Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)

2017 Annual Report

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CENTRE DIRECTOR'S MESSAGE

It is my great honour to introduce the first Annual Report for the Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) at the Faculty of Health. Formed in early 2017, IMPACCT is now the home of the: Palliative Care Clinical Studies Collaborative (PaCCSC); Cancer and Supportive Care Clinical Studies Collaborative (CSCCSC); and Improving Palliative Care Through Clinical Trials in NSW (ImPaCCT:NSW). IMPACCT's transdisciplinary research program is dedicated to improving the care, outcomes and quality of life for people affected by a range of chronic conditions or who have palliative care needs.

Living with life-limiting illness presents many challenges not only to the people who suffer from them but also to their carers and families, health professionals, the health system, and society as a whole. Our clinical academics undertake high quality research on a range of chronic illnesses such as heart failure, advanced cancer, chronic obstructive pulmonary disease, and peripheral artery disease; care transitions – from acute to chronic care and from chronic care to palliative care; and health services research.

With a focus on quality and safety, dignity and physical function, and evidence-based approaches, we are committed to informing impeccable assessment, treatment and management of complex care problems. We recognise that meaningful engagement with the community contributes to the quality, relevance and translational effectiveness of our research. Through our partnership with consumers, we conduct research that is influencing policy development and clinical practice to better address their needs and improve health outcomes.

At IMPACCT, we value capacity building through leadership and collaboration. We remain closely connected to our clinical colleagues through our palliative care clinical trials networks across multiple sites in Australia and our strong engagement with the Translational Cancer Research Network (TCRN) and the Sydney Partnership for Health, Education, Research and Enterprise (SPHERE). Our links with international and national clinical academics continue to expand. Our international work continues to develop and during 2017 IMPACCT worked with the Hong Kong Health Authority to strengthen local palliative care delivery; and the Japanese Organisation for Research and Treatment of Cancer (JORTC) to build palliative care clinical trials capacity and support palliative care clinicians in the Pacific to provide best evidence-based care.

This Annual Report details the scope of commendable work that the IMPACCT Team have contributed to in improving palliative, aged and chronic care outcomes..

Jane L Phillips

Professor Jane Phillips -
RN, BAppSc (Nursing) (CU), PGDipHlth Prom (CU), PhD (WSU), FACN
Director, IMPACCT

OBJECTIVES

Vision

To see each and every patient receive the best palliative and chronic care at all times no matter their life circumstances, state of health or place of residence

"Best care, any place, every time."

Purpose

Our purpose is to see substantial improvements to the quality of life, treatment and well-being of those with terminal, chronic and complex health conditions, their carers and families through:

- Conducting high quality research in partnership with patients, the community and other stakeholders such as healthcare providers.
- Embracing new technologies that improve the quality and availability of evidence-based care and the patient's capacity to take control of their own care.
- Active engagement in policy formation, advocacy and the development and implementation of new, sustainable models of care.
- Involving patients and caregivers at all stages of the research process.

Strategic Objectives

- **Research:** To drive positive changes in care and patient well-being through conducting high quality, trans and multidisciplinary research in palliative, complex and chronic care and translating new knowledge into practice.
- **Workforce capacity:** To ensure the clinical workforce has the skills, evidence, capacity and content knowledge to lead change, and address key challenges such as end-of-life care and euthanasia.
- **Gaps in knowledge and care provision:** To address disparities and inequities of access to chronic and palliative care, referrals and other issues.
- **Patients, carers and community:** To actively engage with patients and carers to ensure their voices are at the centre of all we do in improving individual and community health and wellbeing.
- **Models of care:** To assist health services to develop sustainable, safe and cost effective models of care.
- **Technology** To research ways of integrating appropriate technology into new models of care that support and enable patients, carers, health services and families to maximise the quality and availability of care across healthcare settings.

