



**Australian Government**

**Australian Government  
Response to the Senate  
Community Affairs References  
Committee Report: Palliative  
Care in Australia**

**May 2016**

© Commonwealth of Australia as represented by the Department of Health 2016

ISBN: 978-1-76007-268-1

Online ISBN: 978-1-76007-269-8

Publications Number: 11525

### **Creative Commons Licence**



This publication is licensed under the [Creative Commons Attribution 4.0 International Public License](https://creativecommons.org/licenses/by/4.0/legalcode) available from <https://creativecommons.org/licenses/by/4.0/legalcode> (“Licence”). You must read and understand the Licence before using any material from this publication.

### **Restrictions**

The Licence may not give you all the permissions necessary for your intended use. For example, other rights (such as publicity, privacy and moral rights) may limit how you use the material found in this publication.

The Licence does not cover, and there is no permission given for, use of any of the following material found in this publication:

- the [Commonwealth Coat of Arms](http://www.itsanhonour.gov.au) (by way of information, the terms under which the Coat of Arms may be used can be found at [www.itsanhonour.gov.au](http://www.itsanhonour.gov.au));
- any logos and trademarks;
- any photographs and images;
- any signatures; and
- any material belonging to third parties.

### **Attribution**

Without limiting your obligations under the Licence, the Department of Health requests that you attribute this publication in your work. Any reasonable form of words may be used provided that you:

- include a reference to this publication and where, practicable, the relevant page numbers;
- make it clear that you have permission to use the material under the Creative Commons Attribution 4.0 International Public License;
- make it clear whether or not you have changed the material used from this publication;
- include a copyright notice in relation to the material used. In the case of no change to the material, the words “© Commonwealth of Australia (Department of Health) 2016” may be used. In the case where the material has been changed or adapted, the words: “Based on Commonwealth of Australia (Department of Health) material” may be used; and
- do not suggest that the Department of Health endorses you or your use of the material.

### **Enquiries**

Enquiries regarding any other use of this publication should be addressed to the Branch Manager, Communication Branch, Department of Health, GPO Box 9848, Canberra ACT 2601, or via e-mail to [copyright](mailto:copyright@health.gov.au) at [copyright@health.gov.au](mailto:copyright@health.gov.au)

## INTRODUCTION

The Australian Government welcomes the Senate Community Affairs References Committee report on Palliative Care in Australia (the Report). The Australian Government thanks the Committee members for their efforts in bringing to light palliative care issues and areas for improvement.

The Australian Government recognises the importance of helping people who are terminally ill access the best care and support available to maintain their dignity and quality of life.

The Australian Government continues to provide financial assistance to state and territory governments to operate palliative care services, a form of sub-acute care, as part of their health and community service provision responsibilities.

On 1 April 2016 the Council of Australian Governments (COAG) agreed a *Heads of Agreement between the Commonwealth and the States and Territories* on public hospitals funding (the Agreement) from 1 July 2017 to 30 June 2020 ahead of consideration of longer-term arrangements. This Agreement retains activity based funding as the main financing mechanism, including the use of the National Efficient Price (NEP), and caps national growth in Commonwealth funding at 6.5 per cent a year.

The Agreement will provide a further \$2.9 billion to states and territories (the States) for public hospital funding over the term of the Agreement.

In return for additional funding, the States have been asked to develop and implement a range of reforms to improve health outcomes and decrease demand for public hospital services by 1 July 2017. These include coordinated care for patients with chronic and complex disease; incorporating quality and safety into hospital pricing; and reducing avoidable hospital readmissions.

In May 2015, the Government announced the successful organisations to receive funding under the National Palliative Care Projects until June 2017. Projects funded will support quality service delivery, by focusing on the following areas:

- service provider skill development (frontline worker education and training);
- service quality improvement (in acute and community health settings);
- research and benchmarking (build and enhance capacity within the palliative care sector);
- advance care planning (strengthen understanding and uptake);
- knowledge building and awareness (improve sector knowledge and community awareness);
- improve collaboration and linkages between all Governments' palliative care activities; and
- collate and distribute palliative care information across the sector.

The Australian Government has considered the 38 recommendations made in the Report, and detailed responses in relation to each recommendation of the Senate Community Affairs References Committee report on Palliative Care in Australia (the Report) are below. Details are correct at time of drafting.

Recommendation No	Recommendation	Australian Government Response
1	The committee recommends that the Australian Commission on Safety and Quality in Healthcare (ACSQHC) consider the proposal to implement a national standard linked to accreditation, noting that reforms should not result in increased regulatory burden or complexity.	<p><b>Supported in principle</b></p> <p>The Australian Government notes that a number of accreditation schemes, covering care in multiple settings, are already in place.</p> <p>The Australian Commission on Safety and Quality in Health Care (ACSQHC) has already developed the National Safety and Quality Health Service (NSQHS) Standards. The purpose of the NSQHS Standards is to protect the public from harm and improve the quality of service provision. The NSQHS Standards have been developed to apply in all healthcare settings, including palliative care. When health service organisations are being assessed against the NSQHS Standards, palliative care services need to be included in this process.</p> <p>The ACSQHC is currently reviewing the NSQHS Standards, with Version 2 due out in 2017. In the next version there will be an increased focus on patient-centred care generally and end-of-life care in particular. This includes potential actions in areas such as having systems to identify people approaching the end of life; working with patients, families and carers to proactively plan for care at the end of life; and assessing physical, psychosocial and spiritual needs and taking action to reduce preventable distress.</p> <p>The ACSQHC has also developed an End of Life Care in Acute Hospitals Consensus Statement (Consensus Statement), which describes the elements that are essential for delivering timely, appropriate and compassionate end of life care to people who are being cared for in acute health care facilities in Australia, and sets out agreed practice for recognising and responding to people in need of end of life care. The Consensus Statement was endorsed by Health Ministers on 13 May 2015.</p>
2	The committee recommends that the Australian Government considers extracting palliative care from sub-acute care category and create a new funding category of 'palliative care'.	<p><b>Not Supported</b></p> <p>Under the 2011 COAG National Health Reform Agreement (NHRA), the Commonwealth and states agreed to introduce national Activity Based Funding (ABF) for public hospital services. Nationally consistent ABF for subacute care, including palliative care, commenced on 1 July 2013.</p>

