Australian General Practice Network submission to the Senate Community Affairs Committee

The provision of palliative care in Australia

April 2012

Australian General Practice Network

PO Box 4308

MANUKA ACT 2603

Telephone: 02 6228 0800

Facsimile: 02 6228 0899

www.agpn.com.au

The Australian General Practice Network (AGPN) currently represents a network of 106 general practice networks (GPNs) as well as eight state based entities. AGPN and its members are collectively known as the Network. More than ninety per cent of general practitioners (GPs) and an increasing number of Practice Nurses and allied health professionals are members of their local general practice network. The Network is involved in a wide range of activities focused on improving the health of the Australian community including health promotion, early intervention and prevention strategies, health service development, chronic disease management, medical education and workforce support.

The Network is currently in transition, providing the foundation for the establishment of the new national network of Medicare Locals (MLs). MLs are regionally-based primary health care organisations responsible for supporting greater coordination of primary health care services regionally, identifying and addressing local service gaps, driving quality improvement in primary health care and helping to deliver on the goals of the Primary Health Care Strategy including prevention and better self-management of chronic disease.

AGPN will soon establish the Australian Medicare Local Network, the national body for the establishing ML network, which will provide leadership to support MLs in driving change management at a regional level, and facilitate high quality performance through MLs.

Australian General Practice Network
PO Box 4308
MANUKA ACT 2603
AUSTRALIA

Telephone: +61 2 6228 0800
Facsimile: +61 2 6228 0899
Email: agpnreception@agpn.com.au
Web: www.agpn.com.au

AGPN acknowledges funding from the Australian Government under the Divisions of General Practice Program.

Contents

Executive Summary

The Australian General Practice Network (AGPN) welcomes the opportunity to provide a submission to the Senate Standing Committee on Community Affairs regarding the provision of palliative care in Australia.

AGPN's response, informed by consultation with our network of members, focuses on the provision of palliative care in primary health care, the health care setting which is the key focus of Network activity and the Network's key area of expertise.

Quality palliative and end-of-life care must be person centred and seek to uphold the patient's considered care preferences, including by planning in advance to address likely future needs. It should also be needs-based and provide patients with access to the right health services at the right time to meet their needs.

Person-centred and needs-based palliative care also provides for the most efficient system of care. Patient-centred palliative care tends to be the most cost efficient, as patients overwhelmingly prefer to die in their own homes, preventing the need for unnecessary hospitalisations and interventions. Needs-based systems support efficiency by recognising that whilst some individuals with terminal illnesses will require regular support from a specialist palliative care team, for many, their palliative and end of life care needs can be primarily met by generalists, often their general practitioner and primary health care team. Needs-based care thus also offers the potential to provide the greatest access to palliative care within the limitations of the current health workforce.

Increasing the capacity of the primary health care system to deliver quality palliative care is key to enabling better access to quality, person-centred and needs-based palliative care. Estimates suggest that close to three quarters of people whose death is predictable and who would therefore benefit from palliative care, largely receive care, through generalists (that is primary health care professionals or specialists working in disciplines other than palliative medicine.) The competency and capacity of the primary health care system to provide quality palliative and end-of-life care, and the accessibility of primary health care services to those with palliative care needs, are key elements determining access to quality palliative care.

Currently, the skills and capacity of primary health care professionals to identify patients with palliative care needs and to identify and address their needs is highly variable. In the absence of a systematic approach for doing so, it is dependent on the clinician's education, experience and interest in palliative medicine and on local relationships between health care and other service providers.

There are also a number of structural barriers to the provision of quality palliative care through primary care. These include: insufficient remuneration to support home visits; difficulty in providing services to residential aged care facilities (RACFs) and in the after hours period and; poorly established local networks between primary care providers, specialist services and other care providers.

There are, however, ready opportunities to enhance access to quality, person-centred palliative care through primary care. These include:

- the introduction of an evidence-based, systematic framework to support primary care professionals to identify patients with palliative needs and identify and address their needs
- providing education for primary health care professionals to increase their skill and confidence to provide best-practice primary palliative care
- supporting the development of advance care plans by enhancing the capacity of primary health professionals to work with patients, their families and carers to develop well-considered plans
- ensuring a regionally-consistent approach to recording advance care plans to ensure that the care preferences they detail can continue to operate and be respected as patients move between services
- establishing a regional coordination function for palliative primary health care to identify and address service gaps and to strengthen local networks and referral pathways.

The introduction of Medicare Locals (MLs) - regional primary health care organisations with responsibility for enhancing local system coordination and integration - provides ready opportunity to support the national roll-out of a systematic framework for primary palliative care and accompanying education in best practice palliative care for primary care professionals. MLs are also well placed to provide regional coordination of primary palliative care and greater integration and networking with Local Hospital Networks (LHNs), aged care providers, and other key stakeholders, to support coordinated care provision.

