Mr Ian Holland
Committee Secretary
Senate Community Affairs References Committee
Parliament House
CANBERRA ACT 2600
Email: community.affairs.sen@aph.gov.au

Dear Mr Holland

Thank you for the opportunity to provide a submission to the Senate Standing Committee on Community Affairs Inquiry into Palliative Care in Australia. My recommendations relating to the Inquiry are below.

1. National Directions in Palliative Care by Australian Government

The "National Palliative Care Strategy: 2010 Supporting Australian to Live well at the End of Life" (2011) was endorsed by the Australian Health Ministers Conference (AHMC). The implementation of the strategy is overseen by the inter jurisdictional Palliative Care Working Group (PCWG) which became part of the AHMAC Committee structure in 2011.

The National Palliative Care Program (NPCP) recognises flexible services for all Australians. Support is offered via community support for patients, families carers, palliative care drugs, workforce education, training. research and quality improvement. The Australian government also provides financial assistance to States and Territories to operate palliative care, a form of sub-acute care, through the National Partnership Agreement on Hospital and Health Workforce Reform (NPA HHWR) (Department of Health and Ageing, 2012) [1].

Through NPCP, the Federal government has funded, *inter alia*, Guidelines for residential and community aged care. The government has published "Guidelines for a Palliative Approach in Residential Aged Care" (APRAC Guidelines) (2011) and funded the development of training resources to assist staff. The other resource is "Guidelines for a Palliative Approach for Aged Care in the Community Care Setting" (COMPAC guidelines). Both Guidelines are approved by the NHMRC. The government is developing an education and training package for health personnel (GPs nurses, care workers) to assist them in using these guidelines. An external evaluation of NPCP projects will be completed in 2012-13 (Department of Health and Ageing, 2012) [1].

The Government supports Palliative Care Australia (PCA) under the NPCP to develop and implement standards to improve service quality. The "Standards for Providing Quality Palliative Care for all Australian" (the PCA Standards) were revised in 2005. These standards can be used in conjunction with, or as part of, service accreditation of bodies such as the ACHS Equip, Quality Improvement Council, RACGPs, or Aged Care Accreditation Standards. PCA was funded to undertake National Standards Assessments Program (NSAP) in 2007. There has been a national roll out for NSAP and currently there are 161 participating services.

The National Framework for Advance Care Directives (2011) is AHMC's work to assist States and Territories policy makers and planners. There are guidelines for advanced care directives and end of life medical decisions by health professionals (Department of Health and Ageing, 2012) [1].

[1] http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/palliative_care/submissions.htm submission 98

2. Stakeholder concerns about Clinical Practice Guidelines and staff training

Several stakeholders expressed concern at the public hearings for this inquiry about the need for improved staff training. mechanisms to facilitate care across the continuum and improved advanced care directives. They argued for updated Clinical Practice Guidelines in several areas relating to palliative care, standardised advanced care directives, timely diagnosis especially for dementia, pain management and improved case management to facilitate more cost effective service provision.

3. Clinical Practice Guidelines for Palliative Care

The NHMRC Clinical Practice Guidelines (CPGs) portal includes the following CPGs for Palliative care which are shown below in Tables 1 and 2. These can be obtained from the NHMRC website http://www.clinicalguidelines.gov.au/

Table 1: NHMRC list of CPGs at the NHMRC Guidelines Portal

Title	Publication year	Primary developer
Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers	2007	Collaborating Authors
Clinical practice guidelines for the management of adult gliomas - astrocytomas and oligodendrogliomas	2009	Australian Cancer Network
Clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients	2010	Centre for Palliative Care
End of life care - the importance of advance care planning	2010	Collaborating Authors
End stage heart failure patients. Palliative care in general practice	2010	Collaborating Authors
Family meetings in palliative care - multidisciplinary clinical practice guidelines	2008	Collaborating Authors
Guidelines for a palliative approach for aged care in the community setting. Best practice guidelines for the Australian context	2011	Department of Health and Ageing
Guidelines for the prevention, detection and management of chronic heart failure (updated October 2011)	2011	National Heart Foundation
Gynaecological cancer palliative care	2008	New South Wales Health
Palliative care in the neonatal nursery. Guidelines for neonatal nurses in Australia	2010	Australian College of Neonatal Nurses

