National Palliative Care Grant Recipients’ Forum

**7-8 April 2016 | Vibe Hotel, Canberra Airport**

**Project Information Form**

**Project:** Palliative Care Clinical Studies Collaborative

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| **Key objectives** | The Palliative Care Clinical Studies Collaborative (PaCCSC) is a national research network that aims to:• Generate high quality research evidence to support the use of medicines and other interventions at the end of life to better manage or alleviate symptoms in patients such as: pain; confusion; breathlessness; appetite; and gastrointestinal problems including nausea; bowel obstruction; and constipation.• Build capacity within the health workforce in the conduct of high quality clinical research in patients nearing the end of life and the translation of research results into clinical practice.Many medications and other interventions that are commonly used at the end of life to assist with managing or alleviating patients’ symptoms have little or no evidence to support their use. Pharmaceutical companies are generally not attracted to this area of clinical research because there are few, if any, commercial gains given that these medications are mostly off-patent. However, results from this area of clinical research have demonstrated benefits, can reduce harms and enable better use of scarce health resources. The role of PaCCSC is to engage in high quality research which will provide the evidence base to underpin end-of-life care. |
| **Key outcomes***(e.g. resource development, education and training)* | **Strategic Direction-1**Maintain a network of national and international members who collaborate to conduct high quality clinical research in the end of life setting.**Strategic Direction-2**Conduct high quality clinical research to build the evidence base to support the quality use of medicines and positively influence healthcare practice in people nearing the end of life. This work may impact on and/or promote access to registered (AUST-R) medicines for use in palliative care.**Strategic Direction-3**Build national capacity in the palliative care sector to support/facilitate high quality clinical research and its translation into clinical practice. |
| **Target audience***(e.g. who is the target audience/s for your project activities?)* | There are a range of audiences that PaCCSC targets the activities and results from the work of the collaborative. These include: Pharmaceutical companies; the general public; the clinical sector including: Pharmacy, Palliative Care, Oncology, and a range of other disciplines and other research networks, both national and international; government and those involved in policy development. |
| **Outcomes to date** | The establishment of the PaCCSC research network including:* Governance structure (Management Advisory Board, Scientific Committee and Trials Management Committee, along with a number of sub-committees)
* Membership structure
* Formal strategic directions
* A program of clinical research studies across six symptom nodes: nausea; pain; breathlessness; cognitive disorders; gastro-intestinal symptoms and anorexia/appetite:
	+ The completion of eight phase III clinical trials; with a further three either actively recruiting or in the initiation stage;
	+ The development of an international pharmacovigilance program with over 80 sites in 18 countries participating;
	+ The conduct of over 10 pilot studies at various stages;
	+ The undertaking of a number of correlative studies;
* Training and education of a palliative care professionals to increase the research capacity of individuals in the discipline.
* The development of many resources to aid the conduct of clinical studies in palliative care.
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| **Challenges & lessons learnt***(e.g. were there any difficulties which may assist others?)* | The challenges in establishing a research network and conducting clinical trials will continue, however these are a few significant points:**Bringing people together:** Facilitating the cooperation of a diverse group of stakeholders is very challenging. It takes considerable time, energy and resources to bring disparate groups or individuals together to establish a truly successful research network, and this process is repeated again and again for each individual trial.**Resources, stakeholders and value adding to routine clinical practice:** There are issues of paying for/funding clinical trials and there is limited availability of incentives for health practitioners to participate in clinical research. The work requires key opinion holders, strong leaders, and individuals who value the conduct of the research and the evidence generated to enable research to become the ‘norm’ in all health care settings. **Evidence gathering:** There are significant gaps in the evidence underpinning numerous medications routinely used in palliative care practice and yet people nearing the end of life often experience a number of comorbidities and have complex needs. Drug-drug and drug-host relationships can go unnoticed or under-investigated furthering the likelihood of adverse reactions and further patient suffering. |
| **Plans for 2016 and 2017** | * The publication of the results from recently closed phase III clinical trials and the implementation of the program of dissemination for these results to ensure they are integrated into routine palliative care practice.
* The completion of the final Department funded phase III study.
* Conduct of the PaCCSC annual scientific meeting, the PaCCSC Annual Research Forum, the seventh Forum was held in March 2016.
* Ongoing prospective investigation of medications commonly used in palliative care through the pharmacovigilance program and prompt publication of the results to add to the often limited evidence that is available.
* Continue attempts to attract funding to support the conduct of clinical studies in palliative care.
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