The benefits of enhancing the capacity of the primary health care sector to provide quality palliative care will be maximised, if they are supported by investments to enhance the capacity of the aged and community care sector to deliver palliative care and support the development of advance care plans, and to ensure access to 24/7 palliative care support for Australians, regardless of the setting in which they are dying.

Definitions and terminology

AGPN supports the definition of palliative care provided by the World Health Organisation (WHO), which also highlights elements of quality palliative care: "*Palliative care is an approach that improves the quality of life of 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. Palliative care:*

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*

- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."*

AGPN believes that palliative care can be provided by both generalist (including primary generalists such as general practitioners and practice nurses) and specialist providers, and that quality palliative care is more likely to be provided in circumstances where strong networks exist between generalist and specialist providers.

AGPN notes a distinction between palliative and end of life care, where palliative care is care that may be provided over the course of a life-threatening illness/condition and end of life care is care provided in the last weeks or days of life (i.e. when death is imminent.) End of life care is only one element of quality palliative care.

About the Australian General Practice Network

AGPN is the national organisation representing 110 general practice networks (GPNs) and eight state-based organisations (SBOs). AGPN and its members are collectively known as the Network. AGPN coordinates and disseminates general practice and other primary health care programs through the Network, including those with a focus on:

- Chronic disease management
- National primary mental health care initiatives
- Indigenous health
- Immunisation
- eHealth and information management
- Prevention and lifestyle modification
- Nursing in general practice
- Quality use of medicines.

GPNs represent the community-based infrastructure which enables general practice to provide services to patients in the community and in their homes. GPNs:

- deliver local health solutions through general practice to ensure all Australians have access to high quality primary health care
- increasingly deliver services directly to patients – particularly through allied health and nursing
- are in tune with their local communities. They understand their communities' health needs and socio-demographics as well as how these two interact - which makes them a solid foundation for strengthening Australia's primary health care system
- are involved in a range of activities including

  - health promotion
  - early intervention and prevention strategies
  - health service development and delivery
  - medical education
  - workforce development and support
  - eHealth and other strategies to connect care.

The Network is unmatched in its locally based support services which penetrate the vast array of communities across Australia – it is the only national, state and regional/local infrastructure of its type.

The Network has worked to enhance the provision of palliative care at a local level, most particularly through the Rural Palliative Care Project (RPCP.) The RPCP, which ran for three years from 2008-2011, increased the capacity of primary health care providers to provide quality palliative care to rural and remote Australia, by building multi-disciplinary teams through integrated systems of communication and education, and support for evidenced based best practice palliative care services. It also enhanced the experience of care for the palliative patient and their carer(s) by strengthening the links between specialist palliative care services and mainstream health service delivery.

The Network is currently in transition, providing the foundation for the establishment of the new national network of Medicare Locals (MLs.) MLs are regionally-based primary health care organisations, responsible for:

- supporting greater coordination of primary health care services across their region
- identifying and addressing local service gaps and areas of need
- driving quality improvement in primary health care.

The Government has announced that initial focus areas for MLs will include after-hours services, mental health care and care for older Australians. MLs focus on supporting primary health care access for older Australians and their broader focus on coordination and integration, provide opportunities to enhance the provision of palliative and end of life care at the local level. AGPN has also recently argued through its submission to the Federal Budget, the merits of using the ML network to roll-out a systematic framework to identify and address palliative care needs through general practice and primary care services.

The first and second of three tranches of MLs have been established, with the full national network of 62 MLs expected to be operational by 1 July 2012.

The Commonwealth Government has made clear its intention that AGPN will evolve to become the national body for the network of MLs (known as the Australian Medicare Local Network - AMLN) during 2012. AMLN will provide leadership to support MLs in driving change management at a regional level and driving high quality performance through MLs.

Response to inquiry terms of reference

The following outlines AGPN's response to the terms of reference for this inquiry. This response has been informed by consultation with the Network and is focused on the provision of palliative care in primary health care, the health care setting which is the main focus of Network activity and the Network's key area of expertise.

(a) factors influencing access to and choice of appropriate palliative care that meets the needs of the population

Access to quality palliative care that meets the needs of the local population and provides them with meaningful choice in care is highly variable and inconsistent across Australia. Inconsistency in quality, availability and accessibility of services is associated with:

- variable funding arrangements across jurisdictions. Funding arrangements to support the provision of palliative care are complex and include both State/Territory and Commonwealth Government sources, provided through multiple programs and schemes. Jurisdiction-specific funding arrangements have a significant impact on the type of services provided and their availability, as well as coordination and integration of services. For example, the West Australian government provides significant funding to support home-based palliative care, providing access to comprehensive palliative care services in a patients' home, which is not widely available in other states and territories.
- lack of a systematic approach to support primary care professionals in identifying and addressing patients with palliative care needs. As a result, determination of which patients receive palliative care, and by whom, is often dependent on the knowledge and skills available locally (for example through the individual GP, primary care team, non-palliative care specialist, local networks, local referral pathways or service admission criteria) rather than on agreed best-practice protocols.
- lack of a systematic approach to support aged care teams, particularly those providing care in residential aged care facilities, to recognise when a patient's palliative care needs should be assessed, and how to trigger such an assessment.
- lack of a nation-wide effort to support coordination and integration of local services. This deficit can mean that in some areas, services are well-networked and provide access to well-coordinated care for patients, whilst in other areas this coordination is lacking. Whilst there has been Commonwealth investment to support local networking and locally-tailored initiatives, such as through the Rural Palliative Care Project, this activity has not, to date, been supported across Australia. Furthermore, the short-term nature of the project means that there are not the resources to continue to maintain many of the advances made through the project over the long term. MLs and Local Hospital Networks (LHNs) have been established as new infrastructure to drive better coordination of health care services and so provide opportunity to achieve this coordination goal, along with cross-sectoral integration, at a regional level.
- inequitable distribution of health professionals (both specialist and generalist), including notable shortages and limited access to health professionals in many rural and remote areas.

- residential status – that is, whether or not a patient is living in the community or in a residential aged care facility (RACF). In some instances the variable, and too often limited, access of residents in RACFs to GPs and primary care professionals can impede timely access to primary palliative care or referral to specialist care. As discussed elsewhere in this submission, poor access to primary health care professionals for residents in RACFs is linked to a number of barriers including insufficient remuneration to justify health professionals providing services outside of their clinic/practice.
- local availability of after-hours primary and specialist care services.
- local availability of required medications, particularly medicines that are not listed on the Pharmaceutical Benefits Schedule (PBS). Accessibility of these medications for patients in the community varies with local contexts. Lack of access to these drugs for patients in the community, and their cost, can result in patients being hospitalised in order to access medicines, as these medicines tend to be more readily available in hospital settings and the cost of their provision is also covered.

Whilst service accessibility is variable across the country, in general, access to quality, patient-centred palliative care that supports patients to die in accordance with their care preferences, is suboptimal. Tellingly, whilst older Australians, overwhelmingly express a preference to die in their home only around 16% do so.[1]

Access issues are particularly acute for specific sub-populations, including for Aboriginal and Torres Strait Islanders and for people from culturally and linguistically diverse backgrounds, as they are often compounded by:

- limited awareness and understanding amongst service providers of cultural meanings, attitudes and practices around death and dying
- lack of awareness of service availability and communication barriers associated with limited English speaking and reading skills.

Further, whilst Indigenous Australians, like non-Indigenous Australians, overwhelmingly prefer to die in the familiar surroundings of home, in some communities there can be added complexity to providing effective, quality care associated with the poor standard of/limited access to basic services in these communities.

In addition to the recommendations made through this submission to enhance access to quality palliative care, specific steps are required to ensure better access to care that is culturally appropriate. These include:

- providing ongoing education to health and aged care workers regarding the need to work with patients, their families and carers, to understand, and appropriately respond, to diverse understandings of death and dying
- the flexibility in service delivery models, and the funding arrangements that support them, to enable the provision of care that is responsive to specific cultural requirements

---

1 See http://www.caresearch.com.au/caresearch/tabid/407/Default.aspx (accessed 4/4/2012.)

- ensuring ready access to interpreter services and information tailored to different cultural and linguistic contexts.

The Productivity Commission, following its recent inquiry into aged care, made a number of recommendations relating to aged care that have relevance to the provision of culturally appropriate palliative care. They recommended that the national network of 'Seniors Gateways' - which they proposed as a mechanism to support older people to access assessment services and aged care information - also assume responsibility for facilitating service access for people from culturally and linguistically diverse backgrounds, through the provision of specific 'hubs' for older people with limited English skills or specific cultural needs. They further recommended that aged care funding take into account additional costs associated with providing quality care for people from non-English speaking backgrounds (such as for interpreter services) and associated with providing care in remote locations. AGPN supports these recommendations.

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent

As noted above, funding arrangements to support the provision of palliative care are complex. Funding is provided through both State/Territory and Commonwealth Governments, and streamed through multiple programs and schemes. Associated with this is variability in service availability and quality and, too commonly, fragmentation across the system - services and programs often operate independently and there is limited integration with other providers in the region. As a result, too often, care received is suboptimal and the frustration of trying to navigate a complex system compounds an already difficult and challenging time for patients, their families and carers.

As highlighted throughout this submission, the new regional coordinating infrastructure provided by MLs and LHNs, provides opportunity to facilitate greater service networking and integration at a regional level, and thereby provide for better connected and coordinated care. GPNs through the RPCP have demonstrated that a regional coordinator can achieve greater service connectivity and collaboration at a local level, and thereby help realise greater patient access to well-coordinated and comprehensive palliative care.