HIGHLIGHTS FOR THE YEAR

Research Productivity & Capacity Building

- 138 publications
  - 126 published peer reviewed manuscripts
  - 1 invited editorial
  - 4 book chapters
  - 7 in-press peer reviewed manuscripts
- $17.3M in new competitive research grants as Chief Investigators
  - $1.5M to UTS
- 51 PhD candidates including:
  - 4 PhD submissions (under examination)
  - 6 PhD completions
- 5 International visiting scholars
- 3 UTS academic international collaborative visits

Teaching and Learning

- 8 postgraduate subject coordinator and teaching roles
- 1 undergraduate subject teaching role

Services to the University and Community

- 104 Committees
  - 17 International committees
  - 54 National committees
  - 17 NSW State committees
  - 16 UTS University committees
- 20 Editors - peer reviewed journals

The team

- 15 Academics
- 3 Project Managers
- 23 Part-time Research Assistants / Support staff
- 20 Adjunct Professors
- 24 Honorary Associates
- 15 Associate Members

NEW INITIATIVES

PaCCSC moves to UTS

In early 2017, we welcomed Professor David Currow and the Palliative Care Clinical Studies Collaborative (PACCSC) t to IMPACCT and UTS. PaCCSC under Professor Currow's stewardship has grown into the world's largest palliative care clinical research collaborative. The Collaboratives' move to IMPACCT provides a unique opportunity to leverage off the corporate trials knowledge held within PACCSC to undertake robust chronic disease and aged care trials.

The PaCCSC Annual Research Forum held on the 2 March 2017 provided the ideal opportunity to formally welcome the Collaborative to its new home at UTS and celebrate PaCCSC 10th anniversary. Over the past decade, PaCCSC has developed a unique capacity in the conduct of collaborative clinical research in a discipline where multisite clinical research was previously an anomaly. Having a semi-autonomous governance structure, collaborating members, highly skilled recruiting sites and a centralised supporting infrastructure, PACCSC has been able to complete nine adequately powered randomised controlled trials, involving more than 1870 palliative patients.

These achievements provide a solid foundation on which to grow the program of research while being embedded in a dynamic and rapidly growing new interdisciplinary palliative, aged and chronic care research Centre as reflected in the 2018-2021 Strategic Plan (https://www.uts.edu.au/research-andteaching/our-research/IMPACCT/paccsc/whatpaccsc).

Consumer Engagement: Establishment of the Consumer Advisory Group

The establishment of the IMPACCT Consumer Advisory Group In 2017 has enabled us to involve consumers into all of IMPACCT's research, educational and student initiatives. Consumers input is enhancing the quality, relevance and translational effectiveness of our work and helping to ensure that we focus on the issues that are most important to patients and their families.

IMPACCT's Consumer Advisory Group members have extensive knowledge and experience across a large range of life-limiting illnesses and/or of caring for someone with aged or palliative care needs. Its members are representative of diverse populations, including Aboriginal and Torres Strait Islander (ATSI) communities, culturally and linguistically diverse (CALD) communities, and have an understanding of healthcare services in rural, regional and metropolitan Australia. This diversity helps strengthen IMPACCT's research initiatives and develop culturally sensitive projects and protocols.

Members of the IMPACCT Consumer Advisory Group are all:

- actively involved in the design, implementation, evaluation and dissemination of IMPACCT's research projects;
- involved in shaping the content for the new Master Palliative Care coming in 2019;
- provide general guidance regarding IMPACCT's strategic directions; and
- provide feedback on the current practices in the healthcare system to identify effective practices and areas for improvement.

The Consumer Advisory Group supports IMPACCT's commitment to continuing dialogue and close collaboration with consumers to ensure that research activities reflect best possible care for people affected by life-limiting illnesses.

IMPACCT Consumer Advisory Group: *Mrs Meg Brassil, Mrs Dea Close, Mrs Imelda Gilmore, Mr Padmanabhan Karamil, Mrs Bev Noble, Mr John Stubbs, Mrs Noelene Trotter*

Advancing care for Japanese people with a terminal illness

In November 2017, PaCCSC conducted a two-day symposium in Japan, funded by the Australian Department of Foreign Affairs and Trade (DFAT). Hosted by the IMSUT Hospital, The Institute of Medical Science and the The University of Tokyo, Japan, the symposium provided an opportunity for members of the Japanese Organisation for Research and Treatment of Cancer (JORTC) to build a clinical trials network in palliative care in Japan.

