Palliative Care Australia

Submission to the Department of Health on the Review of Medicare Locals

December 2013

Palliative Care Australia

Palliative Care Australia (PCA) is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life. Our mission is to influence, foster and promote the delivery of quality care at the end of life through ongoing policy and advocacy, education, and developing collaborative relationships in Australia and internationally.

We believe that palliative care must be available regardless of location, age, income, diagnosis or prognosis, social and cultural background, to support Australians to live well at the end of life.

But we remain a very long way from achieving our goals. In 2011, nearly 147,000 Australians died. Of these, 107,000 would have benefitted from access to palliative care services, yet only one third to one half did. Recognition of the potential role of Medicare Locals offers opportunities to improve these outcomes.

Palliative care is delivered across a broad range of settings including hospitals, hospices, aged care facilities, in the community and in people's own home. Whilst delivery of complex palliative care is best managed by specialist teams, the majority is managed by health professionals delivering generalist palliative care. This is especially true of the primary care workforce.

All people diagnosed with a life limiting illness, as an absolute minimum, require access to primary care providers that have knowledge and skills in the care of people with a terminal illness. These skills, attributes and knowledge applied within the context of a primary care relationship are sometimes referred to as a palliative approach or generalist palliative care (in contrast to specialist palliative care). A palliative approach uses the basic principles of palliative care, adapted to recognise and reflect the different expertise, experience and resources of primary care providers. [1]

A number of access pathways need to be in place for patients, primary carers and families requiring palliative care support. Many patients receiving primary care will already have an established and ongoing relationship with their primary care provider. For these patients, generalist palliative care will be introduced as part of the ongoing and comprehensive care they are already receiving. Access to primary care providers will generally utilise existing referral and relationship mechanisms.

With regards to palliative care, the term 'primary care providers' includes general practitioners, community and hospital based doctors, nurses and allied health staff, and staff of residential aged care facilities whose substantive work is not in palliative care. As these health professionals, and those within specialist palliative care teams, are split across the Medicare Local and Local Hospital Network frameworks, it is essential that clear mechanisms exist both geographically and systemically to ensure a continuum of care.

PCA recognises the important role that Medicare Locals can play to impact on enhanced system level integration of care for those with palliative care needs. From our perspective, this critical aspect of the health reform agenda creates the opportunity to enable people with terminal conditions to have seamless access to quality health services.[2]

Given that the establishment of localised primary health organisations in the form of Medicare Locals provided a unique opportunity to improve the provision of well coordinated multidisciplinary healthcare, PCA regrets the fact that palliative care was not addressed in the original governance and functions of Medicare Locals.

Levels of understanding of palliative care vary substantially amongst primary health professionals, so education and support mechanisms will need to be improved. Medicare Locals could play a vital leadership role in developing better integration of care services for people with terminal conditions,

[1] Palliative Care Australia, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005. http://www.palliativecare.org.au/Default.aspx?tabid=2016
[2] Palliative Care Australia, *Health System Reform and Care at the End of Life: A Guidance Document*, PCA, Canberra, 2010.

including developing and implementing the necessary referral criteria and the enhanced workforce education that will be necessary.

Clearly care of the dying must be a standard education provision for every health professional across their career. Medicare Locals could play a role in monitoring levels of knowledge amongst primary care professionals in their catchment, and assisting in the coordination of educational opportunities.

This could be further facilitated through the expansion of the Procedural GP program to include palliative care, hence beginning to redress the lack of access to quality palliative care in rural and remote communities.

Palliative Care Australia is currently part of a consortium funded by the Federal government to establish better linkages between aged care and specialist palliative care through a 24/7 telephone advice line, ongoing education and resources, and the development of innovative practices. This is a complex project engaging with GPs, aged care professionals and specialist palliative care services. Medicare Locals could be an important adjunct to this project and others if their linkages with aged care and the Local Hospital Networks (where most specialist palliative care is located) were more clearly defined.

