

Chapter 3

The federal funding of palliative care in Australia

Introduction

3.1 Funding of the Australian health system is complex and governed by a number of agreements of the Council of Australian Governments (COAG). Responsibility for providing and funding health care services is shared between the commonwealth and the states and territories. Generally:

- (i) the states are the system managers of the public hospital system; and
- (ii) the Commonwealth has full funding and program responsibility for aged care (except where otherwise agreed) and has lead responsibility for GP and primary health care.¹

3.2 The responsibility for palliative care service provision remains with the state and territory governments although funding support is provided by the Commonwealth:²

The Australian Government does not directly fund palliative and hospice care services but does provide financial assistance to state and territory governments to operate such services as part of their health and community service provision responsibilities. The use of this funding and the delivery of palliative care services in each jurisdiction is the responsibility of individual state and territory governments.³

3.3 This chapter examines the current funding arrangements for palliative care. It explores how funding is distributed and whether or not the current models of funding are resulting in the efficient use of resources and the effective provision of care.

How palliative care is funded in Australia

3.4 The Department of Health and Ageing (DoHA/the department) explained how the federal government provides funding to support the states and territories in their palliative care service provision. The department informed the committee that financial assistance is provided by the federal government as a part of its national

1 Council of Australian Governments, National Health Reform Agreement, 2 August 2011, p. 4.

2 Australian Health Ministers Conference, *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*, 2010, p. 5.

3 Department of Health and Ageing, answer to question taken on notice (question 2), received 23 May 2012.

health agreements with the states and that the funding for palliative care is provided as a part of the funding for subacute care services:⁴

There are two national partnership agreements that have specifically provided funding for subacute care...: the National Hospital and Health Workforce Reform and the National Partnership Agreement on Improving Public Hospital Services.

...subacute care includes palliative care, rehabilitation, geriatric evaluation and management and psychogeriatric care—and in this NPA it also included subacute mental health.⁵

National Partnership Agreement on Hospital and Health Workforce Reform

3.5 The National Partnership Agreement on Hospital and Health Workforce Reform (the workforce reform agreement) was agreed to by the Council of Australian Governments (COAG) on 29 November 2008.⁶ The agreement committed \$3.042 billion 'to improve efficiency and capacity in public hospitals'. The two (of four) components of the workforce reform agreement of interest to the committee's inquiry include the introduction of an Activity Based Funding approach, and the commitment to enhance the provision of subacute services.⁷

Activity based funding

3.6 The workforce reform agreement described activity based funding (ABF) as 'a management tool that has the potential to enhance public accountability and drive technical efficiency' by:

- (a) capturing consistent and detailed information on hospital sector activity and accurately measuring the costs of delivery;
- (b) creating an explicit relationship between funds allocated and services provided;
- (c) strengthening management's focus on outputs, outcomes and quality;

4 Mr David Butt, Deputy Secretary, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, p. 12.

5 Ms Ann Smith, Assistant Secretary, National Partnership Agreement Branch, Acute Care Division, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 10–12.

6 Council of Australian Governments, National Partnership Agreement in Hospital and Health Workforce Reform, p. 3.
<http://www.ahwo.gov.au/documents/COAG/National%20Partnership%20Agreement%20on%20Hospital%20and%20Health%20Workforce%20Reform.pdf> (accessed 27 August 2012).

7 Council of Australian Governments, National Partnership Agreement in Hospital and Health Workforce Reform, p. 3.
<http://www.ahwo.gov.au/documents/COAG/National%20Partnership%20Agreement%20on%20Hospital%20and%20Health%20Workforce%20Reform.pdf> (accessed 27 August 2012).

- (d) encouraging clinicians and managers to identify variations in costs and practices so these can be managed at a local level in the context of improving efficiency and effectiveness; and
- (e) providing mechanisms to reward good practice and support quality initiatives.⁸

3.7 ABF will achieve this through 'the development and implementation' of:

- (a) activity based funding for public hospital services;
- (b) nationally consistent classifications and data collections for hospital provided care including admitted care, sub-acute care, emergency departments, outpatient sub-acute and hospital-auspiced community health services [including palliative care, hospital in the home and other services for which public hospitals are responsible]; and
- (c) a nationally consistent costing model and, if COAG agrees, a nationally consistent funding model for hospital provided treatment (in admitted care, sub-acute care, non-admitted care emergency departments and hospital-auspiced community health services) as well as non-clinical hospital services including teaching and research.⁹

3.8 The Independent Hospital Pricing Authority (IHPA), established under the National Health Reform Agreement, has been given the authority to progress ABF and although ABF will not commence for subacute care until 1 July 2013 the IHPA has:

...a process in place now with all jurisdictions. It also has called for public submissions to see how activity-based funding is best structured to meet the needs in subacute care, because, while I would hesitate to say that acute care is simple, it is much simpler than subacute care because of the venues where subacute care can be provided and what is covered under the National Health Reform Agreement.¹⁰

3.9 The department explained to the committee that ABF is 'the long-term real answer to the consistent measurement.'¹¹ Stakeholders however, are not without concerns as to how ABF will be implemented.

8 Council of Australian Governments, National Partnership Agreement in Hospital and Health Workforce Reform, p.11
<http://www.ahwo.gov.au/documents/COAG/National%20Partnership%20Agreement%20on%20Hospital%20and%20Health%20Workforce%20Reform.pdf> (accessed 27 August 2012).

9 Council of Australian Governments, National Partnership Agreement in Hospital and Health Workforce Reform, p.11
<http://www.ahwo.gov.au/documents/COAG/National%20Partnership%20Agreement%20on%20Hospital%20and%20Health%20Workforce%20Reform.pdf> (accessed 27 August 2012).

10 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

11 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

3.10 The Victorian Healthcare Association¹² expressed some concerns of moving palliative care funding into the ABF model:

It is imperative that appropriate funding arrangements acknowledge the priorities of providing palliative care and do not overlook patient preferences. However, the current funding arrangements and other monetary factors, such as patient co-payments and accommodation, skews palliative care provision towards bed-based options in a hospital as opposed to services provided 'in place'.

The introduction of activity based funding (ABF) in hospital-auspiced palliative care from 1 July 2013 is still yet to be articulated. The current Palliative Care Resource Allocation Model (PCRAM) weights funding based on a number of variables including rurality and low socioeconomic status. It is unclear whether the application of ABF will include a similar weighting structure. This is of particular concern for block funded small rural hospitals in Victoria that may be unable to provide the same level of services under ABF as under the PCRAM if the extra costs inherent are not taken into account.

