

30<sup>th</sup> March 2012

Strategic Review of Health & Medical Research

Dear Mr McKeon,

Thank you for the opportunity to contribute to the Strategic Review of Health and Medical research in Australia. Our submission focuses on promoting investment in research funding and training which are urgently needed to underpin end of life care.

#### **The Centre for Palliative Care**

Palliative care focuses on supporting patients diagnosed with advanced, incurable disease; it is 'family centred', with the patient and their family (the unit of care) being core to all its functions.<sup>1</sup> The Centre for Palliative Care is part of St. Vincent's Hospital (Melbourne) and is a Collaborative Centre of The University of Melbourne, Australia. The Centre has a state-wide role in palliative care education and research in Victoria, with networks and collaborative projects extending nationally and internationally. The Centre plays a pivotal role in the development and implementation of training and education programs for health professionals from a variety of disciplines, while undertaking cutting-edge research to set benchmarks and improve practices in palliative care.

This submission focuses upon two of the questions raised by the Panel as detailed below.

*What are the health and medical research strategic directions and priorities and how might we meet them?*

(Terms of Reference 5, 12 and 13)

#### **Issues related to research in palliative care**

Disease focused cancer care in the last weeks of life can be futile and have a negative impact on patients' and family quality of life. Vast amounts are spent on caring for cancer patients in their last weeks of life yet there is an extraordinarily small proportion of research funding allocated to the study of palliative and end-of-life care. Data on UK research funding in 2010 show that, of the 508 million pounds awarded for research into cancer, just 0.24% was allocated to palliative and end-of-

life care research. Similarly, in the USA, of the National Cancer Institute's total appropriation for 2010 of US\$5 billion, only 1% was allocated to palliative care research. 2

We are unable to access similar data within Australia, however our experience of more than a decade in this field reveals a significant shortage of palliative research investment (both grants and positions) in comparison to cancer disease control. This is inequitable; particularly given the fact that approximately 40-50% of cancer patients will die within five years of diagnosis. In addition, most cancer patients are inadequately palliated at the end of life, with basic symptom control such as pain relief unmet. Early palliative care interventions have been shown to reduce symptoms, improve quality of life, and reduce the use of anti-cancer therapy while improving survival. A substantial investment in research into palliative and end-of-life care is urgently required to inform the transition from disease-directed to palliative care, to improve symptom control. 2

In addition to the need for research investment for patient care, evidence to underpin family care is also required. According to a recent review 3 resources and research investment to improve family carer support is urgently required, because family carers:

- Should receive evidence based support from health professionals as per national and international policies and standards.
- Are receiving support which is ad hoc and based on minimal evidence.
- Are prone to physical and psychological morbidity.
- Are responsible for numerous tasks, such as symptom management.
- Are financially disadvantaged.
- Become socially isolated.
- Report unmet needs.
- Have needs equal to and/or greater than the needs of patients.
- Have very limited first hand exposure to death and dying.
- Are pivotal to achieving 'successful' palliative care at home (where most people prefer to die).
- Make a remarkable economic contribution to health care.
- May significantly enhance the well-being of patients when they are well supported.

### **Recommendations for research**

Develop a nationally funded framework for palliative care research that:

1. Provides funding for the development of research programs specifically addressing symptom management, psychosocial support (including family carers and bereavement), and health service evaluation.
2. Invests in capacity building by developing a critical mass of palliative care researchers.
3. Creates a "whole of health" approach to palliative care research that incorporates cancer care and non malignant diseases.
4. Focuses on strategies to translate research into practice in specialist and generalist settings.

*How can we optimise translation of health and medical research into better health and wellbeing?*  
(Terms of Reference 4, 8, 9, 10 and 11)

In the palliative care sector, we believe a series of measures are required to optimise translation of research findings into clinical care with the resultant improved clinical outcomes sought. These measures include:

- Ongoing support of centralised databases of research findings in palliative care from both the published and grey literature.
- The establishment of knowledge transfer officers / positions who are credible people in the field whose central role is to distil the latest evidence into packets of knowledge for practitioners – many of whom are clinicians with little time or training to be able to do this task themselves.

Thank you once again for the opportunity to contribute to this review. We would be very happy to be contacted for further information or discussion as required.

Yours Faithfully



Prof Peter Hudson

Director, Centre for Palliative Care



A/Prof Jennifer Philip

Dep. Director, Centre for Palliative Care