To improve end of life care for all Australian communities, infrastructure and models of care will require substantial improvement, especially in the areas of after hours access, medication access, and funding. Palliative Care Australia is currently working closely with the sector to review the *Standards for providing quality palliative care for all Australians*[3]. This process will include a focus on aspects of the Standards relating to primary care, and Medicare Locals could play an important role in dissemination of information regarding the Standards and encouragement of their broad adoption.

It would also be valuable for Healthy Communities Reports to include specific information on palliative and end of life care, such as statistics for the numbers of supported home and hospital deaths, the percentage of the community who have been assisted by a health professional to develop an advance care plan, and levels of training and adoption of a palliative approach across local primary and aged care services.

As well as driving more efficient use of our health resources, Medicare Locals should be expected to drive – and deliver – more *effective* use of our health resources to achieve truly integrated services to the benefit of all Australians. This needs to include engagement with subacute services including palliative care; bereavement support and related models of care; and the need to, and means of, identifying patients with palliative care needs, and to assess those needs.

PCA recommends that the Strategic Objectives for Medicare Locals should include the following additional points:

1. **Improving the patient journey through developing integrated and coordinated services**
   - Integration with key national stakeholders (including Palliative Care Australia) and participants in the National Palliative Care Program funded by the Australian Government such as PEPA, NSAP, PCOC, PACCSC, Respecting Patient Choices and CareSearch.
2. **Provide support to clinicians and service providers to improve patient care**
   - Medicare Locals must be tasked, and enabled, to support general practitioners (GPs) and other health professionals to gain the skills and resources needed to identify those patients needing palliative care, and to achieve effective integration of that care within the broad health system. It is vital to improve education of GPs and other health professionals about palliative care.
3. **Identification of the health needs of local areas and development of locally focused and**

[3] Palliative Care Australia, *Standards for providing quality palliative care for all Australians*, PCA, Canberra, 2005. http://www.palliativecare.org.au/Default.aspx?tabid=2016

responsive services

- maintain a population health database including community health and wellbeing measures, provide input to population health profiles, and undertake population health needs assessment and planning, ensuring inclusion of end of life care needs;
- undertake detailed analyses of primary health care service gaps including those regarding death and dying, and identify evidence-based strategies to improve health outcomes and the quality of service delivery in local area populations, including for disadvantaged or under-serviced population groups;
- conduct joint service planning with Local Hospital Networks and other appropriate organisations; and
- facilitate a reduction in inappropriate or inefficient service utilisation and avoidable hospitalisations through education and services to deliver palliative care in the community (whether home or RACF).

4. **Facilitation of the implementation and successful performance of primary health care initiatives and programs**
    - Medicare Locals must be mindful of the need to provide workforce support.
5. **Be efficient and accountable with strong governance and effective management**
    - Medicare Locals must involve key national stakeholders (including Palliative Care Australia).

Medicare Locals could seize this challenge to support GPs and other health professionals to gain the skills and resources needed to identify those patients needing palliative care, and to achieve effective integration of that care within the broad health system. It is essential to improve education of GPs, practice staff, community health and allied health staff about palliative care.

Given that we are already aware of the fractured journey that many patients must navigate to achieve quality care at the end of their life, PCA has significant concerns about the ability of the system to achieve the necessary integration between acute, subacute, and primary care services if Medicare Locals are not actively engaged in this space.

The current experience of end of life care in Australia is disparate and inconsistent. We cannot, in good faith, promise all people at the end of their lives access to care that is customised to their preferences and reliably delivers good pain and symptom control. The inability to manage preventable pain in the home or in residential aged care facilities, combined with difficulties in accessing medication and community care services, contribute to the current overloading of hospital services. Our health care system can do better.

Medicare Locals have the potential to play a vital role in enhancing primary care to offer a team based range of services including general practice, allied health and nursing supports, with referral pathways to and from specialist services, to ensure that they can provide well coordinated multidisciplinary care to meet the needs of people at the end of life. This cannot be achieved without improved funding and planning of community care, and expanded workforce education.

Medicare Locals provide an important opportunity – and challenge – to better integrate palliative care within the broad health system and thus limit the current barriers to the provision of seamless, quality care for people nearing the end of their life.