VHA members have expressed some concern regarding the implications of moving these palliative subacute services into an ABF model as it places restriction on the capacity to truly cater for patient needs. The transition of subacute services into ABF must allow the mobility of funds into programs that are in the home and community, not just in hospitals. Home and community based programs provide specialised, patient-centred medical care and care coordination that are enabled by block funded grants.¹³

3.11 The Victorian Healthcare Association explained its concerns to the committee:

Our members have expressed some concern regarding the federal introduction of activity based funding through the IHPA, or Independent Hospital Pricing Authority, mechanisms, and how those mechanisms might play through to some of the subacute and blended community hospital type models that many of our members here in Victoria are currently involved in. There are also discrepancies between what might be available through some palliative care funding mechanisms and for aged care providers who in fact provide palliative care at end of life within the residential setting. We need to remember that the whole construct of residential care is to create a homelike environment. That environment essentially becomes the substantive home for that resident and really the access to some of the funding mechanisms that meet the more deliberate and, perhaps at various stages, the more resource intensive nature of palliative care should be

12 The VHA is the major peak body representing the public healthcare sector in Victoria. Its members include public hospitals, rural and regional health services, community health services and aged care facilities. Established since 1938, the VHA promotes the improvement of health outcomes for all Victorians, from the perspective of its members. Source: Victorian Healthcare Association, *Submission 57*, p. 1.

13 Victorian Healthcare Association, *Submission 57*, p. 3.

available within that setting. Currently, it is quite convoluted and complex for that to occur.

When we talk about efficiencies in palliative care, I note there is a suggestion that palliative care can reduce costs by reducing hospital admissions but this part of the conversation is not a cost-saving driven conversation; it is more to talk about the effectiveness of care providing the best economic outcome and the best economic outcome will have a range of considerations including price efficiency, quality of care for the patient and the consumer driven element of it from an economic perspective.¹⁴

3.12 Palliative Care Australia expressed a view that the ABF model may be too simplistic, particularly in the multidisciplinary team setting:

At the moment with activity based funding the concept of a service event is of one patient and one clinician. It does not include people such as pastoral workers; it only includes the specific clinician. So, if care was given by, say, a pastoral worker, that would not count within the activity based funding. And, whilst bereavement care does count, other care of the family group does not count. That is something that we really need to address while we are putting the activity based funding together. It does not come into effect for subacute care until next year, so we certainly have enough time to address this now, but we need a rethink of what it means.¹⁵

3.13 Eastern Palliative Care Association Inc (EPC)¹⁶ suggested that ABF will not enable innovation in service delivery as service providers will no longer be able to allocate the funding they receive as they consider appropriate and effective. EPC explained how the current funding method, what they refer to as 'bucket' funding, enables them to do this:

Because we have a bucket of funding that we do not have to acquit—and the government has said that we must spend 25 per cent on nursing—we have been able to work around things. We have also been able to get some philanthropic funds straight to health support. So we have used our funding very innovatively. The priority assessment team cost us \$130,000 for the year, for a pilot, but the results were so good we just had to incorporate it.

14 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 11.

15 Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 14.

16 Eastern Palliative Care is an organisation that was developed following the competitive tendering of community based palliative care in 1997. Three agencies—the Order of Malta, St Vincent's Melbourne and Melbourne East Palliative Care Association—tendered for the right to provide services. They were successful and invited Outer East Palliative Care Service to be part of EPC so that the new organisation could provide services right across the entire eastern region of 2,963 square kilometres, and that includes a lot of metropolitan areas. Since 1997, members of these partner bodies have been the governing body. Source: Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc, *Committee Hansard*, 4 July 2012, p. 1.

Down the track, particularly with activity based funding, we are worried a little bit about our funding coming in; we really are. But we find that that program is so beneficial that we have to look at other things to trim rather than that, because when someone is desperately needing a service—they are going to die within seven days—we need to be able to respond to the community well because that actually helps our profile, that helps the community and that builds a capacity within the community and people can see that death is not that awful thing that should happen in a hospital.¹⁷

3.14 EPC also identified the importance of recognising the role of the carer and the complexity of palliative care in ABF and identified that these are just two of the risks for the future funding of palliative care:

Ms Moody: Recognition of the carer in ABF. I actually think that is our biggest one.

Ms Pedley: The complexity of care too... There is the increased number of carers that we are getting, either who have mental health histories themselves or their clients have mental health histories. We are palliative care specialists, but we are dealing with an enormous amount of complexity within families. More and more, we have people with quite extreme mental health conditions that make caring for people at home quite difficult. We do it well, I think, but it is certainly becoming increasingly more demanding, and that does require more of our time—more planning and input into them.

Ms Moody: One more risk is the impost of occupational health and safety on our staff. Our staff are out there at night, driving alone in a car. We provide them with some resources. The technology is not really out there to monitor them in their car that well. So the impost of occupational health and safety on our staff and how we have to manage that is another risk.¹⁸

3.15 Although stakeholders were cautious of the ability of the IHPA to adequately determine the funding needs for palliative care, particularly at the 'more end-of-life palliative care and the higher level symptom management,'¹⁹ the committee heard that the IHPA has established a sub-acute care advisory committee comprising palliative care medicine specialists, geriatricians and rehabilitation positions. The establishment of this committee had allayed the concerns of some. The Royal Australasian College of Physicians (RACP), a member of the sub-acute care advisory committee welcomed the establishment of the advisory committee.²⁰

17 Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 7.

18 Ms Jeannette Moody, Chief Executive Officer, Ms Christine Pedley, Manager, Allied Health, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 8.

19 Mr Nicolas Mersiades, Senior Aged Care Adviser, Aged and Community Services Australia, *Committee Hansard*, 10 July 2012, p. 26.

20 Dr Leslie Bolitho AM, President, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 9.

3.16 The Council of the Ageing (COTA) were supportive of the IHPA being given the role of 'pricing' palliative care provided it is regarded as a specialist health service and not merely a component of aged care:

I do not think there needs to be a separate pricing authority for palliative care. I would have thought that IHPA would be doing it for the health system as the full suite of health services.

It is important that specialist palliative care is seen as a health service and that aged care is not asked to pick up a health service.