Recommendation No	Recommendation	Australian Government Response
	<p>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 allocation of funds to community sector service providers would require rigorous and transparent governance arrangements to be established.</p>	<p>The Australian Government does not support the creation of a new funding category for palliative care services delivered by public hospitals because the existing ABF classifications used to price and fund palliative care services appropriately account for the complexities and costs associated with delivering palliative care services in Australia.</p> <p>The Independent Hospital Pricing Authority (IHPA) is responsible for classifying and pricing public hospital services eligible for Australian Government funding, including palliative care. The IHPA uses the Australian National Subacute and Non-Acute Patient classification system (AN-SNAP) to price palliative care services. AN-SNAP classifies palliative care services based on the setting, phase of care, and patient-related factors such as age, and provides a technically sound and clinically relevant means for defining and pricing palliative care services delivered in public hospitals. The IHPA reviews the price of public hospital services, including palliative care, annually.</p> <p>The Australian Government notes that the provision of palliative care services in the community sector is an emerging area of service delivery and further exploration of this is warranted.</p>
3	<p>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.</p>	<p><b>Not supported</b></p> <p>The IHPA has established the Subacute Care Working Group (SCWG) to provide technical advice regarding implementing nationally consistent ABF for subacute services, including palliative care.</p> <p>The SCWG is responsible for advising the IHPA on:</p> <ul style="list-style-type: none"> <li>• The development of a new classification system for subacute care services in Australia that supports effective, contemporary models of care;</li> <li>• The international research on subacute models of care and classification systems that support those models;</li> <li>• Testing and trialling methods to validate the feasibility and effectiveness of any proposed classification system; and</li> <li>• The implementation of a new classification system for subacute care.</li> </ul>

Recommendation No	Recommendation	Australian Government Response
		<p>The SCWG membership includes a wide range of clinical experts, including a palliative care representative and representatives from each jurisdiction. The SCWG is well-equipped to provide the IHPA with support to develop a robust and clinically valid classification and funding model for subacute care, including palliative care.</p>
4	<p>The committee recommends that the development and introduction of consistent national data collection specifically provide for the recording and reporting of palliative care data.</p>	<p><b>Noted</b></p> <p>Under the 2011 COAG National Health Reform Agreement (NHRA), the Commonwealth and states agreed to introduce national Activity Based Funding (ABF) for public hospital services. Nationally consistent ABF for subacute care, including palliative care, commenced on 1 July 2013.</p> <p>This means that from 1 July 2013, activity data for subacute care, including palliative care, has been reported in the following nationally consistent data sets:</p> <ol style="list-style-type: none"> <li>1. Activity Based Funding: admitted subacute and non-acute hospital care Data Set Specification (ASNC ABF DSS); and</li> <li>2. Activity Based Funding: non-admitted patient care data set specifications.</li> </ol> <p>The IHPA is currently undertaking further development of the AN-SNAP classification which will ensure the classification of admitted subacute and non-acute remains valid. The revised classification will identify key cost drivers, evaluate counting issues for subacute and non-acute patients, and reflect and incorporate changes in patient mix, medical practice, and clinical assessment tools.</p>
5	<p>The committee recommends that the government, with the assistance of the Council of Australian Governments, take steps to improve the provision and timeliness of information to palliative care patients, their carers and families. Processes should be</p>	<p><b>Noted</b></p> <p>The Council of Australian Governments (COAG) is the peak intergovernmental forum in Australia, responsible for agreeing high level policy direction.</p> <p>Individual states and territories, as health system managers, are best placed to determine the need for improved information provision to palliative care patients, their carers and families.</p>

Recommendation No	Recommendation	Australian Government Response
	<p>put in place to ensure that patients, their carers and families are provided with the right amount of information, in the right format, at the right time and that a 'show bag' approach be avoided.</p> <p>The committee recommends that this process begin with a review of the CareSearch website.</p>	<p>However, the National Safety and Quality Health Service Standards, which have been developed to apply in all healthcare settings, including palliative care, currently recognise the importance of information provision. For instance, Standard 2.4 identifies the need for organisations to consult consumers on patient information by seeking feedback from both patients and carers about the publications provided. Feedback is then incorporated into materials prepared by the health service organisations for distribution to patients.</p> <p>CareSearch is undertaking a review of the website to ensure currency of content. The review is part of an ongoing evaluation process undertaken by CareSearch to ensure currency of content.</p>
6	<p>The committee recommends that all governments work together to fund minimum levels of bereavement service provision for all families and carers of people with a terminal illness.</p>	<p><b>Noted</b></p> <p>Under the national ABF arrangements, the Australian Government provides a funding contribution for services delivered in public hospitals in accordance with the pricing and classification determinations of the IHPA. The pricing for bereavement services provided to family and/or carers is included in the national efficient price being set by the IHPA.</p> <p>Under the NHRA, states are recognised as system managers of the public hospital system. As system managers, states are responsible for the planning and purchasing of services delivered by public hospitals.</p>
7	<p>The committee recommends that Government give careful consideration to the special circumstances of families caring for terminally ill children when considering future changes to the eligibility criteria for the Carer Allowance and/or Child Care Rebate.</p>	<p><b>Supported</b></p> <p>The Australian Government recognises the difficult circumstances of caring for children who are terminally ill.</p> <p>The Australian Government provides a range of payments to assist people caring for someone with a disability or medical condition, including those caring for a terminally ill child. Payments available to carers of children are Carer Payment, Carer Allowance, Child Disability Assistance Payment and Carer Supplement. Income and assets tests apply to Carer Payment. Any changes</p>

