

Palliative Care Clinical Studies Collaborative (PaCCSC)

An introduction to the first National palliative clinical trials group - you might want to get involved.

The Palliative Care Clinical Studies Collaborative (PaCCSC) is an Australia-wide research network that aims to improve the wellbeing of people with life-limiting illnesses through:

- The generation of high quality research evidence to support effective palliative care clinical interventions including medications.
- Building capacity within the health workforce in the conduct and understanding of high quality palliative care clinical research.
- The translation of palliative care research results into clinical practice and policy.

Why does PaCCSC exist?

Public health and clinical advances have led to people living longer and, as a consequence, having a higher likelihood of warning of death. The role of PaCCSC is to engage in high quality research that provides the evidence base to underpin and optimise quality healthcare practice for people with life-limiting illnesses.

Where is PaCCSC?

- PaCCSC is a national, member-based research network.
- PaCCSC has a participating network of hospitals and health services where the benefits from the research can be applied directly to patients and, more broadly, to health policy.
- The PaCCSC national office is located at the University of Technology Sydney, Ultimo, NSW.

PaCCSC Strategic Directions 2018-2021

Strategic Direction-1:

To continue to support and grow a network of researchers who collaborate to conduct high quality clinical research in palliative care.

Strategic Direction-2:

To build the evidence base to support the quality use of medications and other interventions to positively influence healthcare practices and policies for people with life limiting illnesses.

Strategic Direction-3:

To continue to build national capacity to support and facilitate high quality clinical research in palliative care and its translation into clinical practice, policy and community awareness.

PaCCSC Annual Research Forum

The PaCCSC Annual Research Forum is the premier annual event held every February/March. The Forum brings together palliative care clinical researchers from around the country to present and discuss clinical research in the palliative and supportive populations. The program includes: guest speakers; new study presentations; results presentations; and member presentations. Due to the sharing of new study concepts all attendees are required to sign a confidentiality agreement to protect the intellectual property of individual members discussed during the Forum.

The Forum provides an opportunity for the Collaborative to bring members of its various governance committees together to meet face to face. The PaCCSC Management Advisory Board, Scientific Committee, and Trials Management Committee take place on the day either side of the presentation day, and meetings of the Symptom Node Subcommittees and the Qualitative Research Subcommittee are also held face to face pending time.

For more information on the PaCCSC Annual Research Forum visit www.uts.edu.au/paccsc

PaCCSC National Team

David Currow, Chief Investigator



Professor David Currow is an internationally recognised expert in improving the delivery of palliative care. He is a Professor in the Faculty of Health, UTS and the Chief Investigator of the Palliative Care Clinical Studies Collaborative (PaCCSC). Professor Currow is an active researcher with contributions in clinical trials, population-based planning and codifying the evidence base underpinning palliative care. He has published more than 400 peer-reviewed articles, editorials and books. He is senior associate editor of the Journal of Palliative Medicine and on the advisory board for the Journal of Pain and Symptom Management.

Linda Brown, National Manager

Linda directs, manages and delivers on the operational plans and activities of PaCCSC, working closely with Chief Investigator and the Management Advisory Board. The role entails professional leadership, management and development of the research program to ensure that the activities of the Collaborative meet the strategic directions and comply with regulatory requirements. This includes strategic and operational planning, project management, quality oversight of studies, financial management, governance support and stakeholder engagement.



Belinda Fazekas, National Project Officer



Belinda has been with PaCCSC since its commencement and is integral in the implementation of clinical trial protocols including; protocol design, form design, data management, ethics submissions, and reporting of site progress. Belinda is directly involved in working with each site to undertake study initiation, maintain trial requirements, undertake safety and data monitoring checks, and performance of study closure activities. Belinda ensures the Collaborative conducts its trials in line with the principles of Good Clinical Practice.

Louise Fazekas-Giles, Administration Officer

Louise's responsibilities are pivotal to the day-to-day operations of the PaCCSC office and include coordinating meetings, making travel arrangements, event management, providing PA assistance to the National Manager, general secretarial duties for PaCCSC, and undertaking data checking and correcting.



Aaron Shannon-Honson, Data Assistant



Aaron is part of the PaCCSC data management team. Using the PaCCSC standard operating procedures, he makes changes to the database, maintains data logs for various studies and assists in resolving data issues. Aaron's primary responsibility is to ensure the integrity of the research data and to investigate abnormalities when they occur.

Zac Vandersman, Data Administrator

Zac provides a range of data administration functions including assistance with the RAPID program; with establishing research data management platforms for study conduct; checking study data; and ensuring adherence to the PaCCSC standard operating procedures to make any necessary corrections to the databases. Zac maintains data logs to ensure the resolution of issues and assist with maintaining complete and accurate study databases.



Priyanka Bhattarai, Project Officer



Priyanka is a Clinical Nurse Specialist and a PhD Candidate with interest in chronic and palliative care. She works within the PaCCSC's National Team providing assistance with implementation of clinical trials across various sites. She is involved in carrying out data monitoring, and safety reporting of clinical trials. Priyanka also provides assistance to the study sites while ensuring that trials related activities are carried out as per the protocol and ethical requirements.

RAPID Pharmacovigilance Program

RAPID is an international, multi-site, consecutive cohort, post-marketing study of the real-world net clinical effects (benefits and harms) of medications and non-pharmacological interventions used in hospice/palliative care.

Palliative care continues to improve its evidence base for clinical prescribing. A complementary way of adding to the evidence base includes pharmacovigilance studies. Sometimes referred to as phase IV studies, post marketing data, or adverse drug reaction reporting, these studies are usually conducted retrospectively using clinical data of varying quality. The RAPID methodology uses active surveillance that collects analysis and provides data on widespread and longer-term use of medications or non-pharmacological interventions captured from the time of prescribing.

RAPID uses minimal resources, is timely, involves prescribers from around the globe, and publishes each series to genuinely add to the knowledge for clinical prescribing and use of non-pharmacological therapies that are common place in palliative care practice. By defining the net benefit (clinical response together with toxicity) on data from the target audience, in this case palliative care practices around the world.

Objectives

To prospectively collect information on:

1. The therapeutic benefit of medications and interventions commonly used in palliative care;
2. The toxicity of medications and interventions commonly used in palliative care; and
3. Any significant drug/drug interactions of medications commonly used in palliative care.

Primary outcome

- The primary outcome is to evaluate the benefit and toxicity of medications and interventions commonly used in palliative care.
- Secondary outcomes include: to describe the indications for medications and interventions being used in palliative care, and to document the frequency of prescribing of common medications and interventions in palliative care.

Program

The program has ~40 active sites from ~15 countries around the world that are participating, and with 10 publications the series continues to attract new participating sites and interested palliative care clinicians and researchers. The program has expanded to include a medication series across six symptom areas commonly experienced in palliative care including: pain, breathlessness, gut dysfunction, nausea, mood and cognitive disorders and appetite and cachexia.

A non-pharmacotherapeutic intervention series is also running concurrently to the six medication series.

The methodology is continuing to be adapted and improved and PaCCSC is now running a range of extraordinary series in addition to the above.

For more information on the current series, please contact the PaCCSC National Office.

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