Funding to support primary palliative care

A notable barrier to the provision of quality palliative care through the primary health care system is insufficient remuneration to support and encourage GPs and primary health care professionals to provide care to:

- residents in RACFs, for whom palliative care requirements are common (in 2008 the percentage of separations by death in RACFs was 87.8[2])
- patients in their own homes

---

[2] Australian Institute of Health and Welfare (2009). *Residential Aged Care in Australia 2007- 2008: A statistical overview*, Canberra.

- patients after hours. This is often essential to providing quality end of life care that accords with a patient's wishes. Rapidly changing health status is common at the end of life and can mean patients require prompt care to avoid prolonged discomfort and unwanted (and otherwise unneeded) hospitalisation.

Services of these types provided by GPs are subsidised through the MBS are insufficiently remunerated to make their routine provision economically viable for many providers. As a result, access to GP services in RACFs is often poor[3] and in many areas there is limited or no access to GPs providing home visits, to afterhours face-to-face services or to afterhours homecare, which is often essential to provide palliative care that accords with a patient's wishes and enables them to continue receiving care in their home or RACF.

MLs have been tasked with assessing and providing locally-tailored solutions to after-hours GP service needs in their regional jurisdictions from 1 July 2012. Whilst this can be expected to enhance access to after-hours face-to-face services it is not yet clear to what extent it will address the barriers to care provision in RACFs or to home visits. The barriers to GP service provision in RACFs are both financial and practical. Overcoming these to ensure timely access to GP services for residents of RACFs demands increases in remuneration for GP services provided in RACFs to more realistically compensate for lost clinic time associated with travel, service provision and follow-up paper work. This currently applies to RACF visits both in and out of normal care hours. These increases should be accompanied by measures tailored to overcome locally-specific barriers, including relationships between RACF clinical staff and attending GPs, and the efficiency of communication systems between GPs, RACFS, community pharmacies and hospital services. Overcoming many of these barriers can be realised by imbuing MLs with both the responsibility and resources to broker GP services for RACFs in their region.

(c) the efficient use of palliative, health and aged care resources

Key elements to using available resources efficiently in the provision of timely access to quality palliative care are:

- **Needs-based care provision:** AGPN believes that the most efficient and effective way to provide quality palliative and end of life care for all those who require it is in accordance with a needs-based system of care. Needs-based systems of care seek to provide care on the basis of individual need, rather than on the basis of diagnosis. They recognise that, whilst some individuals with terminal illnesses will require regular support from a specialist palliative care team, for many, their palliative and end of life care needs can be primarily provided by generalists, often their general practitioner and primary health care team.

  In Australia, we currently lack a systematic approach to implementing a needs-based system of care. To ensure patients access care matched to the relative complexity of their needs, we need a national systematic approach to support the recognition of

---

[3] For example, a survey of 90 catholic aged care facilities found *that 15% experienced difficulty in accessing GPs to the extent that access issues sometimes compromised* patient care. See: Catholic Health Australia. (2010) Survey of access to general practice services in residential aged care. (Accessed on 24/01/2012 via: http://www.cha.org.au/site.php?id=15)

people with palliative and end of life care needs, and standardised tools to determine patient and carer needs that match the care provided and the care providers to identified patient needs. Further, we need to provide primary health care professionals, particularly GPs, with the knowledge and skills to implement such a systematic approach.

- **Equipping primary health care teams to provide quality palliative care:** The majority of people whose death can be predicted are cared for at home in an ad hoc way by their GPs.[4] Enhancing the capacity of primary care to provide quality palliative and end of life care will likely lead to gains in efficiency as well as, importantly, in patient wellbeing.

  Investment in GP led care is expected to reduce the frequency of hospital admission and improve quality of life for those whose death can be predicted[5]. The proactive involvement of GPs enables more terminally ill patients to die at home - the preference of many patients and their carers - as well as providing a cost-effective alternative to hospitalisation[6].

  Yet, providing high-quality care at the end of life is among the most complex challenges in general practice[7]. Patient symptoms may be severe, disease trajectories difficult to predict, family issues complex, and the GP's and nurse's own beliefs and fears about death and dying challenging[8]. There are also a number of structural and resource barriers including lack of time, remuneration, training, knowledge and resources[9].

  To provide quality palliative care, primary care teams need to be able to identify patients with palliative and end-of-life care needs, assess the needs of the patient and their carer and establish effective management plans. To support them in doing so in an evidence-based way we need to develop, and facilitate the implementation of, a systematic approach to support GPs and primary health care teams to:

    - identify patients with palliative and end of life care needs
    - assess these needs, including consideration of who would benefit from specialist palliative care services and
    - address these identified needs, including both physical and emotional ones.

  Addressing patient needs within a needs-based system of care, demands that such a systematic approach is complemented by strong partnerships and networks between primary care providers, aged care services, disease specific organisations and services, and specialist palliative care services.

---

[4] Murray, S & Sheikh, A 2008, 'Care for all at the end of life'. *BMJ*, vol. 336, pp. 958.