Recommendation No	Recommendation	Australian Government Response
		<p>to eligibility for the payments would take into account the variety of circumstances affecting carers, including those caring for a terminally ill child.</p> <p>The Government will spend almost \$40 billion on child care support over the four years. This significant investment includes an increase of more than \$3 billion to support the implementation of the <i>Jobs for Families Child Care Package</i>.</p> <p>From July 2017, the Child Care Subsidy will replace the Child Care Benefit, Child Care Rebate and Jobs, Education and Training Child Care Fee Assistance.</p> <p>Family eligibility for the Child Care Subsidy will be determined by a family income and a three-step activity test which more closely aligns hours of subsidised care with the amount of work, training, study or other recognised activity undertaken. There will be exemptions to the activity test for parents who legitimately cannot meet the activity test requirements, including those with caring responsibilities.</p> <p>Prior to implementation of the new Child Care Subsidy, there will be further consultation on the specific elements of the subsidy including determining what is a recognised activity and the range of exemptions for those who legitimately cannot meet the activity test requirements.</p> <p>In addition to the Child Care Subsidy, the Government will invest \$852 million to establish the Child Care Safety Net. The Child Care Safety Net will provide targeted assistance to disadvantaged communities and vulnerable children and at-risk children and their families to address barriers to accessing child care, while encouraging parents to enter and return to the workforce.</p> <p>The Child Care Safety Net has three components</p> <ul style="list-style-type: none"> <li>• Additional Child Care Subsidy – this will provide targeted additional fee assistance to children and families who are genuinely disadvantaged.</li> <li>• A new Inclusion Support Programme – to assist services to be more inclusive and improve access for children with additional needs.</li> </ul>



Recommendation No	Recommendation	Australian Government Response
		<ul style="list-style-type: none"> <li>Community Child Care Fund – a competitive grants programme designed to assist services to reduce barriers to accessing child care.</li> </ul> <p>Through the Additional Child Care Subsidy, the Government will support grandparents on income support who are the primary carers of their grandchildren to assist them with the cost of care.</p> <p>For more detail <a href="https://docs.education.gov.au/system/files/doc/other/overview_jobs_for_families_child_care_package_5.pdf">Jobs for Families Child Care Package</a>:  <a href="https://docs.education.gov.au/system/files/doc/other/overview_jobs_for_families_child_care_package_5.pdf">https://docs.education.gov.au/system/files/doc/other/overview_jobs_for_families_child_care_package_5.pdf</a></p>
8	The committee recommends that a process be put in place by the Independent Hospital Pricing Authority to ensure that the calculation of activity based funding for the provision of palliative care takes into account its complexities, including the contribution of carers, and the desirability of its provision across a range of different settings.	<p><b>Noted</b></p> <p>The IHPA currently has in place arrangements that ensure that the calculation of ABF payments for palliative care take into account the various complexities associated with this care type.</p> <p>Under the NHRA, the IHPA is required to take into account the following factors in pricing public hospital services:</p> <ul style="list-style-type: none"> <li>Timely access to quality health services;</li> <li>Appropriateness of setting and model of care;</li> <li>Based on patient rather than provider-related characteristics; and</li> <li>Minimising undesirable and inadvertent consequences.</li> </ul> <p>The complexity of palliative care is captured in the AN-SNAP classification system. AN-SNAP version 3 has 150 classes, of which 34 are exclusively for palliative care.</p>
9	The committee recommends that medical workforce training include being educated about existing pathways to specialist palliative care, ensuring that this care is	<p><b>Supported</b></p> <p>In May 2015, the Australian Government announced funding for palliative care education and training to:</p>

Recommendation No	Recommendation	Australian Government Response
	applied effectively to best meet patient need.	<ul style="list-style-type: none"> <li>• Queensland University of Technology to continue educating and training the health workforce to provide quality palliative care;</li> <li>• Children’s Health Queensland Hospital and Health Service for a national project to improve paediatric palliative care;</li> <li>• Flinders University of South Australia to fund the development of education modules on end of life care in acute hospital settings; and</li> <li>• Australian Healthcare and Hospitals Association to continue online education and training to assist health workers in the use of the Guidelines for a Palliative Approach for Aged Care in the Community Setting.</li> </ul> <p>These projects will provide skill development, education and training to palliative care service providers, including the medical workforce.</p> <p>The Australian Government also notes the role of state and territory governments in educating their medical workforce.</p>
10	The committee recommends that the Australian government create an ongoing and dedicated national scholarship fund for postgraduate studies in palliative care nursing.	<p><b>Noted</b></p> <p>The Australian Government funds scholarships for nurses, midwives and allied health professionals through the established Nursing and Allied Health Scholarship and Support Scheme (NAHSSS).</p> <p>Nurses undertaking a postgraduate palliative care course are able to apply for a NAHSSS postgraduate scholarship.</p> <p>In the 2015-16 Budget the Government announced a new Health Workforce Scholarship Scheme which will start on 1 July 2016. It is a consolidation of the NAHSS and a number of other scholarship schemes into the one scholarship programme. The Government considers that the administration of a single scheme to be the most cost effective approach to manage health scholarships while still providing stability to ensure that areas of greatest workforce need are able to be strengthened. The single scholarship will also allow the Government to target its scholarship investment to areas of the greatest workforce need and using the most effective</p>

Recommendation No	Recommendation	Australian Government Response
		<p>methods to achieve that goal. There will be a return of service obligation on the majority of these scholarships.</p>
11	<p>The committee recommends that service delivery models include greater emphasis on community-based care, 'dying in place', and a reduction in unnecessary hospital admissions.</p>	<p><b>Noted</b></p> <p>The Australian Government notes that state and territory governments operate palliative care services, a form of sub-acute care, as part of their health and community service provision responsibilities.</p> <p>The Australian Government is committed to ensuring people and their families have the support and assistance to allow end of life planning to be about personal control and choice. The Government recognises that care providers need to be appropriately skilled to look after people needing palliative care in the community.</p> <p>The Australian Government notes that community-based palliative care supports people to die at home, if that is their wish, and may be a cost effective model that could reduce the demand on hospital services. The Australian Government funds the \$49.2 million Better Access to Palliative Care in Tasmania Programme, which is trialling a community-based palliative care model and aims to increase access to community-based palliative care for people with life limiting illness nearing the end of their life.</p> <p>In May 2015, the Australian Government announced funding for palliative care education and training including:</p> <ul style="list-style-type: none"> <li>• Queensland University of Technology to continue educating and training the health workforce to provide quality palliative care; and</li> <li>• Australian Healthcare and Hospitals Association to continue online education and training to assist health workers in the use of the Guidelines for a Palliative Approach for Aged Care in the Community Setting.</li> </ul> <p>These projects will assist in skill development, education and training to palliative care service providers, including those who work in the community setting.</p>

