevant stakeholders and the community. If contestability is introduced, new (and existing) PEoLC services need to ensure coordination of complex care across multiple services and they must be regulated for quality and safety. Careful monitoring and evaluation, and transparent, publicly accessible reporting, is essential.

As the Commission highlights, people needing PEoLC should be able to access care that not only matches their preferences, but matches their clinical needs. For many Australians their clinical need may require care from a specialist in palliative medicine. It's estimated that, in NSW, more than three-quarters of all people who die in this state could benefit from specialist palliative or end-of-life care.[1] The NSW Government plan to increase access to palliative care 2012-2016 highlights gaps in specialist services, especially in rural areas, and recognises that culturally appropriate palliative care services for Aboriginal people are lacking.[2] The NSW

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[1] Agency for Clinical Innovation. Diagnostic Report to inform the model for palliative and end of life care service provision. 2014

[2] NSW Ministry of Health. The NSW Government plan to increase access to palliative care 2012-2016. 2012.

Government's Agency for Clinical Innovation's (ACI) Clinical Network for Palliative Care has also identified gaps in specialist services for end-of-life care in NSW.[3]

Any reforms will require a detailed assessment of current and future needs and an analysis of the current gaps in service provision for every local health district. The focus should be on strengthening what is already on offer, including specialist palliative care services, to meet community needs. Cancer Council NSW would not support reform that decreases the availability of specialist palliative care services or adds extra burden on already overstretched services.

Background to Cancer Council NSW's involvement in PEoLC

Cancer Council NSW has worked to improve PEoLC for people with cancer for many years with initiatives including:

- Supportive Care programs is *Understanding Cancer* resources, 131120 information and support service; telephone support groups; pro bono legal support, financial assistance; transport to treatment and home help;
- Advocacy to the NSW government to increase funding for specialist palliative care workforce and develop culturally appropriate palliative care for Aboriginal people;
- Local and regional partnerships, including trialling a palliative care respite service;
- Collecting data about PEoLC experiences and service access, from the community
- Research projects including:
    - Acute hospital-based services utilisation during the last year of life in New South Wales, Australia: methods for a population-based study
    - End of Life experiences for Aboriginal and Torres Strait Islander patients dying from cancer study
    - Caring at end of life: Understanding the nature and effect of informal community care networks for people dying at home
    - Who decides and at what cost? Comparing patient, surrogate and oncologist perspectives on end of life care.
    - Enhancing community knowledge and engagement with law at the end of life.

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[3] Agency for Clinical Innovation. Palliative and end of life care - a blueprint for improvement. 2014

Response to section 3: End-of-life-care

Cancer Council NSW supports, in principle, the Commission's draft recommendations about end-of-life care. However they could be broadened and there are a number of areas requiring explicit attention as highlighted in the following dot points:

- **Ensure access to specialist palliative care services:**

  Cancer Council NSW's advocacy emphasises that, when people affected by cancer need it, they should be able to access specialist palliative care services where and when required. These services need to include specialist palliative physicians and palliative care nurses who are trained to prevent and relieve suffering through early identification; and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.

  There are several useful documents that highlight the role of specialist palliative care in a comprehensive approach to PEoLC. For example, the NSW Palliative Care Role Delineation Framework describes the relationship between specialist palliative and primary care services.[4] Also, the NSW Agency for Clinical Innovation, Palliative Care Network has developed the Framework for the statewide model for palliative and end of life care service provision that illustrates a networked approach to quality end-of-life care.[5] The model includes the principle that, when their needs exceed the capabilities and resources of primary care providers, people approaching and reaching the end of their life have access to specialist palliative care consultation and direct care services. It also highlights that, where needed, patients with complex end of life care issues should have access to a higher level specialist palliative care, either directly or indirectly, on an episodic or ongoing basis as appropriate to their need.[6] The principles underpinning the model are comprehensive and any reform in the area of PEoLC nationally could benefit from ensuring these principles are included in service planning, and that rigorous evaluation against these principles occurs.

  Reform to PEoLC services would also require an increase in the specialist palliative care workforce to meet community needs, and to allow palliative specialists to support other

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[4] NSW Ministry of Health, NSW Palliative Care Role Delineation Framework, 2007

[5] NSW Agency for Clinical Innovation Palliative Care Network, Framework for the statewide model for palliative and end of life care service provision. 2013

[6] NSW Agency for Clinical Innovation Palliative Care Network, Framework for the statewide model for palliative and end of life care service provision. 2013

service providers, who deliver non-specialist PEoLC. Palliative Care Australia suggests that there should be a minimum of 1.5 FTE palliative physicians per head of population.[7]

- **Coordination of PEoLC:** Coordinating the needs of people affected by cancer who require PEoLC is already difficult in the health care system. This could be exacerbated by the introduction of contestability, in particular when service providers are new to the provision of this service. A patient's needs can change multiple times, and quickly, during their end of life trajectory. Someone being cared for at home may need hospital-based services, such as palliative radiotherapy, and this would need careful coordination between a local health district and a non-government community-based service. Their care may also involve potentially complex admissions and discharges to, and from, a specialist team. It is essential that the problems already experienced in relation to care coordination are not exacerbated and that the needs of the patient at this vulnerable time are kept at the forefront as they move through complex systems. The government should remain accountable for ensuring recognised standards of excellent care wherever or whenever the care is provided, irrespective of who is providing it.