[5] Mitchell, GK et al. 2008, 'Do case conferences between general practitioners and specialist palliative care services improve quality of life? A randomized controlled trial'. *Palliative Medicine,* vol. 22, pp. 19.

[6] *ibid*.

[7] *ibid*.

[8] National EOL Framework Forum. *Health System Reform and Care at the End of Life: A Guidance Document.* Palliative Care Australia, 2010 pp. 35

[9] Rhee, JJO et al. 2008, 'Attitudes and barriers to involvement in palliative care by Australian urban general practitioners'. *Journal of Palliative Medicine,* vol. 11, pp. 980–5.

- **Patient-centred care and support to die at home:** Quality palliative and end of life care should be directed at supporting individual self-determination, enabling patients, to the greatest extent possible, to live the last period of their life in accordance with their care preferences. Patient-centred palliative care also tends to be the most cost efficient, as patients overwhelmingly prefer to die in their own homes, preventing unnecessary hospitalisations and interventions.[10]

  Too often, however, patients are hospitalised, against their wishes, during the last period of their life. Often this is associated with:

  - inability to access required medication or care when health status changes, particularly outside of standard hours
  - insufficient planning and poor communication to ascertain and communicate a patient’s care preferences across the care team in cases of predictable health status changes and
  - limited access to care in the home as care needs increase and carers fatigue.

  Supporting patients to live and die in accordance with their care preferences requires:

  - health professionals suitably trained to work with patients, their families and carers, to develop realistic and well-considered advance care plans
  - access to health care services matched to their level of need provided in the patient’s home, whether this be in the community or in a RACF
  - ready access to 24 hour support for palliative patients to ensure their needs can be met in the home environment when a change in their health status leads to medical care requirements outside of standard hours
  - established networks and communication channels between all involved in the care team, including established mechanisms for communicating advance care plans, to minimise risk of unnecessary and unwanted hospitalisation
  - consumers/patients to be aware of their rights to die in accordance with their care preferences and opportunities to enhance the chance of doing so through advance care plans and directives.

  Investing to realise these elements of a palliative care system should be prioritised as a way to provide cost-effective, patient-centred care.

- **Caring for carers**: Carers play a vital role in providing the level of care and support necessary to assist people with a terminal illness to spend the final stages of their life at home. It is often, and understandably, the fatigue of carers that can lead to institutionalisation or hospitalisation of a person with a terminal illness. Evidence attests to an inextricable relationship between the wellbeing of carers and that of patients[11]. Carers too often have limited access to support them to continue their caring role and, at the same time, to care for themselves. Yet investing in support for carers is a resource-efficient approach to person-centred care.

---

[10] Mitchell, *op cit*.

[11] L. Higginson et al. (1990). ‘Palliative care: views of patients and their families.’ *BMJ* Vol 301; 277-81.

Critical to supporting carers maintain their caring role is access to sufficient and timely in-home care for the patient, including access to 24 hour care. To better support carers, there must also be systems in place to:

- provide ready access to information and education regarding palliative and end of life care
- provide ready and regular access to flexible respite arrangements
- develop and implement tools to assess carers' health and wellbeing needs, and approaches to address these needs
- ensure carers are involved as much as possible, and with the consent of the patient, in care discussions and decisions
- provide subsidised access to bereavement support for carers and families
- provide sufficient financial support to enable the carer to perform their caring role.

(d) effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

As detailed above, access to, and quality of, palliative and end of life care across Australia is inconsistent and variable. This inconsistency extends to the effectiveness of palliative care provided in particular settings including general practice and primary care settings and RACFs, and in conjunction with community care.

Primary care

Whilst the majority of people whose death is predictable in the near future are primarily cared for through general practice, the quality of palliative care provided through general practice and primary health care services is variable. In the absence of a systematic approach to support primary health professionals to identify and address patients' palliative care needs, the quality of care provided is in large part reliant on the individual knowledge and experience of the GP and the primary health care team, who commonly have had limited access to relevant training and resources. Indeed, providing high quality care at the end of life has been identified as one of the more complex challenges GPs experience, further complicated by cultural barriers to discussing death and dying.

As noted above, there are also a number of structural barriers to the provision of quality palliative care through general practice and primary care. Whilst providing quality palliative care can require lengthy consultations, home care and after hour visits, many GPs are reluctant to provide these services which are insufficiently remunerated through the current MBS and which add to already heavy workloads.

The strength of local networks, relationships between primary care services and specialist services, can have a significant impact on the comprehensiveness, timeliness, and adequacy of care received. Whilst again, there is much local variability in this, too commonly there are poorly established local networks between different providers and GPs and primary care providers have limited relationships with specialist services. This again is one area that the newly established MLs and LHNs could assist with.