...Our view is that it is a health service and should be priced by IHPA, and that pricing should be able to have a look at what is done with aged care.²¹

The National Partnership Agreement on Improving Public Hospital Services

3.17 As DoHA explained, funding for the provision of palliative care services is also provided under the National Partnership Agreement on Improving Public Hospital Services.

3.18 The National Partnership Agreement on Improving Public Hospital Services, (the agreement) signed in February 2011, is intended to 'drive major improvements in public hospital service delivery and better health outcomes for Australians' by facilitating 'improved access to public hospital services, including elective surgery and ED [emergency department] services, and subacute care.'²² The agreement specifies that the federal government will:

...provide up to \$1.623 billion dollars in capital and recurrent funding from 2010–11 to 2013–14 to States and Territories to deliver and operate over 1,300 new subacute care beds nationally, in hospital and community settings, by the end of this period.²³

3.19 The agreement identifies where the new subacute beds will be established:

21 Mr Nicolas Mersiades, Aged and Community Services Australia; Ms Jo Root, National Policy Manager, COTA, *Committee Hansard*, 10 July 2012, p. 26.

22 Council of Australian Governments, *The National Health Reform Agreement – National Partnership Agreement on Improving Public Hospital Services*, p. 4
[http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/npa-improvingpublichospitals-agreement/\\$File/National%20Partnership%20Agreement%20on%20Improving%20Public%20Hospital%20Services.pdf](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/npa-improvingpublichospitals-agreement/$File/National%20Partnership%20Agreement%20on%20Improving%20Public%20Hospital%20Services.pdf) (accessed 27 August 2012).

23 Council of Australian Governments, *The National Health Reform Agreement – National Partnership Agreement on Improving Public Hospital Services*, p. 43
[http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/npa-improvingpublichospitals-agreement/\\$File/National%20Partnership%20Agreement%20on%20Improving%20Public%20Hospital%20Services.pdf](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/npa-improvingpublichospitals-agreement/$File/National%20Partnership%20Agreement%20on%20Improving%20Public%20Hospital%20Services.pdf) (accessed 27 August 2012).

Table E1: Estimated Distribution of New Subacute Beds across States and Territories

Year	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	Total
2010-11	107	82	66	34	24	8	5	3	329
2011-12	215	163	133	67	49	15	11	7	660
2012-13	321	245	199	101	73	23	16	10	988
2013-14	428	326	265	135	97	30	21	14	1,316

Source: National Health Reform Agreement—National Partnership Agreement on Improving Public Hospital Services, Schedule E, p. 45.

3.20 It also sets out how the \$1.623 billion in funding will be allocated to deliver these outcomes:

E31 State and Territory funding allocations for these reforms are as follows:

Table E3: Estimated Distribution of New Subacute Beds Guarantee Funding^{1,2,3}

Year	NSW (\$m)	VIC (\$m)	QLD (\$m)	WA (\$m)	SA (\$m)	TAS (\$m)	ACT (\$m)	NT (\$m)	Total (\$m)
2010-11	76.0	58.2	46.9	24.1	17.0	5.7	3.6	2.1	233.6
2011-12	102.6	78.4	64.4	32.1	23.9	7.0	5.6	3.6	317.6
2012-13	145.0	111.1	89.8	45.9	32.8	10.6	7.0	4.3	446.5
2013-14	203.8	154.7	125.9	64.3	46.0	14.0	9.9	6.9	625.5

¹ Estimated funding allocations are contingent on performance, and assume a national roll-out.

² Funding for subacute beds has been estimated by estimated population distribution.

³ Columns and rows may not add due to rounding. Actual payments will be calculated to the nearest dollar.

Source: National Health Reform Agreement—National Partnership Agreement on Improving Public Hospital Services, Schedule E, p. 48.

3.21 In response to the committee's questions concerning progress of the creation of the new subacute care beds, the department explained that as at 30 June 2011, 104 of the new beds created since the government's commitment had been dedicated to palliative care:

**National Partnership Agreement on Improving Public Hospital Services – Total
Planned Palliative Care Beds and Bed Equivalent Services and Palliative Care
Funding by jurisdiction – 2010-11 to 2013-14 (as at 30 June 2011)**

Planned State and Territory Palliative Care Beds / Bed Equivalents and Funding under Schedule E of the NPA IPHS (as at 30 June 2011)*			
	NPA Target (by S/T)	Total Palliative Care Beds/Equivalents identified by States	Total Funding for Palliative Care Beds/Equivalents identified by States
STATE		Beds and Bed Equivalents	Allocated Funding
NSW	428	51.00	\$27,893,925
VIC	326	22.10	\$644,515
QLD	265	25.50	\$16,960,000
WA	135	4.00	\$2,200,000
SA	97	0.00	\$0
TAS	30	0.00	\$0
ACT*	21	0.00	\$86,935
NT	14	2.00	\$2,075,376
Total	1316	104.6	\$49,860,751

* Whilst the ACT is not planning to deliver any palliative care beds or equivalent services, it has allocated funding for the purchase of palliative care equipment to support people in the community.

Source: Department of Health and Ageing, answers to questions on notice (question 4), received 23 May 2012.

3.22 The department explained however that the national partnership agreements provide the states and territories with flexibility to 'redirect funds allocated across the elective surgery, ED [emergency department] and subacute Schedules to the highest priority within their jurisdiction'. As a result, given that subacute care is bundled,²⁴ it is 'extremely difficult' to determine exactly how much each state and territory spends on palliative care and therefore how many of the subacute care beds will be specifically set aside for palliative care:

[t]he states and territories decide on what they are going to spend and where they are going to spend it. The Commonwealth has no direct control in determining that palliative care beds should go to Queensland or that rehabilitation beds should go to Victoria. The states and territories provide that. What they then do is provide the Commonwealth with an implementation plan about how they plan to spend the money, obviously for all of the NPA funding but this area particularly. Then they provide us with progress reports on a six-monthly basis.²⁵

24 'Bundling' refers to the fact that the category of subacute care includes palliative care, rehabilitation, geriatric evaluation and management, psychogeriatric care and in some cases subacute mental health.

25 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 10–12.