Recommendation No	Recommendation	Australian Government Response
		<p>The Australian Government also funds :</p> <ul style="list-style-type: none"> <li>• Specialist Palliative Care and Advance Care Planning Advisory Service, to improve the palliative care skills and advance care planning expertise of aged care service staff in both the residential and community care sectors. The Advisory Service aims to improve the quality of care for aged care recipients and to prevent unnecessary hospital admissions; and</li> <li>• The Better Health Care Connections (BHCC): Short Term, More Intensive Health Care for Aged Care Recipients Program to improve access to more complex health care services for aged care recipients in residential and community settings.</li> </ul> <p>The Australian Government funded:</p> <ul style="list-style-type: none"> <li>• The Palliative Approach Toolkit (PA Toolkit) for residential aged care facilities (RACF) to enable effective day-to-day practice by staff caring for residents who are at the end of their lives. The PA toolkit has been provided to every RACF across Australia and is available electronically on the CareSearch Website.</li> </ul>
12	The committee recommends that the Council of Australian Governments consider developing and implementing a case management model.	<p><b>Noted</b></p> <p>The Council of Australian Governments (COAG) is the peak intergovernmental forum in Australia, responsible for agreeing high level policy direction.</p> <p>The Australian Government notes that responsibility for developing and implementing a single palliative care case management model would lie with state and territory governments, which as the health system managers, are responsible for determining the mix of palliative care services in their jurisdictions.</p>
13	The committee recommends that the Council of Australian Governments develop and implement a uniform national palliative care pathway that	<p><b>Noted</b></p> <p>The Council of Australian Governments (COAG) is the peak intergovernmental forum in Australia, responsible for agreeing high level policy direction.</p>

Recommendation No	Recommendation	Australian Government Response
	<p>clarifies when general palliative care moves into specialist palliative care and maps the diagnosis and referral process to ensure that a palliative patient’s journey involves coordinated access to all necessary services.</p>	<p>The Australian Government notes that responsibility for developing and implementing a uniform national palliative care pathway would lie with state and territory governments, which as the health system managers, are responsible for determining the mix of palliative care services in their jurisdictions.</p>
<p>14</p>	<p>The committee recommends that the Council of Australian Governments review the Medicare Locals structure to consider how the provision of palliative care services, both general and specialist, is integrated into primary health care at the local level.</p>	<p><b>Supported in principle</b></p> <p>The Council of Australian Governments (COAG) is the peak intergovernmental forum in Australia, responsible for agreeing high level policy direction.</p> <p>Following consideration of the Review of Medicare Locals the Government announced in the 2014-15 Budget that funding would cease to Medicare Locals on 30 June 2015 and that they would be replaced by Primary Health Networks (PHNs) from 1 July 2015.</p> <p>31 PHNs were established on 1 July 2015 with the objectives: to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes; and to improve coordination of care to ensure patients receive the right care in the right place at the right time.</p> <p>In addition, the Government has agreed to six key priorities for targeted work by PHNs. These are mental health, Aboriginal and Torres Strait Islander health, population health, health workforce, eHealth and aged care.</p> <p>PHNs will analyse the health needs of their populations through formal planning processes to identify local priorities and to better target available resources and services. Palliative care may be an issue that is identified through the needs assessment and population health planning process.</p>

Recommendation No	Recommendation	Australian Government Response
		<p>PHN boundaries are generally aligned with Local Hospital Networks to facilitate collaborative working relationships and opportunities to establish shared objectives, such as reducing avoidable hospital admissions.</p> <p>PHNs will also work with primary and secondary care providers to support the development of innovative and locally responsive primary health care based programmes and services. PHN Boards will be informed and supported by GP-led Clinical Councils and Community Advisory Committees, which are being established in each PHN.</p> <p>The Department of Health is developing a PHN Performance Framework with national, local and organisational level indicators, to monitor and report on PHN Performance.</p> <p>Furthermore, at the COAG meeting of 1 April 2016 jurisdictions reaffirmed their commitment to work together to implement coordinated care reforms that will keep people healthy and out of hospital. This commitment includes the introduction of Health Care Homes by the Commonwealth to improve care for people with multiple chronic diseases. Increased access to care coordination through the Health Care Home model will offer patients with a likelihood of mortality earlier support to make decisions about end of life care and access to home based palliative care.</p>
15	The committee recommends that the Commonwealth government increase its support for paediatric palliative care research.	<p><b>Supported in principle</b></p> <p>The Australian Government recognises funding for medical research is one of the best long-term investments a government can make for the health of its people. Consistent long-term funding for medical research lifts national productivity, improves quality of life and boosts life expectancy.</p> <p>The National Health and Medical Research Council (NHMRC) is the Australian Government's main health and medical research funding body. The majority of research supported by NHMRC is investigator-initiated.</p>

Recommendation No	Recommendation	Australian Government Response
		<p>Generally, increased support for paediatric palliative care research is dependent on the research proposals for paediatric palliative care being submitted by researchers and assessed as successful as part of the NHMRC research funding process.</p> <p>NHMRC is investing in a Centre of Research Excellence (CRE) in End of Life Care. This CRE aims to design and evaluate innovative service models and interventions to improve outcomes for people at the end of life and ensure the transfer of research findings into health policy and practice.</p> <p>As part of the 2014-15 Budget, the Australian Government announced the establishment of the \$20 billion MRFF as a dedicated vehicle for investment in medical research.</p> <p>The Minister for Health recently established the independent Australian Medical Research Advisory Board (Advisory Board) which will provide advice to Government on disbursements from the MRFF.</p> <p>The Advisory Board will develop the Australian Medical Research and Innovation Strategy Priorities. Criteria for identifying the Priorities will include consideration of:</p> <ul style="list-style-type: none"> <li>• the burden of disease on the Australian community;</li> <li>• how to deliver practical benefits from medical research and medical innovation to as many Australians as possible;</li> <li>• how to ensure that financial assistance provides the greatest value for all Australians;</li> <li>• how to ensure that financial assistance complements and enhances other financial assistance provided for medical research and medical innovation; and</li> <li>• any other relevant matter.</li> </ul> <p>The development of the Strategy and Priorities will be subject to consultations with the health and medical research sector and other expert parties. It is in this context that further support for palliative care research could be considered.</p>
16	The committee recommends that Cancer Australia, in reviewing the	<b>Noted</b>