Attended by health professionals from palliative care and other disciplines, researchers and trialists, the symposium provided an opportunity for researchers from Australia and Japan to jointly agree and develop a clinical trial protocol in an area of significance to palliative patients in both countries.

Day 1 of the symposium included presentations from PaCCSC and JORTC members on conducting clinical trials in palliative care; presentations of an array of new palliative care study concepts and a formal signing ceremony outlining the future partnership between the two investigator-driven research groups.

Day 2, of the symposium included: a half-day workshop targeting nurses aimed at developing vital clinical research nurse skills; and a concurrent invitation only workshop, to enable the pilot study concept chosen from Day 1 to be developed into a pilot/feasibility protocol.

This project has helped lay the foundations, for the development of an interdisciplinary palliative care clinical trials network. It has also assisted with the establishment of a governance framework and specialist training for doctors, nurses and other experts who will collaborate to conduct future palliative care clinical research.

IMPACCT TEAM

Jane Phillips, PhD, RN, Grad Dip Health Promotion, BN, FACN

IMPACCT Director and Professor of Palliative Nursing

Professor Jane Phillips is Director of IMPACCT - Improving Palliative, Aged and Chronic Care through Clinical Research and Translation at UTS and Chair of Palliative Nursing at UTS with experience in delivering evidence based palliative care across diverse settings, including rural and regional Australia.

Professor Phillips has led and evaluated complex health service reforms and has led a number of major cancer and palliative care reform initiatives at the local and national levels. Her research aims to improve care outcomes for people in their last year of life by strengthening the nexus between research, policy and practice. She is currently evaluating non-pharmacological interventions to improve pain, breathlessness and delirium; looking at health services that can improve care for older people with cancer; and undertaking translational research in the areas of pain management and symptom management. She has developed and evaluated nurse-coordinated models of palliative care and has extensive experience in cancer and chronic disease nursing and research. She currently supervises 14 doctoral students.

Professor Phillips is a Fellow of the Australian College of Nursing and the current President of Palliative Care Nurses Australia. She is Chair of both the National Palliative Care Clinical Studies Collaborative Trials Management Group and the Clinical Oncology Society Australia (COSA), Palliative Care Group.

Meera Agar, PhD, MBBS, FRACP, FaChPM, MPC

Professor of Palliative Medicine

Professor Meera Agar is a palliative medicine physician and clinician scientist. She leads a large clinical research portfolio including investigatorled clinical trials, development and evaluation of innovative palliative care service models, and evaluating interventions to address the supportive care needs relating to impacts of advanced illness on the brain. She is a chief investigator for the NHMRC partnership centre – dealing with cognitive and associated functional decline in the elderly, focusing on translational research to improve outcomes for people with advanced cognitive impairment. She led a recently completed large cluster randomised controlled trial of case conferencing in advanced dementia and a randomised controlled trial of haloperidol and risperidone for delirium symptoms in palliative care. She is currently undertaking studies evaluating: medicinal cannabis in cancer anorexia, acetazolamide in raised intracranial pressure in primary brain tumours, and non-pharmacological approaches to delirium prevention.

Professor Agar is on the scientific committees of the Cooperative Trials Group – Neuro-oncology (COGNO), the Psycho-oncology Cooperative Research Group and the National Health and Medical Research Centre (NHMRC) Cognitive Decline Partnership Centre. She is a Board Member of the European Delirium Association, the lead of assessment, Palliative Medicine Education Committee, Royal Australasian College of Physicians (RACP), and on the advisory group for Choosing Wisely Australia. She is the President of the Australian and New Zealand Society (ANZSPM) for Palliative Medicine. She is the Chair of Improving Palliative Care through Clinical Trials, the NSW Palliative Care Clinical trials group.

David Currow, PhD, MPH, BMed, FAHMS

Professor of Palliative Medicine

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 FAHMS is the Chief Cancer Officer of NSW and Chief Executive Officer of the Cancer Institute NSW, the NSW Government's cancer control agency.

Professor Currow is an active researcher whose research track record includes: better understanding and treating chronic breathlessness; Phase II, III and IV clinical trials; populationbased planning for palliative care; and codifying the evidence base underpinning palliative care; and competitive funding has included the National Health and Medical Research Council (NHMRC) and the National Institutes of Health (NIH).