3.23 While explaining the difficulty associated with determining the amount that each state and territory spends on palliative care, the department also informed the committee that at present the federal government has no consistent or standard reporting mechanism to review how the states and territories allocate the funding they receive under the agreements:

It has been an ongoing concern for the Commonwealth. Most states report in a similar manner, but not all states do. They all come out of very different reporting systems. We looked at subacute care as a total. Rehabilitation is the most advanced in reporting because they simply seem to have had more systems in place for a longer period of time. All of the other areas of subacute are still under some level of development and the states and territories have taken individual approaches to that.²⁶

3.24 As explained above, the new NPA on Hospital and Health Workforce Reform has introduced a requirement for standardised reporting. The department advised the committee that progress on standardising reporting has been made and that they hope to have 'something' that has a 'fairly consistent approach' to the COAG Reform Council in the 'next couple of months'.²⁷ The department explained that this information should eventually be published and although complete consistency will not be possible, explanatory information will be provided where it differs.²⁸

3.25 The department explained that the information will be used for 'measurement and counting' under the ABF model.²⁹

3.26 Professor David Currow, professor of palliative and supportive services at Flinders University, suggested to the committee that the 'key challenge' of funding is to ensure that it is maintained at a level 'that genuinely reflects the improvement in health that can be delivered across the community by good palliative care'.³⁰ Professor Currow suggested that what was needed was a review of how resources are utilised within current budgets.³¹

3.27 In addition to funding provided under the National Partnership Agreements, the government also provides funding for palliative care through the National Palliative Care Program (NPCP) which was established in 2002.

26 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

27 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

28 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

29 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

30 Professor David Currow, Professor of Palliative and Supportive Services, Flinders University, *Committee Hansard*, 2 July 2012, p. 63.

31 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

The National Palliative Care Program (NPCP)

3.28 The NPCP funds initiatives to ensure quality palliative care and to improve access to services for people who are dying and their families.³²

3.29 The NPCP aims to achieve these outcomes by providing funding support in the following four areas:

- support for patients, families and carers in the community;
- increased access to palliative care medicines in the community;
- education, training and support for the workforce; and
- research and quality improvement for palliative care services.³³

3.30 Support for patients, families and carers in the community is provided by the NPCP through the provision of grants to 'local groups, health and aged care providers and church and charitable organisations' to assist these groups provide services and support for palliative care recipients and their families.³⁴

3.31 Funding to support increased access to palliative care medicines in the community is provided to the Palliative Care Clinical Studies Collaborative (PACCSC). The PACCSC:

...manages multi-site clinical drug trials in order to gather the scientific evidence required to register palliative care medicines on the Australian Register of Therapeutic Goods and possible listings on the PBS.³⁵

3.32 The NPCP supports education, training and the palliative care workforce through the Program of Experience in the Palliative Approach (PEPA). PEPA is 'a work placement training program for health professionals in a specialist palliative care service of their choice.'³⁶

3.33 The fourth area through which the NPCP supports improved access to and quality of palliative care services is through the provision of funding for:

32 Department of Health and Ageing, *Submission 96*, p. 6.

33 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

34 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

35 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

36 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

- [the Palliative Care Outcomes Collaboration (PCOC)] a consortium of four universities forms the Australian Palliative Care Outcomes Collaboration. PCOC supports services to consistently compare and measure the quality of their outcomes, and through this ensure continued quality improvement.
- [t]he Palliative Care Research Program, managed by the National Health and Medical Research Council, [which] aims to improve the quality of palliative care, inform policy development, improve clinical practice and develop researcher capacity, by funding priority driven research grants, training awards and research development grants;[and]
- [t]he Palliative Care Knowledge Network (CareSearch)... a web-based one stop shop of information and practical resources for clinicians, other health care professionals providing palliative care, researchers, patients and carers.³⁷

Calls for funding changes

3.34 Throughout its inquiry, the committee received evidence which suggested there is much inconsistency in the standard of palliative care delivered in Australia. The committee sought to understand the inconsistencies by reviewing the funding of palliative care. The committee's findings suggest that the inconsistencies may be in part the result of the complexity of the funding framework.

3.35 In their submission to the inquiry, Palliative Care Australia (PCA), the peak national organisation 'representing the interests and aspirations of all who share the ideal of quality care at the end of life for all' explained that there is not enough funding dedicated to palliative care and as the method of funding these services has changed over time there is 'definite jurisdictional inconsistency'.

3.36 Stakeholders were consistently critical of the current way in which funding for palliative care was distributed and although views differed as to what should or could be done, the theme common amongst all was the need for increased transparency in how 'bundled' funding was allocated.

3.37 PCA were of the opinion that funding should be 'ring fenced':

I think you have to ring fence the funding for palliative care... So long as it is bundled in with subacute care, and the different states and territories will make a decision as to how that is divided up, it will tend to be spent on things other than palliative care. That has been the indication thus far.³⁸

37 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

38 Dr Yvonne Luxford, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 14.

3.38 PCA identified in their submission that:

Of its \$39,973 sub-acute funding South Australia committed \$11,970 to palliative care. On the other hand, Queensland allocated none of the sub-acute funding to palliative care, but committed to undertake a review of the current palliative care service system in 2009-2010 from within existing state funding, and develop a strategic direction for palliative care. This service provision review has been undertaken, but not publicly released.³⁹

3.39 Palliative Care Nurses Australia raised similar concerns regarding bundled funding:

At present, that funding comes from the Commonwealth to the states, who then decide how that funding is disbursed in that state. Most palliative care takes place in the community, but the funding break-up does not always reflect that. While this is anecdotal—they do not have statistics to back it up—a lot of palliative care funding goes into the more acute areas, rather than the community.⁴⁰

3.40 PCA, which has membership across Australia went further to state that:

We know that many more Australians would benefit from access to palliative care, yet it is clear that bundling funding allocations within the sub-acute category is not leading to improved service provision and access across the country.

If such bundled allocations continue, whether or not in conjunction with Activity Based Funding, a significant level of funding must be specifically allocated to palliative care (as a minimum) to ensure greater access to quality end of life care for Australians in need.⁴¹

3.41 Despite these concerns however, the RACP explained that in their view, funding for palliative care must remain flexible to 'encourage innovative service delivery' and ensure 'the population has access to the right care at the right time and in the right location with the right provider:'

Funding arrangements must encourage palliative care services in a location that best reflects the patient's needs and the patient's choice. The college fully supports adequate funding for modern, responsive palliative care services which allow for this quality service.⁴²

3.42 In its submission to the inquiry, the Australia New Zealand Society of Palliative Medicine (ANZSPM) explained that processes should be introduced to

39 Palliative Care Australia, *Submission 94*, p. 80.

40 Mr John Haberecht, President, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 58.

41 Palliative Care Australia, *Submission 94*, p. 81.

42 Dr Leslie Bolitho AM, President, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 9.

ensure that state and territory governments are accountable for the spending of bundled funding:

A major source of funding over the last few years has been the NPA subacute care funding. This money has been distributed to States and Territories, and covers four areas of subacute care – Palliative care, Geriatric Evaluation and Management, Psychogeriatrics and Rehabilitation. In the initial funding round all States and Territories were required to publish their implementation plans; these were available to the public. The detail of these plans varied from having no breakdown of monetary allocation, to detailed distribution of funds between the different subacute care areas.

