

Submission to the Parliamentary Inquiry into Palliative Care

Monash University is a large and successful university in Australia's Group of Eight research intensive universities, distinguished by its international focus and commitment to innovative research and high quality teaching and learning. It has an excellent reputation for high quality research output, and undergraduate and graduate education and is emerging as an institution that is realising its potential to integrate its diverse strengths into significant research and education programs. As an institution it seeks to improve the human condition and is committed to a sustainable future. Monash has six campuses in Victoria, a campus in Malaysia, a campus in South Africa, a centre in Prato, Italy, and numerous international partnerships and co-operative ventures.

Monash has approximately 57,000 students spread across its Australian and off-shore campuses, and approximately 7,000 full time equivalent staff. Approximately 3,500 of these staff members are academic staff.

The **School of Nursing & Midwifery** ("the School") is a department of the Faculty of Medicine, Nursing and Health Sciences, and is one of the most innovative centres for nurse education in both Australia and the Asia-Pacific Region. The School offers on-campus, distance education and mixed mode studies. The School has a proven reputation in the quality of its teaching and research and has played a leadership role in shaping and providing for the educational requirements of the nursing profession and health industry, enabling students to develop the latest skills incorporating health information technologies as well as gaining knowledge of foundation studies, essential to nursing practice.

Nursing courses are offered at both Peninsula and Gippsland campuses with further students studying in partnership with education providers in the Asia-Pacific Region. Palliative care content is well-represented in both undergraduate and post-graduate curricula.

The **Vivian Bullwinkel Chair in Palliative Care Nursing**, was established in 2003 within the School of Nursing & Midwifery and represents a partnership between Monash University, Peninsula Health, Peninsula Home Hospice and the Royal District Nursing Service. The Professor of Palliative Care leads the **Palliative Care Research Team**, which works with all partners, in creating an environment of palliative care clinical research with translational outcomes.

The Palliative Care Research Team now comprises 3 research fellows (dependent on research funding), and a number of staff of the School who contribute their research time. Over the last few years, the team has attracted an NHMRC Post-Doctoral student and well as 2 NHMRC PhD scholarships. Currently there are 9 PhD students, with 6 successful PhDs and 10 Masters in the last few years; most students return to their clinical environments and many in positions of influence. The team is now well-established, with a significant body of knowledge in teaching and research and an excellent international profile and publication record.

In relation to research, the Palliative Care Research Team has refined its interests to palliative care service systems – workforce; roles, education and resources; decision-making; and service access. We have deliberately chosen not undertake clinical research in relation to symptom management and medications. Projects have attracted funding from a variety of sources including the philanthropic sector, DoHA and NHMRC. Examples of recent projects include:

- The impact on mental health of frequent deaths that occur in high care in aged care settings, on individuals and the resident community;
- Utilization of cancer and palliative care services by different cultural groups;
- Framework for evaluation of after-hours palliative care for the Department of Human Services, Victoria;
- Exploring the palliative care needs of veterans at home;
- Expectations and barriers in the ambulance service and palliative care interface;
- An investigation of care planning decisions in advanced pulmonary and cardiac illness in the Bayside Region.

In making this submission we limit our response to (h) the availability and funding of research, information and data about palliative care needs in Australia.

1. Significant effort was given to the development of palliative care research priorities more than 10 years ago. This exercise enabled groups to be familiar with each other's work, set a direction for further work and coalesced some group's work around national projects. A national strategic plan for palliative care research is well overdue.
2. The low profile and understanding of palliative care in the general community is reflected in research areas, such that it is always difficult to compete in mainstream competitive funding opportunities. Of most benefit to this Team, has been the targeted funding from the DoHA

palliative care budget, managed by NHMRC, for PhD and post-doctoral scholarships as well as research.

3. There have been demonstrable benefits in building the research capacity of individuals, by funding PhD and post-doctoral scholarships, not just in our Team, but around the country.
4. Our Team has a track record spanning almost 10 years. However, dependence on grants for particular projects has created difficulties in both attracting research staff and then once trained to a level of expertise, maintaining them if further grant funding is not received. While some research projects have been well-funded, sufficient funding to create a cohesive research team environment and maintain a secure research program independent of serendipitous funding, has been an ongoing problem.
5. While there is evidence of the success of national research programs that have been well-funded by Government, research about policy and service systems still struggle to receive funding.
6. Work is required to embed research into clinical environments. Perhaps because palliative care is a relatively recently developed discipline, or perhaps because of the busyness of most palliative care environments, research is not prominent in palliative care services. Greater access to funding would assist with funding to enable the active participation of clinical staff in research.
7. The rounds of funding provided by DoHA, under themes, often seem to bear no relationship to the needs of the palliative care services. Small amounts of money have been allocated to individual services to do repetitious research, often by ill-prepared practitioners. This funding could be more wisely distributed, requiring a link to established and experienced researchers.

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