Professor Currow has published more than 500 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. Professor Currow is the Associate Director (Research) for the Wolfson Institute, Hull York Medical School, University of Hull, a foundation partner in the Australian Palliative Care Outcomes Collaborative (PCOC).

Deborah Parker, PhD, MSocSc, GradCert Leadership, BA

Professor of Aged Care (Dementia)

Professor Parker is the Professor of Aged Care (Dementia) in the Faculty of Health. She has received over $35 million in research funding. Her primary areas of research are palliative care for older people, dementia and health services evaluation in aged care. Professor Parker was a coinvestigator on the development of the Abbey Pain Scale, one of the most widely used pain scales for people with dementia. She was the lead investigator on the Palliative Approach Toolkit - an evidence-based knowledge translation product that has been provided to every residential aged care facility in Australia. Professor Parker was the national evaluator for the $15 million Decision Assist program

(2013-2016) which supported aged care services in Australia in advance care planning and palliative care. She is a co-lead on the $15 million End of Life Directions in Aged Care (ELDAC) project (2017-2020), and national evaluator for two current national palliative care grants - Caring Safely at Home for Australians and the Australian Carer Toolkit for advanced disease.

Professor Parker is President Elect of Palliative Care NSW, Board Director of Carrington Care and Board Director Leigh Place. She is an active member of professional organisations supporting palliative care and aged care - Member of the Australian Association of Gerontology, Chair of the Palliative Care Nurses Australia Aged Care Special Interest Group, Chair of the National Policy Chapter for Healthy Ageing Australian College of Nursing and Co-Chair of the Education and Workforce Advisory Committee for the Age and Ageing Clinical Academic Group of SPHERE.

Professor Parker's program of research in palliative care and dementia involves international collaborations. She is co-investigator on a Canadian Institute of Health Research (CIHR) Partnership for Health Systems Improvement Grant - Strengthening a Palliative Approach in Long-Term Care and a CIHR Project Grant Improving Pain Assessment in Nursing Home Residents with Dementia.

Patricia Davidson, PhD, RN

Professor for Cardiovascular and Chronic Care

Since September 2013, Professor Patricia Davidson has been the Dean of the Johns Hopkins School of Nursing and continues to hold the Chair in Cardiovascular Nursing, UTS. She maintains an active co-investigator role on numerous Centre grants and is co-supervising a number of Centre PhD students. Professor Davidson's program of research focuses on supporting individuals living with chronic conditions and developing innovative models of transitional care. A primary objective of her work has been to improve the cardiovascular health of underserved populations through the development of innovative, acceptable, and sustainable initiatives within Australia and beyond. Professor Davidson is a Fellow of the Australian College of Nursing, Fellow of the American Heart Association, Fellow of the Preventive Cardiovascular Nurses Association and Fellow of the American Academy of Nursing. She is Counsel General of the International Council on Women's Health Issues and actively involved in the international activities of Sigma Theta Tau International.

Lawrence Lam, PhD, MAppPsy, MPH, Grad Dip Biostats, B.Sc (Hons), FACE

Professor of Public Health

Professor Lawrence Lam is a Clinical Epidemiologist and Medical Statistician. He has an established track record of having worked with clinicians, initially in the area of trauma and rehabilitation and more recently in cancer management and palliative care. Professor Lam has been involved in many governmental health task forces and committees in the capacity of chairperson or a committee member. He is also an active

member of various professional bodies and a Fellow of the American College of Epidemiology serving full terms on different committees. He has been a longstanding member of the Australia Statistical Society Inc. He serves as a member of the Editorial Board of the Advances in Medicine Journal in the public health domain; Cogent Medicine; International Archives of Addiction Research and Medicine; Austin Addiction Sciences, and as a regular statistical reviewer of the Medical Journal of Australia. He was the former Vice President and the Chair of the Scientific Committee of the Hong Kong Society of Behavioral Health, which is an affiliated body of the International Society of Behavioral Medicine.