Recommendation No	Recommendation	Australian Government Response
	distribution of research funding, discuss with funding bodies the capacity to ensure that appropriate levels of funding are being provided to palliative care research.	<p>Cancer Australia has a dedicated budget for cancer research which is administered through the Priority-driven Collaborative Cancer Research Scheme (PdCCRS). The PdCCRS is an annual, national competitive research project grants scheme that offers a coordinated approach to the funding of cancer research in identified priority areas to help reduce the impact of cancer in the community and improve outcomes for people affected by cancer. Through the PdCCRS, Cancer Australia partners with a range of key cancer research funders to coordinate and maximise investment in cancer research at a national level. Cancer Australia works in partnership with the National Health and Medical Research Council to ensure that PdCCRS research grants funded are of high quality, and research grants are awarded funding in strict merit order.</p> <p>Cancer Australia's PdCCRS research priorities for 2013-2015 include patient support, survivorship issues and end-of-life care, and were informed by data from a national audit of direct funding to cancer research projects and programs in 2006-2011. This audit was undertaken by Cancer Australia to identify the national pattern of investment provided to Australian researchers for direct cancer research project and research program funding in the years 2006 to 2011, inclusive, and to inform future research priorities.</p> <p>The collaborative funding approach in the PdCCRS allows research grants in shared priorities areas to be co-funded by multiple funding partners. This co-funding model allows a greater number of research projects to be funded.</p>
17	The committee recommends that governments encourage care providers to provide data to the Palliative Care Outcomes Collaboration and consider making the reporting of this data a condition of public funding.	<p><b>Noted</b></p> <p>In May 2015, the Australian Government announced funding to the University of Wollongong to continue the Palliative Care Outcomes Collaborative (PCOC).</p> <p>However, as the Australian Government does not directly fund service providers, it is not able to require health care providers to submit data to the PCOC as a condition of funding.</p>
18	The committee recommends that the Australian Government develop a nationally funded framework for palliative care	<p><b>Supported in principle</b></p>



Recommendation No	Recommendation	Australian Government Response
	research, as outlined by the Centre for Palliative Care.	<p>The Australian Government recognises the importance of continued research into palliative care.</p> <p>While palliative care is not currently included as a National Health Priority Area, palliative care research is one of many matters being considered in the ongoing development of NHMRC's strategic directions, and NHMRC will continue to provide funding across the full spectrum of health and medical research, including research related to palliative care.</p> <p>NHMRC has invested in a Centre of Research Excellence in End of Life Care. This will help generate new knowledge about health service interventions and strategies to enhance care for all Australians at the end of life.</p>
19	The committee recommends that the NHMRC publicly report the results of its work on alternative therapy claims in relation to palliative care.	<p><b>Noted</b></p> <p>NHMRC released a Statement on Homeopathy and an <i>Information Paper: evidence on the effectiveness of homeopathy for treating health conditions</i> in March 2015. The Statement's key message, based on a comprehensive assessment of the evidence, is that there is no reliable evidence that homeopathy is effective for treating health conditions.</p> <p>NHMRC also released 'Talking with your patients about Complementary Medicine – a Resource for Clinicians', in April 2014, which aims to promote collaborative discussions between clinicians and their patients about the use of Complementary Medicine.</p> <p>NHMRC will also continue to increase knowledge regarding alternative therapy claims throughout the funding of investigator-driven research through NHMRC's competitive, peer-reviewed grant application processes.</p>
20	The committee recommends that the Council of Australian Governments examine the viability of introducing a national equipment library for palliative care patient needs, examining whether such an approach would	<p><b>Noted</b></p> <p>The Council of Australian Governments (COAG) is the peak intergovernmental forum in Australia, responsible for agreeing high level policy direction.</p>

Recommendation No	Recommendation	Australian Government Response
	allow more efficient and timely provision of available equipment and funds.	State and territory governments, as health system managers, remain responsible for determining the mix of services in response to the needs within their jurisdiction, including the purchase and loan of equipment for patients being cared for in the community.
21	To prevent the mis-prescribing of equipment, the committee recommends that the Australian Government investigate current regulation and consider improving regulation of both private and public palliative care equipment providers.	<p><b>Noted</b></p> <p>As stated in the response to recommendation 20, purchasing and loaning equipment for patients is the responsibility of state and territory governments. Regulatory arrangements are part of this responsibility.</p>
22	The committee recommends that the Australian Government closely monitor implementation of the recent changes to the Home and Community Care program to ensure that the program is meeting the needs of those over 65, and that palliative care recipients who do not fall into the aged care bracket are receiving adequate support.	<p><b>Noted</b></p> <p>On 1 July 2012, the Australian Government assumed full policy, funding and day-to-day responsibility of HACC services for people aged 65 years and over and for Aboriginal and Torres Strait Islander people aged 50 years and over in all states and territories except Victoria and Western Australia.</p> <p>From 1 July 2015 the Commonwealth HACC Programme was replaced by the Commonwealth Home Support Programme (CHSP).</p> <p>The CHSP provides funding for services which support frail older people, aged 65 years and over and Aboriginal and Torres Strait Islander people aged 50 years and over who live in the community.</p> <p>Specialist palliative care is outside the scope of the CHSP as it previously was for HACC. The aim of these programmes is to provide entry level support services helping older people stay independent and in their homes and communities for longer.</p>