- **Impeccable patient records:** There is a potential that patient records may be impacted by the introduction of more providers, particularly if those providers have no prior experience in providing PEoLC services. Record-keeping between local health district services, and non-government community-based services, would need careful management to ensure that patient care isn't compromised or delayed due to lack of clarity of care history or plans between providers**.**

- **Culturally-appropriate, community-based PEoLC for Indigenous people:** The Commission's report would benefit from a specific recommendation about a model of culturally-appropriate, community-based PEoLC for Indigenous people. Care needs to fit with Aboriginal peoples' community values, beliefs, cultural / spiritual rituals, heritage and place which are culturally appropriate, locally accessible and delivered in collaboration and partnership with Aboriginal controlled health services.[8] Ideally, service providers need to have established relationship with Aboriginal Health Workers in the area. These principles are also reflected in the National Aboriginal and Torres Strait Islander Cancer Framework 2015. More research into the PEoLC needs of Indigenous

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[7] Palliative Care Australia. Palliative care service provision in Australia: A planning guide. Palliative Care Australia . 2003. Canberra ACT, Palliative Care Australia

[8] AP O'Brien, MJ Bloomer, P McGrath, K Clarke, T Martin, M Lock, T Pidcock, P van der Riet, M O'Connor: Considering Aboriginal palliative care models: the challenges for mainstream services: *Rural and Remote Health* on-line Journal, 13: 2339, 2013

people, and close involvement of key Indigenous stakeholders, will be required to enable the development of an appropriate model.

- **Collection and use of PEoLC data:** Governments have a clear stewardship role in relation to coordination of data collection and usage. This includes the development of systems to ensure that all providers involved in PEoLC are accountable and that the data is used to improve services. Cancer Council agrees that a national data strategy is required.

Role of non-Government organisations in PEoLC

Not-for-profit organisations may also have a role in providing choice of support services related to PEoLC. Research about palliative care needs and services in NSW, commissioned by Cancer Council NSW and undertaken by the University of Technology Sydney, highlighted that innovative ways of delivering PEoLC tailored information, resources, programs and support services are required.[9] Expanding the role of non-government organisations, such as Cancer Council NSW, provides an opportunity to improve community access, and reach higher need populations who require PEoLC-related supportive care services.

Cancer Councils in each state also have access to a large number of people with advanced/terminal cancer. This provides a valuable opportunity for partnering in research to understand the factors that contribute to optimal PEoLC, including consumer acceptability of different models of service provision.

Response to section 8: Human Services in remote Indigenous communities

Indigenous communities are a disadvantaged and vulnerable population who experience significant disparities in cancer outcomes. The age-standardised incidence rate and mortality rate for all cancers combined is higher for Indigenous Australians than non-Indigenous Australians. The higher incidence rate may be related to high prevalence of cancer-related modifiable risk factors such as smoking, alcohol consumption and Hepatitis B infection, along with lower participation in cancer screening in Indigenous Australians.[10] The higher mortality rate may be partly due to the fact that Indigenous Australians generally have poorer access to health-care services and are more likely to have cancers that are diagnosed at a later stage

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[9] *Review of Palliative Care Needs and Services in NSW*. University of Technology Sydney. 2016 (unpublished)

[10, 12] Cancer Australia, Aboriginal and Torres Strait Islander cancer statistics. Available from https://canceraustralia.gov.au/affected-cancer/atsi/cancer-statistics

than non-Indigenous Australians.[11] Indigenous Australians are more likely to live in regional and remote Australia than non-Indigenous Australians, which affects access to health-care services.

The comments made in the section above, about PEoLC services for Indigenous Australians, are also relevant for the development of timely, appropriate cancer prevention, treatment and survivorship services for Indigenous people living in remote communities.

Cancer Council NSW supports, in principle, the draft recommendations about improved contestability arrangements in human services in remote Indigenous communities, with some caution. In relation to cancer-related services we believe that the focus should always be on improving the quality of, and access to service delivery, as a way of reducing the gap in cancer outcomes between Indigenous and non-Indigenous Australians. Contestability should only be used for this purpose, and not as a way of generating cost savings.

Cancer Council NSW strongly supports the concept that, if it does occur, commissioning includes a strong focus on transferring skills and capacity to people and organisations in Indigenous communities. This will result in a longer term benefits of locally accessible, culturally appropriate services delivered by Aboriginal staff within Aboriginal controlled health services. Overall, Cancer Council NSW supports the progression of models of care that are designed to improve cancer outcomes in remote Indigenous communities. Governments responsible for service planning, delivery and evaluation need to ensure that this is done with strong Indigenous community involvement at every step.

For further information, or questions, regarding this submission, please contact Kelly Williams, Manager of Policy and Advocacy, Cancer Council NSW