Sally Inglis, PhD, RN, BN, BHSc (Hons), NFESC, FAHA

Associate Professor

Currently supported by NSW Cardiovascular Research Network Life Sciences Fellowship supported by the Heart Foundation and the NSW Office for Medical Research

Associate Professor Sally Inglis has a keen interest in chronic cardiovascular disease and has undertaken research across a variety of cardiovascular conditions and research methodologies throughout her research career. Her current research program examines the evidence for the use of telemonitoring and structured telephone support to support people with chronic heart failure, and the use of technology-based education interventions for people with chronic heart failure, as well as, the epidemiology, management and outcomes of people with peripheral arterial disease. A/Professor Inglis' research into the use of telemonitoring and structured telephone support has been incorporated into several national and international heart failure guidelines.

A/Professor Inglis is currently Chair of the Cardiovascular Nurses Council of the Cardiac Society of Australia and New Zealand (CSANZ). She is a member of the Editorial Board of the Cochrane Collaboration Heart Review Group. She is currently supported by a prestigious New South Wales Cardiovascular Research Network Life Sciences Research Fellowship from the Heart Foundation and the NSW Office for Medical Research which is supporting her to continue her program of research to improve outcomes for Australians with chronic cardiovascular disease.

Phillip Newton, PhD, RN, BN (Hons), FCSANZ, FAHA, FESC (until May 2017)

Associate Professor / Director of Research Students

Associate Professor Phillip Newton is the Director of Research Students in the Faculty of Health at UTS. He is a registered nurse with an academic track record that demonstrates a strong interdisciplinary focus and an emphasis on the links between clinical research and translation into the health service. Dr Newton has an established record of cardiovascular research and in particular heart failure research. The main focus of his research has been on risk factor modification and symptom management. He is now leading a team investigating the impact of frailty

on people with chronic heart failure, as well as, people referred for solid organ transplantation. A/Professor Newton is a senior investigator for the Heart Failure Snapshot study, the largest point prevalence study of acute heart failure and investigation of clinical variation across institutions in Australia. A/Professor Newton has a distinguished and consistent record of obtaining competitive funding, having been awarded over $3 million in support from the NHMRC, Australian Research Council (ARC) and Heart Foundation NSW Cardiovascular Research Network (CVRN) and other major funding schemes. He is a member of the Executive Committee for the Cardiovascular Nursing Council of the Cardiac Society of Australia and New Zealand and the Australasian Cardiovascular Nursing Council. He has been elected a Fellow of the Cardiac Society of Australia and New Zealand, the American Heart Association and the European Society of Cardiology.

Michelle DiGiacomo, PhD, MHSc (Hons), BA

Senior Lecturer (Research)

Dr Michelle DiGiacomo's program of research centres on the ways in which vulnerable populations cope and adjust to living with chronic conditions. She particularly focuses on carers, gendered approaches to health, older women, and Aboriginal and Torres Strait Islander peoples. She frequently employs qualitative and mixed methods approaches to facilitate the voices of people from vulnerable populations and received a commendation in the UTS Human Rights Awards for her research with older, recently widowed women. Dr DiGiacomo has been a chief or associate investigator on research grants and program funding totalling $2.8M including ARC Linkage and Discovery project and a NHMRC Capacity Building Grant in Population Health and Health Services Research. She coordinates the postgraduate subjects Evidence Based Practice and Noncommunicable Disease in the Faculty of Health and supervises 11 PhD students.

Tim Luckett, PhD, BSc (Hons)

Senior Research Fellow / Senior Lecturer (Research)

Dr Tim Luckett is a Senior Lecturer in the Faculty of Health at UTS. In 2016, Tim continued projects aimed at informing improvements to self-management of breathlessness, including: a systematic review of online patient resources; interviews with 'expert' patients aimed at learning strategies for avoiding unnecessary Emergency presentations; and secondary analysis of interview data from three RCTs evaluating the hand-held fan. Dr Luckett also continued to contribute as an investigator and member of the Executive Committee of the Stop Cancer PAIN Trial.