Unfortunately, in the second round of funding, there has been no publication of the allocations. The difficulty with the way in which the money has been distributed, is that our members have experienced frustration, firstly at the lack of actual distribution of money, and secondly at what is seen as distribution according to political motives rather than the needs of patients. Many members have complained at the lack of benefit from this money for palliative care provision across Australia.

Recommendation 6. That the Commonwealth ensures that funding for the National Partnership Agreement (NPA) for subacute care:

- is allocated according to population-based needs;
- has its distribution linked to a clear improvement in the quality of service; and
- is transparent, and that details of allocation/distribution are made publicly available to ensure that State and Territory governments and LHHN (Local Health and Hospital Networks) are accountable for the use of this funding stream.⁴³

3.43 Although it did not directly comment on the bundling or unbundling of care, Mercy Health also suggested to the committee that in their experience a speciality like palliative care should not be funded episodically:

...episode funding is not an appropriate way to fund a speciality which provides services across both the acute and non-acute sector. Specifically, palliative care provided in the acute setting is not recognised in the current funding model.⁴⁴

3.44 Submitters however suggest that without sufficient data, the effective allocation of resources will be difficult to achieve. PCA explained that funding is linked to data and at present the data collected for palliative care purposes is deficient:

...we need to find out and get good data about how and where palliative care is delivered now... We need to know how it is delivered now so that we know exactly how large the gaps are and where the gaps are.

43 Australian and New Zealand Society of Palliative Medicine Incorporated, *Submission 33*, p. 10.

44 Mercy Health, *Submission 58*, p. 5.

Another way that we can look at it is to ring-fence some funding for palliative care in the funding that goes out to the states. If there is money going out in the subacute bucket, we need to ensure that there is money ring-fenced for palliative care. It is not necessarily the easiest thing for states to disseminate funding in palliative care. It is often easier to build a bed in a rehab ward than it is to set up a good palliative care service that reaches into the community or to better support such a service.⁴⁵

The complexity of funding palliative care

3.45 Throughout the committee's inquiry it became clear that the nature of palliative care is extremely complex. The fact that palliative care can be required for people from all ages and backgrounds, not just the elderly who reside in aged care facilities, adds to the complexity that is introduced by the joint funding of care by both the federal government and the states and territories.

3.46 Mr Peter Cleasby, President of Palliative Care New South Wales, succinctly explained the complexity when he informed the committee:

As long as we have a federated model, there will clearly be issues about who is responsible for what. What we want to say is that we have the situation in Australia where Palliative Care Australia, which works primarily with the Commonwealth, is the national entity and a good number of great things have been delivered...but, unfortunately, at the state level across the country, the state bodies are struggling big-time to play their role with their local jurisdictions.

...There is a problem with the coordination and I think the Commonwealth is missing out on an opportunity to get a better return on investment. There does not seem to be an overall strategic management of these projects and taking them elsewhere, and finding out what has developed in one state actually can be translated to another state without each state having to do it themselves.⁴⁶

3.47 Dr Yvonne Luxford, Chief Executive Officer of Palliative Care Australia, suggested that although there are both advantages and disadvantages of the federated system, simply consolidating the responsibility for funding the provision of care would not guarantee 'the best possible care or the best possible equitable division of funding':

Just having one funder does not guarantee that you get the best possible care or the best possible equitable division of funding. Perhaps what we need, rather than moving towards one funder, is for the funding to really

45 Dr Yvonne Luxford, Chief Executive Officer; Dr Ian White, National Policy and Communications Manager, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 19.

46 Mr Peter Cleasby, President, Palliative Care New South Wales, *Committee Hansard*, 2 July 2012, pp. 56–57.

recognise what is needed and the level of need out there and to ensure that the funding is fairly distributed.⁴⁷

3.48 When discussing the issue of whether or not funding of palliative care should rest with the federal government or the state and territory governments, submitters pointed to the example of aged care which has, through the decisions of COAG, become the sole responsibility of the Commonwealth and is funded through the Aged Care Funding Instrument (ACFI). However, given the complexities involved in the provisions of palliative care, palliative care services provided through the ACFI, which primarily funds aged care facilities, will not apply to those people requiring palliative care yet who do not meet the aged care threshold requirements.

3.49 Catholic Health Australia explained that although the ACFI '...as a tool is a very useful way of funding services into residential aged-care providers' it does not extend past residential aged care provision and into the community aged-care setting.⁴⁸

3.50 BlueCare identified other limitations of the provision of palliative care under the ACFI:

At the moment, often providers do not claim for the palliative care component of ACFI and there are two reasons for that. Firstly, it comes under the complex care needs area. Often if you have already reached your ceiling point under the ADL section then you do not need to add the ten points that you would get from palliative care because you will not get any more money. The number of claims that go in for palliative care probably do not reflect the number of palliative care clients that are in the system because from a paperwork perspective there is no added value to reclassifying people when they become palliative care patients. I am not sure if that will be changed; we have advocated for that.⁴⁹

3.51 Professor Parker further explained the difficulty accessing palliative care funding under the ACFI given the requirements that 'a GP or specialist nurse sign off on a palliative care plan', both of which are rare in the residential aged care setting.⁵⁰

3.52 Professor David Currow, a professor of palliative and supportive services at Flinders University suggested to the committee that the 'key challenge' is to ensure that funding of palliative care is maintained at a level 'that genuinely reflects the improvement in health that can be delivered across the community by good palliative

47 Dr Yvonne Luxford, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 24.

48 Mr Martin Laverty, Chief Executive Officer, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 37.

49 Associate Professor Deborah Parker, Director, University of Queensland/Blue Care Research and Practice Development Centre, *Committee Hansard*, 2 July 2012, p. 5.

