PalliativeCare
AUSTRALIA

His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd), Governor-General of the Commonwealth of Australia, Patron

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Human Services Inquiry
Productivity Commission
Locked Bag 2, Collins Street East
Melbourne Vic 8003

RE: Introducing Competition and Informed User Choice into Human Services: Identifying Sectors for Reform Productivity Commission Preliminary Findings

Thank you for the opportunity to contribute to the inquiry introducing competition and informed user choice into human services.

Attached is input from Palliative Care Australia (PCA) to the inquiry.

Yours sincerely

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Submission

This paper responds to the call for submissions by the Productivity Commission to their inquiry on Introducing Competition and Informed User Choice into Human Services: Identifying Sectors for Reform. This submission provides comments on the preliminary findings report, and focusses on findings relating to palliative care.

Introduction

Palliative Care Australia (PCA) supports the principle that service users are activated to make informed choices about their care. However, it is our opinion that the primary concern for people with life-limiting conditions is obtaining actual access to a high quality palliative care service. Most consumers are not well placed to make decisions about which service to access, as the Australian public are not well-prepared to face the end of life. Further, many people who die do not have the opportunity to access palliative care at all. Access to high quality palliative care for all people dying from a life-limiting illness should be the primary outcome, and considerations about user choice can follow.

To the issue of user choice – many people who are faced with a life-limiting illness may be unable or unwilling to exercise choice in determining their care. There may not be capacity to do so or there may be no will to engage at all. In addition people who are approaching death are often experiencing existential issues that may inhibit their choices. The nature of illness at the end of life is that it is often unpredictable and frequently changing in nature, which makes for a very frightening time. Any consideration of increasing people's ability to choose providers must consider these changing dynamics in order to protect people from making choices not in their best interest. There is potential for considerable unintended consequences and it would be an interesting activity for the Productivity Commission to understand the level of stakeholder support for this idea, including the support, or not, by people who are currently receiving specialist palliative care services. PCA suspects choice in their health care is likely to be low on their list of priorities at this time.

Some Primary Health Networks are currently looking to commission community-based palliative care services so that they can respond to the currently unmet demand for palliative care and ensure that at home death rates increase. Choice in place of care is a well-supported goal of palliative care, and surveys conducted by PCA over a number of years have consistently revealed 70% of Australians would like to be able to die at home. PHN commissioning of services is to be welcomed however it is acknowledged that commissioning decisions often deliver best value but not necessarily best outcomes.[1] Greater exploration about what constitutes commissioning that is both effective and efficient and ensures appropriate outcomes is required, and should be explored ahead of any changes to current circumstances.

Defining specialist palliative care

The preliminary report is focused on specialist palliative care. However, PCA notes that this is only a small part of the care provided to a person at the end of their lives. Specialist palliative care is important where people have symptoms arising from their treatment or disease that are complex.

Palliative care is often provided by non-specialist services, and care is focused on the management of symptoms. It is an approach that improves the quality of life for patients and their families facing the problem associated with life-threatening 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.

Recommended action

Consider the role of both specialist palliative care as well as palliative care provided by non-specialists. Including both will ensure that conversations about goals of care happen for all people as they approach the end of their lives, and not just those who are under the care of a specialist palliative care team.

Data and information to support findings

While the AIHW collect and report on palliative care services in Australia, this data is patchy and is not linked between data sources. This means that even simple measures such as the number of people accessing palliative care services prior to death is not available. Data on access to palliative care would be an important benchmark in assessing whether people are receiving the best available care at the end of life. Until this data is available, and information on the current providers of palliative care and their service capacity is available, developing a market contestability and competition approach would be very difficult.

The findings outlined in the preliminary report rely heavily on the use of data from the Palliative Care Outcome Collaborative. For example, PCOC data is used to estimate the

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[1] Lesley Russel,' Social Services Futures: The Marketisation of Healthcare Services: When political Mantras win out over evidence and patients' needs' accessed 21/10/16 http://www.powertopersuade.org.au/blog/social-service-futures-the-marketisation-of-healthcare-services-when-political-mantras-win-out-over-evidence-and-patients-needs/7/4/2016

number of patients accessing specialist palliative care (p93 of the preliminary findings report). While PCOC has great coverage with 115 participating services in 2015, participation is voluntary. Not all services participate. It is not possible to tell whether the same patients are included from two different services, including being cared for in an acute service, and also in the community. The lack of data about the number of people accessing specialist palliative care each year is one of the difficulties that will be faced when considering opportunities for market contestability.

Current data collections in place that cover the range of areas that palliative care and end-of-life care are delivered are disparate, and there is no overall strategic lens through which data is analysed. This means that it is therefore difficult identify when and how end-of-life care has been delivered, creating difficulty in assessing readiness for contestability.