Seong Cheah, PhD, MSc, BScEd (Hons)

Postdoctoral Research Fellow: Biostatistician

Dr Seong Leang Cheah is an experienced linked data analyst on national database and a registered Chinese medicine practitioner for acupuncture and Chinese herbal medicine. Dr Cheah's field of interest focuses on developing research models from large epidemiological datasets. He has rich experience in collating, managing and analysing datasets in interstate and national research projects relating to palliative care, aged care, midwifery and child care, acupuncture and Chinese medicine, disability and business expenditure.

Caleb Ferguson, PhD, RN (February - October 2017)

Post-doctoral Research Fellow

Dr Caleb Ferguson is an experienced educator and an early career nurse researcher. His program of research focuses on stroke prevention and patient centred approaches to the management of atrial fibrillation.

Caleb has over a decade of experience as a Registered Nurse and a Clinical Nurse Educator in the UK and Australia, primarily within the clinical areas of neuroscience and stroke. He has previously held positions as Lecturer at the University of Tasmania and more recently as Lecturer and Director of Postgraduate Nursing Studies within UTS Faculty of Health. His key research interests are atrial fibrillation, chronic care, stroke and social media.

He currently holds three grants investigating 1) nurse knowledge in atrial fibrillation; 2) social media use in student nurses; 3) evidence-based practice. He is a registered category 2 research supervisor and is available for supervision of B Honours and PhD studies in his area of expertise.

Annmarie Hosie, PhD, RN, MPallCareAgeCare, BHlthSc

Postdoctoral Research Fellow

Dr Annmarie Hosie is an early career researcher, who commenced as a Post-doctoral Research Fellow within the Centre in May 2016. Dr Hosie's research focus is on developing interventions to improve outcomes for people receiving aged, palliative and end-of-life care; in particular, strategies that support optimal cognition. Her extensive experience as a registered nurse in acute, sub-acute, community and residential aged care settings, and doctoral research into delirium epidemiology, systems and nursing practice in palliative care units, informs her current research into delirium prevention in people with advanced cancer. She is also contributing to a program of delirium in palliative care research with the international 'SUNRISE' collaborative. Dr Hosie is actively involved in delirium and palliative care advocacy through: Palliative Care Nurses Australia, the Australasian Delirium Association, and iDelirium, an international federation of delirium societies.

Mandy Visser, PhD, MSc, BSc

Postdoctoral Research Fellow

Mandy is a postdoctoral research fellow in aged care, nursing and dementia at the Faculty of Health. With her research, she aims to improve the quality of life of people living with dementia, by enhancing social interactions with care providers and family members. In her projects, Mandy examines changes in social and emotional behaviour related to different dementia syndromes, resulting in the development of person centred communication protocols.

Mandy is a multidisciplinary experimental researcher specialised in analysing social and emotional behaviour in day-to-day communication and interaction. In 2015, Mandy achieved her PhD at the Tilburg center for Cognition and Communication in The Netherlands, on how people learn to use and interpret emotional expressions in interactions with others. Her work contributes to a better understanding of how emotional behaviour changes with ageing and how such behaviour is affected by social and cognitive factors. With her postdoctoral research on ageing and emotion recognition at the MARCS Institute at Western Sydney University in 2016-2017, Mandy addressed effects of ageing on the recognition and interpretation of emotional information in social and interactive contexts.

Xiaoyue Xu, PhD MPH, MSc, BN

Postdoctoral Research Fellow: Nursing (Aged care)

Dr Xu is a Post-doctoral Research Fellow at University of Technology, Sydney, with expertise in aged care, public health, nursing, nutrition epidemiology, health policy, health service, chronic disease prevention and biostatistics. She has awarded nursing degree in China (2009), Masters by research of advanced nursing study in the United Kingdom (2011), Masters of Public Health (2012) and PhD (2016) at the University of Newcastle, Australia.