50 Associate Professor Deborah Parker, *Committee Hansard*, 2 July 2012, p. 5.

care.⁵¹ Professor Currow suggested that what was needed was a review of how resources are utilised within current budgets. He told the committee that:

This is not about more money; this is about ensuring that we distribute that money in a way that genuinely engages in ensuring that the health of the whole community is a focus.⁵²

3.53 PCA explained that what they consider is needed is for:

...all levels of government to fund palliative care services using appropriate, equitable and needs based models. Funding needs to be flexible and delivered both as block funding and as activity based funding. Development of the new activity based funding models must recognise that palliative care is unique in its holistic and multidisciplinary nature and that its caring encompasses loved ones and carers in addition to the person with the terminal illness. We need to maintain an effective and appropriate high quality service through ensuring that all locations engaged in end-of-life care adhere to the national palliative care standards. Such national standards will ensure a basis for uniformed consistency in approach to palliative care across the country.⁵³

3.54 In the Productivity Commission's (PC) recent inquiry report into aged care in Australia,⁵⁴ the PC recommended that aged care services be provided through an entitlement system which would involve Australians being assessed to determine their needs and therefore their entitlement to different care services. Throughout its inquiry process the committee sought to explore how palliative care service providers consider the introduction of an entitlement based system would address the needs of palliative care recipients.

3.55 Dr Alan Rouse of the Tasmanian Health Organisation (North West) told the committee how the Tasmanian Health Organisation would be able to provide more services for palliative care if the funding for those services was available on an entitlement schedule:

[An entitlement schedule – a Medicare schedule]... would be a great idea. One of the examples that I will put to you is: these medications that people need within nursing homes, for example, to stop pain. I am talking, for example, about the person who falls very near the end of their life and has a fractured hip. One of the options is a hospital spending \$15,000 to \$20,000 fixing it so that they can either die in hospital or come back to the residential aged-care facility and die in the days after. We have medications that cost, maybe, \$50, which people are reluctant to purchase because they have no money. The alternative is \$50 versus \$15,000. If these aged-care

51 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

52 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

53 Dr Yvonne Luxford, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 19.

54 Productivity Commission, *Caring for Older Australians*, August 2011
<http://www.pc.gov.au/projects/inquiry/aged-care/report> (accessed 8 October 2012).

facilities had access to these medications that were able to afford them on the residents behalf, then we would see even more savings.⁵⁵

3.56 Ms Angela Raguz, General Manager of Residential Care at HammondCare said of the PC's report:

The Productivity Commission has done a good job in understanding and looking at what the issues are that are facing aged care and the reality of how this industry is going to be sustainable over the period of time where we have an explosion of older people. What is lacking is the answer to the workforce question... we can do a lot in our aged-care services and we can certainly do that at a more efficient price for a long period of time, especially with the entitlements system coming into place, than what the public health system is able to offer.

The challenge is making sure we have got the people with the skills, the knowledge and the experience to do that across a broader base. Without that, it can get stuck. We have seen it with our palliative care suite: if we were not an organisation that had a schedule 3 hospital that provided specialist palliative care services, it would really not be that easy to get those things up and running and off the ground. It is about how we get those experts to come on board and to move beyond that view: 'Oh, it's aged care—that's a bit daggy. I don't want to spend time in aged care.' For young doctors and nurses it is not the sexiest part of the industry to select. So it is about getting it within undergraduate training, looking at training people on the ground in the nursing homes across a broad scale. And it is not just about setting up distinct units, even though that is an ideal. It is about lifting the bar across the whole of aged care, be it in people's homes or in facilities.

... It is a whole-of-system question that needs to be answered. If GPs are the primary care physicians, there needs to be a lot of effort and emphasis put at that level as well.⁵⁶

3.57 Associate Professor Rohan Vora, President of Palliative Care Queensland agreed that the Productivity Commission's entitlement system would go some way towards addressing the funding of palliative care in the community palliative setting, particularly if there were an entitlement for case management:

It could do. I guess we would need to have a look at and see what system You have the MBS item system for Medicare. There are a whole lot of gaps in that as to how you fund allied health, how you fund coordination of services—it is a range of things. GPs face exactly the same problem. Their phone calls and coordination of services are not funded; it is your patient in front of you at the time. Of course, in palliative care it is not just the patient

55 Dr Alan Rouse, Tasmanian Health Organisation—North West, *Committee Hansard*, 5 July 2012, p. 5.

56 Dr Peta McVey, Clinical Nurse Consultant, Palliative Care, HammondCare, *Committee Hansard*, 2 July 2012, p. 21.

in front of you; it is the family in front of you or the family that cares for the patient that needs to somehow be in that.⁵⁷

3.58 Professor David Currow, Professor of Palliative and Supportive Services at Flinders University informed the committee of his view in relation to an entitlement based system, in particular, a system which included palliative care services in the entitlement system:

The issue is that palliative care permeates the entire health and social system. The question is: how do we best ensure that people, wherever they have contact with services, are going to be able to get timely, well-planned, proactively considered services? As we think about entitlements, we are talking about the ability to actually say, 'This person now has a life-limiting illness.' At a community level, that will be a huge shift. I think the United Kingdom, particularly England, have made that shift in the last few years, and they have started to create primary-care registers, which have a whole lot of flow-on effects in terms of the entitlements for that person and their carers.

As I pointed out, the one thorn in the side in Commonwealth paperwork at the moment is the carers allowance, which asks a professional to actually prognosticate—and we are either very good at that or very bad, depending on which literature you read—and then hand it back to that family to take to Centrelink. We have to change it.

... We need to change that. If there is one really practical thing we can do today, it is to change that Centrelink paperwork, because it is abhorrent.⁵⁸

3.59 Professor Currow also informed the committee that should an entitlement approach to funding be taken it would be important to ensure that it did not result in 'perverse' outcomes:

By way of how we best provide services, we need to ensure that there is continuity and that there are no perverse incentives, as we think about an entitlement system. We need to think through that very carefully. There are times that hospital—not a hospice, not an aged-care facility—is actually the best place to provide care. And we need to make sure that we do not go down the path of the American system, where their entitlement system has in fact limited hospice and palliative care services and led to some very perverse incentives in how those services then work.⁵⁹

3.60 The Victorian Healthcare Association (VHA) informed the committee that the PC's recommendation to move to an entitlement system was 'consistent with a consumer focus':

57 Professor Rohan Vora, President, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 31.

58 Professor David Currow, *Committee Hansard*, 2 July 2012, pp. 67–68.

59 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 68.