Recommendation No	Recommendation	Australian Government Response
		<p>Specialist palliative care services receive funding through other Commonwealth and State and Territory Government programmes. Palliative care clients can access CHSP services, provided they meet the eligibility criteria of the Programme.</p> <p>State and Territory Governments continue to fund and administer basic maintenance, support and care services for people aged less than 65 years old and Aboriginal and Torres Strait Islander people aged less than 50 years.</p> <p>People who are aged under 65 years, and Aboriginal and Torres Strait Islander people aged under 50 years, who are receiving support services under the National Disability Insurance Scheme (NDIS), can choose to have those services provided under either the aged care system or the NDIS when they turn 65 or 50. Both of these systems will continue to provide support for eligible people and will work alongside the systems providing specialist palliative care.</p>
23	<p>The committee recommends that the Australian government consider changing the eligibility to Home and Community Care (HACC) to include palliative care patients or carers of such patients, regardless of their age. The committee notes that as the HACC program is linked to funding and funding agreements, the Australian government consider this recommendation in the context of considering changes to the funding model for palliative care.</p>	<p><b>Noted</b></p> <p>The Commonwealth Home Support Programme (CHSP) provides funding for services which support frail older people, aged 65 years and over and Aboriginal and Torres Strait Islander people aged 50 years and over who live in the community. The CHSP provides home support services to people with palliative care needs provided they meet the eligibility criteria of the Programme.</p> <p>Palliative care and nursing services that would otherwise be undertaken by the Health system are not funded under the Commonwealth Home Support Programme.</p> <p>These (complementary) services are considered out-of-scope because government funding is already provided for them through other government support programmes. However, a client can receive non-health related CHSP services in conjunction with post-acute and allied health services, for example following a hospital stay.</p>

Recommendation No	Recommendation	Australian Government Response
		<p>State and Territory Governments continue to fund and administer basic maintenance, support and care services for people aged less than 65 years old and Aboriginal and Torres Strait Islander people aged less than 50 years.</p> <p>The NDIS will fund reasonable and necessary supports that are related to the person's functional impairment for people aged less than 65 who meet the eligibility criteria of the NDIS. The NDIS will work collaboratively with the systems providing specialist palliative care where necessary.</p>
24	<p>The committee recommends that the Australian government analyse and identify potential gaps in the provision of palliative care and palliative care funding for people with disabilities, especially in supported accommodation.</p>	<p><b>Noted</b></p> <p>At a national level, the National Disability Strategy (the Strategy) which was launched by the Australian Government in March 2011 outlines a ten-year national policy framework to improve the lives of people with disability, promote participation, and create a more inclusive society.</p> <p>The Strategy guides public policy across governments and aims to bring about change in all mainstream and specialist services and programs, as well as community infrastructure, to ensure they are accessible and responsive to the needs of people with disability.</p> <p>One of the central outcomes of the Strategy is to ensure that people with disability attain the highest possible health and wellbeing outcomes throughout their lives. This means, in practical terms, that people with disability should have the same access to mainstream health services, including palliative care and related support, as all other Australians.</p> <p>The interaction between mainstream service systems (including health services) and the National Disability Insurance Scheme (NDIS) remains a key priority for the Council of Australian Governments (COAG) and the Disability Reform Council (DRC) to ensure the financial sustainability of the scheme.</p> <p>The NDIS Applied Principles and Tables of Supports, which have been agreed by COAG, identify the respective roles and responsibilities of the Health system and the NDIS. These include identifying the health system as being responsible for sub-acute services such as palliative care.</p>

Recommendation No	Recommendation	Australian Government Response
		<p>These Principles include that the interactions of people with disability and other service systems should be as seamless as possible, and that both systems will work together to ensure that services are either delivered together when required, or that there is a smooth transition from one system to the other.</p> <p>DRC agreed that there should be escalation procedures to address areas where operationalisation of the <i>Applied Principles and Tables of Supports</i> results in gaps at the local level, this is being put into effect through the bilateral agreements between the Commonwealth and the States and Territories for transition to full scheme.</p> <p>COAG and the DRC will continue to monitor any service gaps that are reported, including for participants in supported accommodation as well as other settings.</p>
25	<p>The committee endorses the recommendations of Palliative Care Australia that, in relation to Commonwealth funded programs, it support:</p> <ul style="list-style-type: none"> <li>• Appropriate training and education about cultural perspectives relating to palliative care and end of life issues, in core curricula for all health workers and health practitioners providing services to Indigenous people; and</li> <li>• Inclusion of palliative and end of life related topics in the core curricula for Aboriginal health worker Certificate III and IV; continuation of PEPA to build on or develop cultural</li> </ul>	<p><b>Supported in principle</b></p> <p>The Australian Government supports the Committee's view that every effort should be made to ensure that the needs and wishes of Aboriginal and Torres Strait Islander people requiring palliative care are met and that Aboriginal and Torres Strait Islander people should have access to high quality, culturally appropriate palliative care.</p> <p>In May 2015, the Australian Government announced the following funding for palliative care education and training projects that are providing cultural perspectives relating to palliative care and end of life issues:</p> <ul style="list-style-type: none"> <li>• Queensland University of Technology to continue educating and training the health workforce to provide quality palliative care;</li> <li>• Austin Health to continue Respecting Patient Choices, a national program to assist individuals to choose their end of life care and to inform their families, carers and health professionals;</li> <li>• Australian Healthcare and Hospitals Association to continue online education and training to assist health workers in the use of the Guidelines for a Palliative Approach for Aged Care in the Community Setting; and</li> </ul>

Recommendation No	Recommendation	Australian Government Response
	appropriate education for Indigenous health workers.	<ul style="list-style-type: none"> <li>• Cabrini Health Limited to develop an Advance Care Planning online resource, taking account of various religious and cultural considerations to assist in end of life decision making.</li> </ul> <p>Health Workforce Australia's <i>Growing Our Future</i> report highlighted the need to develop a culturally inclusive, interdisciplinary Aboriginal and Torres Strait Islander health curriculum framework able to be integrated into tertiary level health profession training. In 2013, Health Workforce Australia (HWA) contracted Curtin University to develop the framework. With the closure of HWA, the Department of Health is now managing this contract. The framework has been finalised, and a communication strategy is being developed to ensure that stakeholders are aware of and have access to the framework and to maximise its implementation into all Australian universities. It is intended that the framework will improve the knowledge and capabilities of health professionals to work with Aboriginal and Torres Strait Islander people and contribute to better health outcomes for Aboriginal and Torres Strait Islander communities<sup>1</sup>.</p> <p>The Australian Government funds the Leaders in Indigenous Medical Education (LIME) Network, a project of Medical Deans Australia and New Zealand, hosted by the Onemda VicHealth Koori Health Unit (University of Melbourne). LIME improves cultural awareness through collaboration and by delivering education on Aboriginal and Torres Strait Islander health to medical students. It provides professional development opportunities and support for medical educators to effectively deliver Indigenous health curriculum and engage Indigenous students. LIME also provides expanded opportunities for collaboration among academic staff of schools of medicine, health science, nursing and allied health disciplines, to increase the capacity of these schools to deliver high quality Indigenous medical and health care.</p> <p>A national framework has been developed for medical curricula (Committee of Deans of Australian Medical Schools - CDAMS Indigenous Health Curriculum Framework).</p>
26	The committee recommends that the Australian Government	<b>Noted</b>

<sup>1</sup> On 7 August 2014 the policy, programme and funding responsibilities of Health Workforce Australia transferred to the Department of Health.