Dr Xu's PhD project titled 'Dietary intake, diet quality, dietary pattern and Nutrition-Related NonCommunicable Diseases (NR-NCDs) among older Chinese population', was designed to improve people's diet in the prevention of NR-NCDs. This project is significant as it fills the knowledge gap on diet and nutrition status in the older population. The project results have been produced a 'Policy brief' which proposed policy recommendations for the Chinese Nutrition Society. Dr Xu has been working on a number of projects including the ARC Linkage-funded project entitled "Fit for Future: Safeguarding the health & well-being of the NSW nursing & midwifery workforce", and NHMRC Partnership Project-funded study of health service use and clinical outcomes of people with Type 1 diabetes. She has also contributed to various government and non-government reports, such as: United Nations, Department of Economic and Social Affairs; World Health Organization and Chinese Centre for Disease Control and Prevention.

Centre Research Support Personnel

- Sabine Allida, PhD, BMedSci (Hons), Research Assistant
- Ingrid Amgarth-Duff, BSc (Hons), PhD candidate, Research Assistant
- Teresa Assen, BScBEd, Research Assistant
- Robyn Attwood, RN, MHM, Clinical Research Nurse, Care-IS and PRESERVE studies.
- Molly Cao, RN, MHM, Research Assistant, Stop PAIN project
- Kaniz Fatema, PhD, MSc, BSc (Hons), Research Assistant
- Sally Fielding, RN, MPH, Research Assistant, Stop PAIN project
- Maja Garcia, BIntSt.BMedSci (Hons), Research Assistant
- Anna Green, MDev, BSocSci, PhD candidate, Research Assistant
- Layla Hall, BAppPH, Research Assistant
- Nicole Heneka, MHumNutr, PhD candidate, Research Assistant
- Serra Ivynian, BMedSci (Hons), PhD candidate, Research Assistant
- Slavica Kochovska, PhD, MA, BA (Hons), Senior Research Assistant
- Catherine Lambert, GCBA, Executive Assistant
- Elyn Montgomery, RN, MN, Heart Failure Clinical Trials Nurse
- Angela Rao, RN, BN (Hons), PhD candidate, Clinical Trials Nurse
- Alison Read, MPH, BN, Project Manager, Stop PAIN Project

PACCSC NATIONAL TEAM

Linda Brown, MBus, BBus(Mgmt)

National Manager

Linda directs, manages and delivers on the operational plans and activities of PaCCSC, working closely with the 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, BN

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.

PaCCSC Research Support Personnel

> Priyanka Bhattarai, RN, BN (Hons), PhD candidate, Project Officer
> Louise Fazekas-Giles, Administration Officer
> Jane Hunt, RN, Research Assistant
> Debbie Marriot, Executive Assistant
> Bronwyn Raymond, RN, MSc, Grad Cert (BCN), BAppSc, CM, Research Assistant
> Aaron Shannon-Honson, BIT, Data Assistant
> Zac Vandersman, BIT, Data Administrator

IMPACCT:NSW TEAM

ImPaCCT:NSW (Improving Palliative Care through Clinical Trials and Research) is the New South Wales (NSW) collaborative research group in palliative care. ImPaCCT's mission is to improve outcomes for people in NSW living with life-limiting illness and inform high quality palliative care services through transdisciplinary collaborative research. This initiative is led by Professor Meera Agar and the Project Officer is Dr Valentina Naumovski.

Valentina Naumovski, PhD

Research Fellow/Program Coordinator ImPaCCT, University of New South Wales, Sydney, NSW

Tina is a researcher in the fields of pharmaceutical sciences and pharmacology, with a specialisation in complementary medicine. Her current work though ImPaCCT:NSW involves evidence-based clinical research, and she is the program coordinator of the medicinal cannabis for anorexia in advanced cancer clinical trial. She is based at the School of Medicine, University of New South Wales and is an Honorary Associate of the Faculty of Health, University of Technology Sydney.

External Academic Appointments

Prof Jane Phillips

- Adjunct Professor, School of Nursing, University of Notre Dame Australia, Sydney, NSW
- Honorary Professor, School of Nursing, Hong Kong Polytechnic University, Hong Kong
- Visiting Professor, School of Medicine, University of Sydney, NSW
- Visiting Professor, School of Nursing, Sun Yat-sen University, Guangzhou, China

Prof Meera Agar

- Conjoint Associate Professor, South West Sydney Clinical School, University of New South Wales, Sydney, NSW
- Conjoint Associate Professor, University of Notre Dame Australia, Sydney, NSW
- Senior Lecturer/Topic coordinator, Palliative and Supportive Services, Flinders University, Adelaide, SA