I would say that would not be inconsistent with some of the key themes that we would see as potentially adding value, particularly from that funding side of the equation. If the person in receipt of the care is actually in control of the funding and determining from an appropriately referenced panel of providers, presumably, where they purchase their services from, I think that is a terrific model.⁶⁰

3.61 The VHA suggested that if such a system were to provide fairer access to services and resulted in greater funding flexibility they would 'generally' be supportive:

I say generally. The proviso and the concerns that we have had in the past have been around some of the smaller rural communities, where there is not an active market. Sometimes in those communities you can get skewed outcomes, or unintended outcomes as opposed to skewed outcomes, as a result of that type of approach. The viability of those public health services in smaller rural communities is really quite critical to the way in which those communities see themselves. So we have got to be careful with all of the funding leavers that those unintended consequences do not flow. With that proviso, I think generally where there is an active market then that should be supported.⁶¹

3.62 The VHA went on to explain that the difficulties associated with those in residential care receiving better access to resources could be 'overcome' through such a system:

If the person in residential care ended up requiring palliative care they should, by definition, because that is their principal place of residence, be just as eligible to the entitlement voucher as the person still living in the community. The complicating factors always are that the person is an environment where they are already receiving some care so to what extent should that be discounted or should that other care be taken into account that?

...You have the one element where the person in the community might still be living at home and therefore not paying 87½ per cent of their pension for the residential care they are in receipt of, but then the person in residential care does not have the maintenance cost of a home. There is a variety of debates. The fundamental thing is that the entitlement should not be any different because of the percentage of pensioners paying for residential care, not necessarily for palliative care.⁶²

3.63 The Special Interest Group of the Occupational Therapists also explained that given the importance of multidisciplinary teams in the provision of palliative care, any move to an entitlement system would need to be coupled with a broadening of the

60 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 13.

61 Mr Trevor Carr, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 13.

62 Mr Trevor Carr, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 15.

definition of 'health professional' to ensure that allied health professionals were included particularly to support people staying longer in the community before necessarily entering aged care or hospice facilities:

Ms Bourke: I think that is an access issue that occurs outside of the specific pall care units where there is a higher profile. There is that trickle-down effect. Someone sees the patient and has to think to refer to you. If they do not, it does not happen. Or they might then ask someone to write the referral, and it might not happen. I would be interested to know the people who probably need it and have it translate into an actual referral, but I think it would be a very tiny number compared to the unmet need that has been written about.

Ms Boffa: I had an interesting conversation with someone in the community yesterday. It was very clear that this person is receiving in-home palliative care. The focus of that care is very much about bed based care and not acknowledging that there were functional goals or quality of life issues that might also be addressed as part of that care. I think that nursing, bed based terminal care thought process or view of things does limit the likelihood of the generation of a referral and acknowledging and identifying functional goals and quality of life.⁶³

3.64 When Resthaven, a service provider, was asked to comment on the Productivity Commission's suggestion they identified a number of issues that may present in developing an entitlement funding framework:

What we would understand is that an entitlement assessment is an assessment at a point in time. If the pricing was correct at that time then the matching of, as you describe it, the assessed need and the payment that goes with that assessed need would work at that time. The challenge that I think we all face is what happens five minutes, five days or five months after that time and, in a system which requires a sense of independence in the assessment of that need, how does that practically work for people who are in a changing phase? That is the whole dilemma with anything associated with palliative care; it is often not until after the person is deceased that you can map back and see what the signs were where you could say that this person was very obviously in their terminal phase for the last few days of their life. But the practicality of having an assessment in a timely way which then gets those resources in—particularly if that assessment has to be done by an independent, separate body making those assessments before the provider could move into that space—those are the procedural and technical issues that go with designing these systems. What we are saying at the moment is that there is provision in the existing ACFI system and there is a pay point associated with making a claim for palliative care. Our

63 Ms Jenni Bourke, Senior Occupational Therapist, Representative, Occupational Therapy Oncology Group, Occupational Therapy Australia; Ms Rebekah Boffa, Acting Co-Convenor, Victorian Palliative Care Special Interest Group, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 21.

experience of that has been that it is very legitimate to make that assessment.

The process of reviewing that decision sometime later by somebody who is reviewing the paperwork rather than reviewing the person, and therefore making that assessment—

... It is really problematic. So what we see is either that there is an underclaiming of those payments [or a subsequent clawback] ... because with hindsight people are being very cautious in terms of when they are making those claims, which is probably too late, so then the funding is not necessarily supporting that as well as it might.⁶⁴

3.65 Resthaven explained that one of the problems facing the sector and reform is the fact that there has never been a mechanism to formally cost any aspect of aged care, including palliative care:

The point that we have made in our submission is that there has been no formal costing study of the actual costs of care for any aspect of aged care. There is a historical pattern in terms of designing that.

...So I think that if we were going to move down a path which assumes some relativities in terms of the payment models as you are describing them—which is effectively how funding works in health as you have described it—then as an industry we would want to be very comfortable that the starting point was actually a real rather than a theoretical starting point.⁶⁵

3.66 Professor David Currow reminded the committee however that although the majority of palliative care recipients may be residing in aged care facilities, palliative care applies across the entire spectrum of the population, not just aged care, and that one in three people who die expected deaths are under the age of 65:

We also need to be incredibly clear about the demography of the people who are seen by palliative care services—that is, the people who die expected deaths in our community. One in three of those people are under the age of 65. It is important that we acknowledge the full age spectrum as we start to think about the services that need to be provided. Excluding dementia, for every two people seen with cancer it would be expected that a person with a non-cancer diagnosis would also be seen. We have a national strategy; we need to back that, to resource it and to implement it.⁶⁶

Settings of care – cost, effectiveness and efficiency

3.67 Throughout its inquiry the committee received much evidence from palliative care service providers. The information detailing the different ways in which services

64 Ms Susanne McKechnie, Executive Manager, Community Services, Resthaven Inc., *Committee Hansard*, 5 July 2012, p. 11.

65 Ms Susanne McKechnie, Resthaven Inc., *Committee Hansard*, 5 July 2012, p. 11.

66 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

are delivered further highlighted the complexity of adequately funding the provision of quality palliative care.

3.68 Palliative care is provided in many settings: in hospitals; in the community through not-for-profit organisations/charities; and in aged care facilities and hospices. As discussed above, funding of the services provided through these different models is a complex arrangement of state and territory government money, federal government funding and grants, and bequests and donations from community members.