Residential aged care facilities and community care

The quality of palliative and end of life care in RACFs is, like the quality and accessibility of palliative care across the country, inconsistent. Too commonly there is limited discussion around death, dying and care preferences and sub-optimal management of symptoms such as pain and dysphasia. Too often, common end-of-life health changes, such as respiratory failure, are treated as medical emergencies resulting in hospitalisation. Sub-optimal palliative and end-of-life care in residential facilities is associated with a range of factors, many of which differ across jurisdictions and are linked to the widely variable funding arrangements across the country. These include:

- lack of adequate funding to support provision of quality care, including lack of funding to purchase required equipment (ACFI[12] palliative care funding requirements are insufficient in many instances and often can not be met by the RACF due to limited access to health professionals and the focus of the requirements on pain which may not be experienced by all patients who would benefit from palliative care)
- lack of systematic approaches to support RACF staff to make appropriate decisions when a patient's health status changes quickly
- limited access to GPs, nurses and other primary health care professionals, required to provide comprehensive care and to administer opioids for pain relief and symptom control
- inadequate access to specialist palliative care consultancy services to augment care provision for people with complex needs, sometimes associated with lack of awareness amongst the health care team of the availability of specialist services
- limited access to required medications, particularly to palliative medicines that are not PBS-subsidised but which are commonly available through hospitals where they are funded by the State Government
- lack of skills and experience amongst aged care staff and primary care professionals attending the facility in providing palliative care, including in supporting the development of advance care plans.

Likewise there are inconsistencies in access to, and the quality of, palliative and end of life care for community care recipients. Whilst there are examples of programs and jurisdictions providing broad access to high-quality palliative care, coverage is patchy and sub-optimal care remains common. Many of the barriers to quality care in RACFs are also relevant to community care. In addition, community aged care funding does not include explicit provision for palliative care, with the apparent assumption that this will be provided through the health system. Yet, as detailed above, there are significant barriers to the provision of quality palliative care in the community.

After hours care

Access to care outside standard clinic hours is a limitation to the provision of quality palliative care for people dying in the community and in residential facilities. During the last stages of life a person's condition can change rapidly. Maintaining comfort and

---

[12] ACFI: Aged Care Funding Instrument

providing sufficient support for family members and carers at the onset of symptoms that can be distressing often requires prompt responses. Too often, timely access to required services (be they primary or specialist) outside of standard service hours is unavailable, frequently resulting in hospitalisations that would have otherwise been avoidable. Conversely, evidence suggests that access to '24/7' care and support can reduce unnecessary hospitalisations and enable more people to die at home in accordance with their care preferences[13].

Care interfaces

As Palliative Care Australia have elsewhere articulated, "many of the problems associated with the effective provision of end of life care… relate to the barriers that occur at the interfaces between the settings, between services and between health care professionals…"[14] Trying to navigate between services that are not well-integrated can be complicated and stressful for patients and their families and carers. Poor communication between services can result in a number of unnecessary, avoidable and potentially damaging events. These include:

- poor medication management
- health assessment and treatments based on incomplete information
- duplication of assessments and tests that can be unpleasant or distressing for the patient and
- provision of care that is unwarranted, unwanted and contrary to the preferences detailed through a patient's advance care plan.

Recommendations to enhance quality and consistency of care

There are a number of opportunities to enhance the way primary care, aged and community care services support access to quality palliative care, through effective use of the new national infrastructure provided by the network of MLs. These include:

- the development of an Australian Primary Palliative Care Framework that, like the Gold Standards Framework successfully implemented in the United Kingdom, supports GPs and primary health care teams to take a systematic, best practice approach to:
    - identifying patients with palliative care needs and
    - identifying and addressing these needs, including through the development of clinical care plans and advance care plans.

---

[13] Department of Health NHS (2008). End of life care strategy: Promoting high quality care for all adults at the end of life. (Accessed 24/01/2012 via: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf)

[14] Palliative Care Australia. (2010). Health system reform and care at the end of life: a guidance document. Canberra, p.40.

MLs are well placed to provide the necessary practice support, education and training opportunities to support broad uptake of such a Framework and embed it within general practice, and should be resourced to do so.

- supporting the establishment of strong local networks between primary care, specialist palliative care, aged care, community care and social care services, and of referral pathways (where they do not already exist) based on best-practice. As regional service connectors and coordinators, MLs, if supported by adequate resourcing, are well-placed to work in partnership with local stakeholders to map and network local services.
- supporting timely access to GPs and primary health care professionals for residents in aged care facilities through locally-relevant initiatives that address the practical and financial barriers to the provision of primary health care services in these settings. As service coordinators with strong connections to local GPs and primary health care providers, and with experience performing similar access brokerage roles under the Aged Care Access Initiative, MLs are well positioned to perform this role.
- resourcing MLs to coordinate the provision of care coordination services for community-based patients with complex care needs, including those with palliative care needs. Care coordination has been shown to support better access to health services, better health outcomes and improve the patient experience. Provision of care coordination service is a role many MLs, in their previous iteration as GPNs, have shown themselves to perform competently.