Recommendation No	Recommendation	Australian Government Response
	increase funding to palliative care programs for Indigenous communities in rural and remote areas, with particular emphasis on return to country.	The Australian Government provides funding to states and territories to support subacute care delivery, including palliative care, but the mix of services and distribution of subacute care beds and services across jurisdictions is determined by states and territories as health system managers.
27	The committee recommends that the Australian Government give increased attention to the need for improved research, education and services to support the perinatal and neonatal palliative care needs of health professionals, pregnant women and their families and newborn infants.	<p><b>Noted</b></p> <p>The Government recognises the needs of pregnant women, their families and newborn infants as well as health care professionals in relation to perinatal and neonatal palliative care. However, the provision of palliative care services is the responsibility of state and territory governments as health system managers.</p> <p>In May 2015, the Australian Government announced funding for the Children’s Health Queensland Hospital and Health Service to conduct a national project to improve the quality of paediatric palliative care services.</p>
28	The committee recommends that, within twelve months, the Australian Government review the implementation and evaluation of the recommendations of the Paediatric Palliative Care Service Model Review, and publish the findings of that process.	<p><b>Noted</b></p> <p>The Australian Government recognises the importance of delivering effective paediatric palliative care. The allocation of funding to paediatric palliative care services is a state and territory responsibility. The Paediatric Palliative Care Service Model Review was completed 10 years ago and utilisation of the Model is a matter for state and territory governments.</p>
29	The committee recommends that there be appropriate formal recognition of the Australian and New Zealand Paediatric Palliative Care Reference Group, and that the Australian Government work with the organisation on the	<p><b>Noted</b></p> <p>The Australian Government commends the contribution of the Australian and New Zealand Paediatric Palliative Care Reference Group to improving paediatric palliative care outcomes.</p> <p>The National Framework for Advance Care Directives was approved by Australian Health Ministers in August 2011 and consists of a proposed national terminology, a code for ethical</p>

Recommendation No	Recommendation	Australian Government Response
	development of a paediatric addendum to the National Framework for Advance Care Directives 2011.	<p>practice and best practice standards for advance care directives. It aims to direct the development of nationally consistent guidelines for advance care directives and the harmonisation of state and territory legislation regarding advance care planning.</p> <p>However, the National Framework for Advance Care Directives 2011 was not intended to provide specific guidance on advance care directives issues relating to paediatric patients or any other group.</p>
30	The committee recommends that the Commonwealth, state and territory governments consult with palliative care organisations, and existing children's palliative care support services Bear Cottage and Very Special Kids, about the feasibility of, and funding required for, establishing similar facilities in other jurisdictions.	<p><b>Supported</b></p> <p>The Australian Government recognises the needs of paediatric palliative care services for both the terminally ill child and the family.</p> <p>The Australian Government is providing \$5.5 million over six years (from 2014-15) for Hummingbird House, to help build the new service in Brisbane that will provide 24 hour care for children with a terminal illness.</p> <p>The Australian Government is providing \$4 million in 2015-16 for Very Special Kids Hospice in Victoria to assist in the purchase of the property the hospice is located on.</p> <p>The Government has also provided a one-off contribution of \$2 million in 2013-14 to support the work of New South Wales's only dedicated children's hospice, Bear Cottage.</p>
31	The committee recommends that the federal government initiate a full review of the medications available on the pharmaceutical benefits scheme for palliative care, particularly schedule 8 drugs.	<p><b>Supported</b></p> <p>The restrictions for all palliative care medicines listed on the Pharmaceutical Benefits Scheme (PBS) were last reviewed in 2010-2011.</p> <p>In the 2014-15 Budget, the Government announced that the Department of Health will be systematically reviewing all PBS Authority Required medicines, including palliative care medicines. Outcomes of this review, undertaken by the Pharmaceutical Benefits Advisory Committee (PBAC), will be published later in 2016.</p>



Recommendation No	Recommendation	Australian Government Response
32	The committee recommends that through the Council of Australian Governments the federal government expedite the introduction of uniform regulations for the supply of schedule 8 drugs.	<p><b>Noted</b></p> <p>The Council of Australian Governments (COAG) is the peak intergovernmental forum in Australia, responsible for agreeing high level policy direction.</p> <p>The role of the Australian Government in relation to controlled (Schedule 8) drugs is limited to making decisions regarding the classification of medicines and poisons (substances) under the Standard for the Uniform Scheduling of Medicines and Poisons (the SUSMP or Poisons Standard) for inclusion in relevant state and territory legislation.</p> <p>The Poisons Standard is about promoting the uniform scheduling of medicines and poisons throughout Australia, thereby forming the basis for a uniform system of access controls for goods containing scheduled substances.</p> <p>While the Standard is intended to provide a uniform scheduling of substances as well as uniform labelling and packaging requirements throughout Australia, the decisions contained in the Poisons Standard are recommendations to the states and territories for implementation through their respective drugs, poisons and controlled substances legislation. States and territories are responsible for the implementation of the decisions in the Standard, which may or may not require an amendment to their respective jurisdictional legislation and may implement a different scheduling decision to that included in the Standard to accommodate local circumstances and/or requirements.</p>
33	The committee recommends that the federal government review the role of nurse practitioners and registered allied health professionals in prescribing palliative care medications to remove barriers to accessing such medications in settings of care	<p><b>Supported in principle</b></p> <p>The prescribing rights for nurse practitioners and other allied health professionals are determined under state and territory law.</p> <p>All medicines in the Palliative Care section of the Schedule of Pharmaceutical Benefits can be prescribed by authorised nurse practitioners. An extensive number of medicines available on the PBS in the General Schedule that can be accessed by palliative care patients can also be prescribed by authorised nurse practitioners. Inclusion of a medicine on the PBS as being eligible to be prescribed by a certain PBS prescriber group, does not confer approval to</p>