PCA recommends that the Productivity Commission look to the advances made in mental health data collections. Over a period of 20 years in Australia, better data collections for mental health have led to a greater understanding of a range of issues relating to mental health. Unlike mental health, palliative care and end-of-life care data collections are not supported at Commonwealth Principal Committee level. The current Mental Health Information Strategy Standing Committee (MHISSC) provides advice to the Mental Health, Drug and Alcohol Principal Committee (MHDAPC) of the Australian Health Ministers' Advisory Council (AHMAC). MHISSC brings together jurisdictional mental health data representatives and key stakeholders including consumers, carers, clinicians, peak bodies and key organisations. The Committee provides a national collaborative forum for the development and implementation of national initiatives in mental health information, and provides expert technical advice and recommendations for the information requirements of the National Mental Health Strategy. In the same way, a high level committee responsible for the palliative care strategy could be responsible for considering information requirements and gaps in current data.

Recommended action

- Support the development of a data strategy for palliative care, including the formation of a standing committee could be formed to provide advice to either the National Health Information and Performance Principal Committee (NHIPPC) and/or Community Care and Population Health Principal Committee (CCPHPC).
- Collect key data items such as the number of people accessing palliative care, the number of episodes of care each person receives, the services provided by palliative care and the quality of their life until death. Data collected should also include whether care was available to the family and carers, as palliative care is a family-centred model of care.

Comments on preliminary 5.1

Placing greater emphasis on user choice could help to better satisfy patient preferences regarding the setting, timing and availability of palliative care.
PCA agrees that the provision of care that meets the needs and preferences of patients and their families. Our survey highlights the difficulties in providing care that meets these preferences, with 70% of respondents indicating a preference to die at home. We know that nationally, around 14% do.

However, patient-centred care requires patients and their families to understand the options available to them, to enable them to make an informed choice. In Australia there is a strong reluctance to talk about death and dying. The vast majority of people have not talked to their family about their end-of-life care preferences and have not documented their wishes. If people are not able to talk about their preferences, it makes it difficult to provide people with information to support their decision-making about preferred care providers.

As noted previously, many people who are faced with a life-limiting illness may be unable or unwilling to exercise choice in determining their care. The nature of the illness trajectories and associated care needs is that it is often unpredictable and frequently changing in nature. This can be difficult for both the patient and their family and carers. Any consideration of increasing people's ability to choose providers must consider these changing dynamics in order to protect people from making choices not in their best interest. This unpredictability could lead to major-market distortion.

We also know that people seeking support for someone who is dying, often requires that support quickly. Many people find accessing palliative care difficult, and people with a diagnosis other than cancer may not even be offered palliative care. In many cases, people are happy to have any palliative care service available to them. Where access is the main concern, choice of provider becomes irrelevant.

There are policy and funding design faults within the Australian health system that provide disincentives to integrated care. PCA have heard many stories of patients in hospitals who are being treated by a specialist medical team – for example oncology, renal, respiratory, cardiac – where the chronic condition of the patient has been deteriorating over time, but the specialists do not recognise that their patient may benefit from a different approach to their care that identifies their ongoing values and wishes for their health care. In some cases the reverse is true as well, PCA have heard stories of patients who perceive they have been forced into palliative care when not all treatment options have been fully explored.

Person-centered care is essential to delivering integrated care and the current barriers to achieving that are often policy related (example lack of exposure for undergraduates in speaking with patients about end-of-life issues, or recognising when someone may benefit from a change in approach to care) or funding related (aged care facilities funded by the Commonwealth unable to access state or territory funded specialist palliative care services). Greater emphasis on user choice would not necessarily satisfy patient preferences regarding the setting, timing and availability of palliative care.

Recommended actions

- Develop systems to ensure that patients have access to a palliative care service that meets their needs. This should be available regardless of whether the person is at home, in an aged care facility or in hospital.
- Support initiatives that help people have conversations about their preferences for care at the end of life.
- Ensure that every clinical and surgical specialist includes teaching outcomes relating to confidence in talking about dying with patients and their families, and matching the person's care plan with their goals of care.

• The quality of specialist palliative care services is highly variable, there are concerns about patients not being able to access services and there is limited performance reporting, particularly in community settings.

PCA would refer you to the letter the Productivity Commission received from Professor Kathy Eagar of the 11 October 2016, where Professor Eagar states that the Productivity Commission have misinterpreted the data provided to it from PCOC. Given the data sources used in the report have relied primarily on PCOC data this presents a significant issue in relation to the evidence provided and arguments for contestability that are put forward. As Professor Eagar states there has been significant reductions in variability over the past five years and that collaboration and cooperation is critical to ensuring improvement in palliative care outcomes. PCA supports the points put forward in Professor Eagar's correspondence.