3.69 The committee consistently received evidence which clearly identified that the cost of providing palliative care in the community setting is cheaper and often more effective as the majority of people prefer to die at home or in a community setting rather than in a hospital.

3.70 Palliative Care Queensland highlighted the risks of not adequately funding the provision of services:

For a lot of us, the issue almost becomes can we afford palliative care? ... if we do not do it they [people requiring palliative care services] end up in the acute system. They queue at emergency, they ramp at emergency and end up in an acute bed, so you are doing it anyway. It is just that you are doing it not in a very good way and it is costing a lot of money. It is hard to know how much cheaper it is... we know that an acute bed in the ICU is \$4,000 to \$7,000 a day. If you are talking about an acute bed in a hospital it is probably around \$1,000 to \$1,300 a day... a palliative care bed in Queensland is costed at about \$950 a day. We know that if you go down to a step-down facility where maybe you do not have as much need for acute intervention, pain management and a whole lot of ancillary services, it is probably around \$600 or \$700 a day. And in a nursing home, as we heard before, maybe it is \$150 to \$200 a day above what is already subsidised to put in the extra care. So it all depends on where the person is.

Of course, we know that, if they are at home and looked after by a carer and want to exploit the carer and pay them nothing, it may be \$60 or \$100 a day—⁶⁷

3.71 EPC highlighted to the committee that the cost of community based care is significantly less than hospital based care even though the average length of stay in the community setting is much greater than that of a hospital stay:

In 2009, the average cost per episode of care in a sub-acute hospital was \$7,654; in the community the average cost per episode was \$2,546. An episode in a hospital was 14.7 days; the average length of stay in the community was 133 days. People may have many hospital admissions during their condition. The cost benefits are clear, however, there are really much more than cost-benefits. We have become so used to going to the

67 Professor Rohan Vora, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 29.

specialist each time we are sick that we fail to realise how much we can manage at home and what our real wishes are.⁶⁸

3.72 Dr Leslie Bolitho AM, President of the RACP suggested that at present the sector faces a 'perfect storm' – 'an ageing population, increasing rates of complex and chronic disease and ever-tightening resources.'⁶⁹ In view of the benefits that could be gained, not only in terms of patient preference, but also to health care budgets, the RACP suggest shifting the provision of palliative care to the community sector rather than relying on the hospital system.⁷⁰

Committee comment

3.73 The committee supports the development and introduction of nationally consistent classifications and data collections for hospital provided care and the development of a nationally consistent costing and funding model for hospital provided treatment which will flow from the introduction of activity based funding (ABF). The committee however does share the concerns of witnesses and submitters to its inquiry that ABF will not adequately account for the complexity of palliative care including the different disease trajectories associated with life limiting illnesses, the different settings in which palliative care can be provided and the key role that multidisciplinary teams, including allied health professionals, play in the provision of care.

3.74 The committee acknowledges that the Independent Hospital Pricing Authority, responsible for progressing ABF, has established a sub-acute advisory committee which includes palliative care specialists in its membership. The committee is not convinced however that the establishment of such a committee will go far enough in ensuring that the unique attributes of palliative care, including the fact that the outcome being sought is rarely curative, will address the specific funding requirements which it has identified throughout its inquiry.

3.75 The committee notes that under the National Partnership Agreement on Improving Public Hospital Services, funding for palliative care is bundled with funding for subacute care and states and territories are given the flexibility to redirect the funding as they consider is necessary. The committee acknowledges the need for flexibility in funding palliative care given the many settings in which care is provided however is concerned that at present there is no consistent or standard reporting mechanism in place to review how money provided to the states and territories is allocated. The committee is concerned by this situation despite the requirement of the

68 Ms Jeanette Moody, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 2.

69 Dr Leslie Bolitho AM, President, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 9.

70 Dr Leslie Bolitho AM, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 9.

COAG process that each state and territory government to provide implementation plans.

3.76 The committee recognises that ABF will introduce a method of measuring and collecting data but considers that the complexity of providing palliative care make its funding a unique challenge. The committee considers that some flexibility needs to be retained as to how each state and territory allocates its funding given their differences in terms of geographic size, dispersion, population, and demographics. However, the committee regards accountability as critical and calls on the government to ensure sufficient governance structures are in place.

3.77 The committee suggests that palliative care differs in nature from the other types of 'sub-acute' care, and this warrants it being considered as a separate funding category. The committee also considers that recognition needs to be formally given to the role of the community sector in the funding arrangements for palliative care, given that evidence clearly shows the cost benefits that can be achieved by transferring the provision of palliative care to the community setting rather than the hospital based environment.

3.78 The committee received evidence in relation to the Productivity Commission's suggestion that the aged care sector moves to an entitlement system (one in which diagnosis would determine funding entitlement and the funding entitlement would follow the patient through the system). The Committee recognises that life limiting illnesses are not limited to those Australians who are aged – palliative care service recipients cross the age spectrum and although generally it is assumed the majority reside in aged care facilities or within the community, this is not always the case. The Committee recognises the concerns that this raises, however, this ought not necessarily preclude palliative care being included in any future move to an entitlement system in the aged care system. Reforms should take account of the complexities of palliative care.

3.79 The committee considers that at times it is forgotten that disease does not discriminate. Although longevity increases the incidence of incurable illnesses such as dementia, incurable and life-limiting illnesses can be suffered by anyone, from the very youngest to the very oldest members of community. Funding mechanisms should reflect this fact, and ensure care is delivered in accordance with the WHO definition of palliative care.

Recommendation 2

3.80 The committee recommends that the Australian government considers extracting palliative care from the sub-acute care category and create a new funding category of 'palliative care'.

3.81 The committee recommends that in determining the appropriate costing for palliative care services the costs of providing care in the community sector also be calculated and allocations made to support the provision of palliative care services by this sector. The committee acknowledges that any allocations of funds

to community sector service providers would require rigorous and transparent governance arrangements to be established.

Recommendation 3

3.82 The committee recommends that the creation of a new palliative care funding category should result in the establishment of a palliative care advisory committee by the Independent Hospital Pricing Authority to advise the Authority on appropriate costing for palliative care services consistent with the activity-based funding approach.

Recommendation 4

3.83 The committee recommends that the development and introduction of consistent national data collection specifically provide for the recording and reporting of palliative care data.