ImPaCCT

Improving Palliative Care through Clinical Trials

The NSW collaborative trials group in palliative care

Submission to the Senate Inquire on Palliative Care in Australia by the Management Advisory Committee (MAC) of Improving Palliative Care through Clinical Trials (ImPaCCT) NSW.

The ImPaCCT MAC would like to make the following submission to the Senate Inquiry on Palliative Care in Australia, (g): "*Availability and funding of research, information and data about palliative care needs in Australia.*"

1) Research has potential to improve the quality of care for people with life limiting illness and should form part of the routine work of all Level 3 palliative care services. Level 1 and 2 services should conduct research according to their capacities.

2) Appropriate advocacy is needed to ensure that the capacity of palliative care services to undertake research is supported by the Commonwealth Department of Health and Ageing, state health ministries, local health districts (LHDs), other service providers, consumer advocacy groups and other relevant bodies.

3) Support is needed not only for research infrastructure but also for staff training to foster a culture of inquiry and build the competitiveness of palliative care clinicians when applying for research project funding.

4) In moving towards a needs-based approach to palliative care and reducing disparities, particular advocacy will be needed for research in non-malignant as well as malignant conditions and across care settings, including residential aged care. Research should also be fostered on issues of special concern- for example, geriatric oncology, coordination of end of life care and the needs of culturally and linguistically diverse groups.

5) There is a need to engage consumers, consumer organisations and all disciplines involved in caring for people with life limiting illness to ensure the evidence-base appropriately reflects the interdisciplinary teamwork of contemporary palliative care.

6) Systems and strategies need to be established to support more rapid translation of research findings into clinical practice. Research implementation occurs within the context of strong evidence, an environment receptive to change and skilled facilitators to drive the change process. Achieving translation requires a commitment at national, state and local heath network levels to address patient, provider and system issues, whilst building sustainable processes to facilitate the translation of palliative care evidence into practice.

7) Palliative care peak bodies and service providers should commit to change practice in response to emerging evidence from suitably rigorous research conducted in Australia and internationally.

8) There is a need for Human Research Ethics Committees (HRECs), Research Governance Offices, and Treasury Managed Funds to develop a better, broader understanding of the aims of palliative care research to allow for collaborative, national palliative care research (e.g. by addressing indemnity issues), research into areas that non-palliative care clinicians may find taboo (e.g. research into the dying process such as respiratory secretions or terminal agitation) and research in non-hospital settings (e.g. at home or in residential aged care).

9) We suggest that collaborative research groups working in complementary ways at national, state and local levels offer unparalleled potential for advancing the palliative care research agenda by encouraging the

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sharing and transfer of expertise, enabling recruitment across multiple sites, and ensuring dissemination of findings through the networks involved.

As NSW's major research collaborative in palliative care, ImPaCCT aims to build capacity through a programme of concept development and research training workshops and investigator-driven research projects. Importantly, ImpaCCT was set up to support and complement the work of the national collaborative research group PaCCSC (Palliative Care Clinical Studies Collaborative) with whom we continue to work collaboratively and share key committee members.

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