Recommendation No	Recommendation	Australian Government Response
	where these professionals have a central role in care.	<p>prescribe that medicine if the practitioner is not authorised to do so under state or territory law.</p> <p>The Australian Health Practitioner Regulation Agency (AHPRA), responsible for the regulation of 14 health professions, has established a prescribing working group (PWG). This group includes chairs of the Allied Health and Nursing and Midwifery registration boards and other relevant stakeholder groups (e.g. NPS MedicineWise). The PWG will review and provide regulatory advice on the prescribing of medicines for registered health professionals. Jurisdictions are also progressing with a nationally consistent scheduled medicines authorities project to develop a report on requirements to promote mobility and consistency across jurisdictional borders for scheduled medicine authorities. Both committees include representation from the jurisdictions and AHPRA and will work collaboratively to achieve priority outcomes for prescribing for health professions. The Health Practitioner Prescribing Pathway (HPPP) Report (and recommendations) which includes steps that a health professional must complete to undertake safe and competent prescribing; and safe models of prescribing for health professionals is being used as a framework to progress this work. This work includes the regulatory authorities developing and gaining Health Ministers' approval for expanded practice standards, and state/territory governments changing drugs and poisons legislation, as the authority to prescribe rests with state and territory governments.</p>
34	The committee recommends that in the next review of aged care accreditation standards, the Australian government consider requiring some form of advance care training as a component of the standards.	<p><b>Supported in principle</b></p> <p>In the 2015-16 Budget, the Australian Government announced its intention to establish a single quality framework across the aged care sector. As a major component of the quality framework, the existing four sets of aged care standards, which include the residential aged care Accreditation Standards, will be consolidated.</p> <p>The Department of Health is developing options for Government which will be co-designed with industry and will take into account national and international best practice. Co-design with stakeholders commenced in 2015.</p> <p>Consideration will be given to advanced care training in the context of reviewing the standards.</p>

Recommendation No	Recommendation	Australian Government Response
35	The committee recommends the Australian Government increase the level of funding for the Respecting Patient Choices program, to support development of training providers in several jurisdictions, significantly expanding the reach of the program in the aged care sector.	<p><b>Noted</b></p> <p>The Australian Government recognises the importance of advance care planning. In May 2015, the Australian Government announced funding for Austin Health to continue Respecting Patient Choices, a national program to assist individuals to choose their end of life care and to inform their families, carers and health professionals. The Australian Government has funded the Respecting Patient Choices (RPC) Program since 2002 to build the evidence base in Australia and develop models of effective advance care planning for various target groups.</p> <p>The Australian Government is also providing funding for a National Specialist Palliative Care and Advance Care Planning Advisory Service for general practitioners and aged care staff caring for recipients of aged care services. The service is being delivered by a consortium of key organisations, led by Austin Health (responsible for delivery of the Respecting Patient Choices project). The objectives of the advisory services are to improve:</p> <ul style="list-style-type: none"> <li>• the palliative care skills and advance care planning expertise of aged care service staff and GPs caring for recipients of aged care services;</li> <li>• the quality of care for aged care recipients; and</li> <li>• linkages between aged care services and palliative care services.</li> </ul> <p>The advisory service nationally commenced in July 2014. This project includes funding to develop and implement a training package in advance care planning and palliative care for aged care staff in both the residential and community aged care settings.</p>
36	The committee recommends that national model legislation for advance care planning be developed, and that all governments pursue harmonisation of legislation as a high priority.	<p><b>Noted</b></p> <p>State and territory legislation governs the status and use of advance care planning and directives within their jurisdictions. Some states and territories have legislated to allow adults to create a formal advance care directive regarding their preferences for medical treatment. In other jurisdictions, Common Law recognises the right of competent adults to refuse medical treatment, either in advance or at the time the treatment is offered.</p>

Recommendation No	Recommendation	Australian Government Response
		<p>The level of variability in the legislative status of advance care plans/directives from jurisdiction to jurisdiction and the resultant difficulties caused by the lack of national consistency was recognised by the Australian Health Ministers Advisory Council (AHMAC).</p> <p>A National Framework for Advance Care Directives (the Framework) was commissioned and agreed to by Australian Health Ministers (in 2011) in recognition of the challenges posed by differing advance care legislation across jurisdictions and the need for a standardised national format for advance care directives. The purpose of the Framework is to provide guidance on policy and best practice in relation to advance care directives. As such it is primarily intended to assist state and territory policy makers and planners to harmonise the use and application of advance care directives in their jurisdictions within the context of agreed national principles and practice.</p>
37	<p>The committee recommends that the Australian Government fund a national public awareness campaign around advance care planning and directives, starting immediately, and expanding once a process of national harmonisation of advance care planning regulation has been undertaken.</p>	<p><b>Supported in principle</b></p> <p>The Australian Government understands the importance of advance care planning for consumers as well as for health professionals.</p> <p>In May 2015, the Australian Government announced funding for national palliative care projects including:</p> <ul style="list-style-type: none"> <li>• Austin Health to continue Respecting Patient Choices, a national program to assist individuals to choose their end of life care and to inform their families, carers and health professionals;</li> <li>• Cabrini Health Limited to develop an Advance Care Planning online resource, taking account of various religious and cultural considerations to assist in end of life decision making; and</li> <li>• Palliative Care Australia for community awareness activity.</li> </ul> <p>State and Territory governments also promote advance care planning within their jurisdictions through a range of measures.</p>

Recommendation No	Recommendation	Australian Government Response
38	<p>The committee recommends that the Australian government ensure that personally controlled electronic health records have the capacity to include palliative care information, including advance care plans.</p>	<p><b>Supported in principle</b></p> <p>Funding of \$485.1 million over four years was provided in the 2015-16 Budget for the redevelopment and continued operation of the Personally Controlled Electronic Health Record (PCEHR) which is to be renamed <i>My Health Record</i>.</p> <p>Palliative care information is able to be uploaded to the PCEHR by a healthcare provider in the form of an event summary - an event summary is a clinical document which summarises one or more episodes of care. Individuals are able to include details of the custodian of their advance care plan in the PCEHR.</p> <p>From 4 April 2016, Advance Care Plans can be uploaded on to My Health Record.</p>