PCA also makes the point that PCOC data are used in the assessment of quality. While PCA does not dispute that there is variability in the quality of provision of specialist palliative care services, there is no data to suggest that this variability in quality is greater than any other area of health in Australia. Variability in quality can be influenced by many factors, including funding, policy, staff availability and integration with other health services. Greater variability is likely to exist in services providing palliative care that are not specialist services, as there is no published standard for care for such services (other than a consensus statement for those in acute services).

Recommended action

- Support a project to identify the minimum requirements for palliative care services in the community, including non-specialist palliative care services.

• There is little evidence that service providers are being held to account for relatively low service quality. Introducing greater contestability could make providers more accountable for their performance and spur the innovation required to lift patient outcomes among the poor performers.

While there is always scope to improve on accountability, it is the view of PCA that specialist palliative care services have been proactive in being accountable for the services they provide. There are few areas of the health sector where data on patient outcomes are regularly reported, as you note has been achieved through PCOC.

Further, the National Palliative Care Standards were developed in 1994, preceding the recognition of palliative care as a medical speciality in 2005[2]. PCA manages the National Standards Assessment Program, which is a structured framework for continuous quality improvement built on the national standards for providing quality palliative care for all Australians. The National Standards Assessment Program Quality Report 2010-2015 reports that 178 centres participated in the program in the six year period[3].

The main concern with regard to accountability relates to the definition of palliative care. There are services, particularly in the community, that promote their service offering as palliative care, that would not meet the expectations of services outlines in the palliative care standards. Dealing with this problem through contestability is the option proposed in the report, but this could also be achieved through policy clearly articulating the requirements of palliative care services and other services providing care to people at the end of their lives.

PCA agrees that accountability could be improved through the collection of data and recommends that a minimum dataset be developed to support standardisation of data collection across Australia. Defining data collection requirements would also support linkage of datasets, providing evidence to support policy and funding decisions in the future.

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[2] http://cancerforum.org.au/forum/2007/march/a-short-history-of-palliative-medicine-in-australia/

[3] http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2016/03/2015-National-Report.pdf

• The potential to increase user choice through greater competition between providers or through more contestable arrangements would depend on market size and the ability to cost-effectively provide user-oriented information, among other things. The preferred reform option will likely vary across regions.

Palliative care is interdisciplinary care, and depending on the needs of the patient and their family the team may include:

- Medical Specialists including palliative medicine specialists
- General practitioners
- Nursing
- Social Work
- Counsellors
- Pastoral Care
- Occupational Therapy
- Speech Pathology
- Physiotherapy
- Pharmacy
- Music Therapy
- Volunteers

For this reason, there is a need for services to either act as commissioners of the required services, or to have them available within their service. For the services to be available in-house, it requires a large enough market size to make employment of those staff a cost-effective model. For this reason, while introducing measures to enhance accountability and efficiency are welcomed, the introduction of greater competition and user choice may only be feasible in the large capital cities in Australia, where the specialist palliative care market is not so thin. It may be that some of the larger aged care providers may be well-placed to provide palliative care in the community, but this would require them to be funded to enhance the services available to patients. In many cases, funding available under aged care packages is insufficient to cover provision of high quality palliative care.

If there is a lowering of barriers for entry for services into the field of specialist palliative care there will be perverse consequences from doing this. Most people wish to die in their own homes, yet nationally only 14% do so. The reasons for this are many and varied. PCA and the Australian Commission on Safety and Quality in Healthcare through it's National Safety and Quality Health Service (NSQHS) Standards program have been working together to ensure that the level of quality of palliative care received both in home and in acute services is of a sufficient level to ensure Australians receive quality care at the end of life, based on best available evidence. Use of standards helps to ensure that not just any service can say it is a palliative care service - there are certain requirements that must be met.

The Australian Commission on Safety and Quality in Healthcare has developed a national consensus statement on end-of-life care, which defines specialist palliative care as, 'services provided by clinicians[4] who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate nonspecialist clinicians who are providing palliative care.' To lower the barrier to entry into this field will have consequences for the delivery of quality palliative care to those who need it.

In 2005, the consensus document 'Palliative Care Service Provision in Australia: A Planning Guide 2nd Edition' was published. This document outlined the essential elements in a service setting, described the settings in which palliative care is provided and sought to estimate the number of people that might require palliative care in order to provide clinical staffing guidelines. However a body of work is required to update this document to ensure that it remains current and useful. This policy work would inform reforms in the palliative care sector.

Recommended action

- Provide funding to support Palliative Care Australia to complete work on updating the consensus document 'Palliative Care Service Provision in Australia: A Planning Guide 2nd Edition'
- Implement the actions identified above before developing a contestability and competition model for palliative care.

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[4] PCA interprets 'clinician' as a multi-disciplinary group of health professionals