Supporting the provision of quality palliative care through primary care as well as through aged and community care services also requires:

- adequate resourcing for RACFs to provide quality palliative care. AGPN recommends that a review of current funding arrangements for RACFs relating to palliative care be undertaken to inform the development of a system more appropriate to covering the costs of the provision of quality palliative care.
- systems to ensure that all RACFs have in place processes and systems to support decision making amongst care staff/case managers
- ongoing education and training for aged and community care workers in palliative and end of life care
- a national roll-out of a systematic approach to advance care planning for residents in aged care facilities
- sufficient funding to ensure access to 24/7 palliative care support for Australians dying in the community or in residential facilities.

(e) the composition of the palliative care workforce, including its ability to meet the needs of the ageing population, and the adequacy of workforce education and training arrangements

As detailed above, the capacity of the health workforce to meet population palliative care needs, will be enhanced through the implementation of a needs-based approach to care, where the relative complexity of patient need determines what sector of the health system is the primary agent of care. In a needs-based system, primary health care professionals and community care and aged care workers are a key component of the palliative care workforce.

Both the aged care and primary health care workforces are plagued by workforce limitations associated with a range of factors, including:

- comparatively poor remuneration when compared to health professionals/workers in other sectors, which limits ability to attract and retain workforce
- ageing of their workforces
- increasing demand for both aged care workers and health care professionals associated with population ageing.

Addressing workforce shortages in the primary health care and aged care sector requires a comprehensive and ongoing approach and will not be achievable without adequate resourcing. One element in addressing workforce shortages is more effective utilisation of the available workforces. This has been recognised at a national level and a number of national projects are now underway with the intention of maximising the capacity of the primary health and aged care workforces.

Enhancing the capacity of the aged care and primary care workforces to provide palliative and end of life care requires a focus on the competency of both the emerging and current workforces to provide best practice palliative medicine and palliative approaches to care.

Currently the Palliative Care Curriculum for Undergraduates Program (PCC4U) supports the incorporation of palliative care education into the curricula of undergraduate (and relevant postgraduate) health degrees. However, uptake of PCC4U remains suboptimal, with the latest evaluation report suggesting that 41% of targeted university courses are not engaged in the program[15]. Continued investment in a robust undergraduate education program that can demonstrate expanding coverage is essential.

This must be accompanied by ongoing education and training in best practice palliative care for qualified and practicing health professionals. This should include education and training targeted at supporting primary health care professionals to take a best practice approach to identifying and addressing patients palliative care needs. These are commonly the best placed professionals to assess, and in many instances address, palliative and end of life care needs. Such education and training will be most effective in supporting a best practice approach to care if it supports, and is supported by, a systematic approach to identifying and assessing palliative care needs in primary care settings.

The aged care and community care workforce also require education and training in the provision of palliative care. To support effective incorporation of palliative care in pre-vocational training for aged care workers, AGPN supports a comprehensive review of vocational education and training for aged care workers as proposed by the Productivity

---

[15] PCC4U (2011) Palliative care curriculum for you: final report. (Accessed 24/01/2012 via http://www.pcc4u.org/images/pdf/About%20PCC4U%20June%202011/Synopsis%20PCC4U%20May%202011%20Final%20report.pdf)

Commission following their recent inquiry into aged care, and recommends this includes a specific focus on palliative care.

(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians

AGPN acknowledges the 'Standards for Providing quality palliative care to all Australians' (the Standards) as values-based, quality-focused and practical. The Standards are appropriate to drive activity toward the provision of quality palliative and end of life care. The detailing accompanying them, which outlines what implementation of the Standards means for primary and specialist care services, also supports the accessibility of the Standards across the health system.

However, the Standards have so far only been applied to drive limited improvement in primary care. As detailed throughout this submission, AGPN believes that the first step to drive improvement in palliative care in primary care settings should be the development and implementation of a systematic approach to identify and address the palliative care needs of patients – such an approach should be built on the foundation provided by the Standards.

Given the breadth of care provided through general practice and primary care services, AGPN believes that the application of the program model implemented through the National Standards Assessment Program (NSAP) to focus on general practice/primary care services is unlikely to effectively engage a broad base of practices/services. Rather, consideration should be given to incorporating palliative care, utilising the Standards, into existing or emerging quality improvement programs for general practice/primary care services (such as the Australian Primary Care Collaboratives.)