Table 2: NHMRC list of CPGs at the NHMRC Guidelines Portal - Tasmania

Title	Publication year	
Palliative care management guidelines - breathlessness	2009	Tasmania Department of Health and Human Services
Palliative care management guidelines - clinical decision making at end of life	2009	Tasmania Department of Health and Human Services
Palliative care management guidelines - constipation	2009	Tasmania Department of Health and Human Services
Palliative care management guidelines - delirium	2009	Tasmania Department of Health and Human Services
Palliative care management guidelines - emergencies in palliative care	2009	Tasmania Department of Health and Human Services
Palliative care management guidelines - fatigue, anorexia and cachexia	2009	Tasmania Department of Health and Human Services
Palliative care management guidelines - nausea and vomiting	2009	Tasmania Department of Health and Human Services
Palliative care management guidelines - pain management	2009	Tasmania Department of Health and Human Services
Palliative care management guidelines - terminal care	2009	Tasmania Department of Health and Human Services
Therapeutic guidelines palliative care version 3	2010	Therapeutic Guidelines

The NHMRC Register shows the following CPG titles that are under development for Palliative Care and indicates the primary developer. This is included at the following NHMRC website http://www.clinicalguidelines.gov.au/in-development/

Table 3: Palliative Care guidelines under development

	Title	Primary Developer
0098	A review and update of the Guidelines for a Palliative Approach in Residential Aged Care	University of South Australia
0113	Clinical pathway for assessing and managing pain in people with cancer	Improving Palliative Care through Clinical Trials (ImPaCCT)

4. International Developments - Clinical Practice Guidelines for Palliative Care

There are six international Clinical Practice Guidelines that could be instructive for the Australian guidelines currently under review and for any others to be reviewed into the future. A selection of highly relevant guidelines are attached. These include the following six guidelines:

- National Institute for Health and Clinical Excellence (NICE) (2012) "Opioids in Palliative care: Safe and effective prescribing of strong opioids for pain palliative care of adults" Issued May 2012; NICE Clinical Guideline 140. guidance.nice.org.uk/cg140.

- US Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ) National Guideline Clearinghouse (2010) "Disease Management, advance directives, and end-of-life care in heart failure: HFSA 2010 comprehensive heart failure practice guideline". (Guidelines Summary NGC - 7987)

- US Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ) National Guideline Clearinghouse (2011) "End of Life during the last days and hours" (Guidelines Summary NGC - 8725).

- US Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ) National Guideline Clearinghouse (2011) "Palliative radiotherapy for bone metastases: an ASTRO evidence based guideline" (Guidelines Summary NGC - 8836).

- US Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ) National Guideline Clearinghouse (2011) "Palliative Care" (Guidelines Summary NGC - 8961).

- US Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ) National Guideline Clearinghouse (2012) Advance Care Planning" (Guidelines Summary NGC - 9005).

Recommendations

1. That the Department of Health and Ageing, relevant bodies of Council of Australian Governments (COAG) and NHMRC consider as a very high priority - the update of a broad range of existing Clinical Practice Guidelines (CPGs) for palliative care and identify *additiona*l CPGs that are required for palliative care, as identified by the stakeholders at the public hearings of this inquiry.

2. In the review of current CPGs and identification of need for new CPGs, careful consideration to be given to existing international guidelines including, *inter alia*, the six attached to this submission by the National Institute for Health and Clinical Excellence (NICE) and the USA Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ) National Guideline Clearinghouse.

3. To facilitate a thorough review by the NHMRC, COAG bodies and Department of Health and Ageing on the need for additional CPGs, careful consideration to be given to the extensive range of clinical effectiveness and cost effectiveness literature on interventions and treatment

modalities available in the Evidence Based Medicine literature and in accordance with NHMRC methodologies.

4. The identification of existing Clinical Practice Guidelines available internationally in the above reviews can be facilitated with reference to the Guidelines and Economists Network International (GENI) website which includes links to relevant organisations.
   http://geni-econ.org/

Yours Sincerely

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Health Economics and Funding Reforms
Deputy Chair Guidelines and Economists Network International (GENI) Board
9 September, 2012

Dr Kathryn Antioch, as Deputy Chair, GENI Board, is working on developments in implementing clinical and cost effectiveness evidence and Clinical Practice Guidelines (CPGs) internationally. She has been involved in ten Australian Senate Committee Inquiries on the Australian Health Reforms since 2010 and she briefed the Council of Australian Governments (COAG) on initiatives to implement Evidence Based Medicine nationally in the context of the renegotiations of the new Health Reform Agreements from 2008 to 2010. She was the appointed Health Economics member of the Principal Committees of the NHMRC for six years to 2009 including the National Health Committee, Health Advisory Committee, Privacy Working Committee and Lead Committee. She led the implementation of EBM initiatives across some Victorian Local Hospital Networks to 2007 as a member of their Senior Management and as a Principal Management Consultant.