(g) advance care planning, including: avenues for individuals and carers to communicate with health care professionals about end-of-life care; national consistency in law and policy supporting advance care plans, and; scope for including advance care plans in personal electronic health records

Advance care planning supports people to take control over the circumstances in which they live the last stages of their life, and in which they die. As such, it can be a key enabler of self-determination and wellbeing at the end of life. Supporting people to consider, and to develop, advance care plans, and for care to be provided, to the greatest extent possible, in accordance with these, should be considered a fundamental element of quality palliative and end-of-life care. Realising this requires:

- education and training for health professionals and aged care providers involved in palliative and end-of-life care to support patients, their families and carers develop considered advance care plans. Some limited education and training in this is currently being provided, but this is not nationally consistent and coverage is far from universal. We live in a context where talking about death and dying is, amongst the dominant culture, somewhat taboo. This makes engaging in meaningful and productive advance care planning discussions challenging for health professionals. It often requires both the health professional and the patient to move past their cultural barriers in talking about death and dying and to develop a language for talking about it. Health professionals need to be trained to take the lead in doing this and supported to develop the confidence in their own ability to do so.

- systems to support the communication of advance care plans across members of the health care team, including communication of amendments to such plans. AGPN supports mechanisms whereby the need for an advance care plan and advance care directive is automatically flagged through personally controlled electronic health records (PCEHRs.) To ensure that plans and directives are noted and observed as patients move through the health system, they need to be flagged in a nationally-consistent manner. As PCEHRs are being introduced on a voluntary 'opt-in' basis, initial uptake can be expected to be relatively low and PCEHRs can not be relied on as the sole communication and "automatic alert" solution. Existing, state-based advance care plan and directives registries should be maintained and well promoted and the development of local cross-service and cross-sectoral solutions for communications about plans and directives should be encouraged.
- a targeted focus on increasing community awareness of the opportunities advance care planning provides to support individuals to live the final stages of their life, and to die, in accordance with their care preferences.

Advance care planning and people with dementia

Early engagement in advance care planning is crucial for people with dementia as declining cognition can inhibit capacity to engage in considered decision-making. Dementia can be difficult to diagnose in its early stages, and there is commonly a lengthy lag between first symptoms and official diagnosis, associated with barriers both in patient help-seeking behaviour and GP's capacity to diagnose dementia. Efforts to support patient-centred care for people with dementia, including through advance care planning, must include a focus on increasing early diagnosis. This requires resources dedicated to supporting education, training and skill development amongst GPs and other primary care professionals as well as targeted community awareness about symptoms of dementia and the benefits of early diagnosis. Both health professional education and community awareness should be framed to support the undertaking of early advance care planning processes for people with dementia.

Advance care directives

AGPN recognises a difference between advance care plans and advance care directives. Advance care plans detail ideas and processes developed by a patient and their informal and formal care team about how care will be provided in likely future circumstances. Advance care directives have a legal status and tend to provide explicit instruction from the patient about how potential future health scenarios should be addressed. Currently there are jurisdictional differences governing advance care directives across Australia. This leads to confusion and unnecessary complexity for health professionals and patients, particularly in instances where the patient moves interstate. This can limit the confidence of the health professional to comply with the directive and, ultimately, the likelihood that the directive will be adhered to. AGPN recommends that Australian Governments work collaboratively to develop and implement nationally consistent legislation and policy in relation to advance care directives.

(h) the availability and funding of research, information and data about palliative care needs in Australia

The development of quality, evidence-based policies and systems demands a strong evidence base built on local knowledge and research. Research priorities should be determined on the basis of the knowledge required to develop effective systems and services. Currently this is likely to include a focus on:

- understanding emerging population need and the capacity of the current workforce and existing models of care to meet these needs
- systems and models for providing palliative care for people with non-malignant terminal conditions, particularly dementia
- the experiences of patients, families and carers at the end of life. Whilst further development of quality palliative care systems demands reforms grounded in patient experience, currently there is a dearth of information about this matter.

Driving quality improvement at systems and service levels requires the routine collection and analysis of data. Currently in Australia there is limited systematic data about practice and patient outcomes in palliative care, particularly in non-specialist service settings.[16] Addressing this shortfall requires the development of nationally standardised data sets that employ consistent definitions of provider types, service features and patient outcomes. To ensure service and system development is person-centred, it must be driven by patient experience, requiring the inclusion of consumer experience within standard datasets.

Driving improvement in primary palliative care requires the collection of data about the outcomes and experiences of patients whose end of life care is primarily provided in primary care settings. There are a number of significant barriers to this including that general practices and primary care services do not commonly employ standardised systems for identifying patients nearing the end of life, and that, even if such information was available, there is no system currently in place to collect and collate such data at a national or jurisdictional level. Overcoming these barriers will require stakeholders to work together to develop and drive the uptake of solutions that work. The proposed development and introduction of a systematic framework for primary palliative care would provide opportunity to support recording of relevant data in a consistent manner through general practice.

---

[16] Whilst the current Palliative Care Outcomes Collaborative (PCOC) supports palliative care service providers to drive improvement by collecting and reporting routine patient data, participation is voluntary and focused on specialist services. Data collected is thus insufficient to provide a national picture and to consider provision of palliative care in non-specialist settings; whilst it supports quality improvement at a service level, it is not able to support quality improvement in a national, and cross-sectoral context.