Prof Deborah Parker

- Adjunct Associate Professor, School of Nursing and Midwifery, University of Queensland.
- Adjunct Professor, Ingham Institute for Applied Medical Research
- Adjunct Professor, School of Nursing and Midwifery/Centre for Applied Nursing Research, Western Sydney University

A/Prof Sally Inglis

- Senior Research Fellow, School of Nursing, Midwifery and Social Work, University of Queensland, QLD

Dr Michelle DiGiacomo

- Adjunct Faculty, School of Nursing, Johns Hopkins University, Maryland, USA

Editorial Roles

MA - Prof Meera Agar; DC - Prof David Currow, MD - Dr Michelle DiGiacomo;

SCI - A/Prof Sally Inglis; LL - Prof Lawrence Lam; TL - Dr Tim Luckett; PJN - Dr Phillip Newton; DP – Prof Deborah Parker; JLP - Prof Jane Phillips, MV – Dr Mandy Visser, XX – Dr Xiaoyue (Luna) Xu

- Editor, Cogent Medicine (LL)
- Editor, Collegian: The Australian Journal of Nursing Practice, Scholarship and Research (PMD, JLP)
- Deputy Editor, Journal of Smoking Cessation (MD)
- Associate Editor, Chronic Illness (JLP)
- Associate Editor, Journal of Pain and Symptom Management (DC)
- Editorial Board, Advances in Medicine Journal – Public Health (LL)
- Editorial Board, Austin Addiction Sciences (LL)
- Editorial Board, Cochrane Heart Review Group (SCI)
- Editorial Board, Contemporary Nurse (PJN)
- Editorial Board, Current Opinions in Palliative and Supportive Care (DC)
- Editorial Board, Journal of Gerontological Nursing (AH)
- Editorial Board, Indian Journal of Palliative Care (DC)
- Editorial Board, International Archives of Addiction Research and Medicine (LL)
- Editorial Board, International Journal of Palliative Nursing (JLP)
- Editorial Board, Journal of Cardiovascular Nursing (SCI)
- Editorial Board, Journal of Nursing Scholarship (SCI)
- Editorial Board, Journal of Opioid Management (DC)
- Editorial Board, Palliative Medicine and Hospice Care (TL)
- Editorial Board, World Journal of Psycho-social Oncology (TL)

UTS University Committees

- Faculty of Health, 12 weeks to Publication' Committee (JLP)
- Faculty of Health, Deans Advisory Committee (DP)
- Faculty of Health, HDR Student Assessment Chair (MD, PJN)
- Faculty of Health, Health & Safety Committee (PJN)
- Faculty of Health, Deans Management Group (JLP)
- Faculty of Health, Research Impact Strategy Committee (MA, LL, JLP)
- Faculty of Health, Research Committee (PJN, JLP, TL)
- Faculty of Health, PhD Thesis Examination Working Group (PJN)
- Faculty of Health & Faculty of Engineering and Information Technologies, Indigenous Health, Wellbeing and Research Innovation Committee (MD)

- Faculty of Health & Graduate School of Health, Research Integrity Officer (DP)
- Graduate School of Health, Heads Advisory Committee (LL)
- UTS Human Research Ethics Committee (TL)
  - Clinical Trials Sub-committee (LL, PJN [Chair])
- UTS Faculty of Science Honours Committee (PJN)
- UTS Graduate Research School Board (PJN)
- UTS Social Impact Framework Committee (MA)

UTS Teaching and Learning

- Teaching and subject coordination (post graduate):
  - Evidence Based Practice [92790] (MD)
  - Faculty of Health & Graduate School of Health Joint Research Methodology Workshops series (LL)
  - Health Care Research Methodology [92648] (PJN)
  - Evidence in Health Care [92568] (TL)
  - Health Promotion and Advocacy [92570] (TL)
  - Introduction to Qualitative Studies [92973] (MD)
  - Non-communicable Disease [96023] (MD)
  - Psychosocial Perspectives in Health [92494] (TL)

- Teaching (undergraduate):
  - Evidence for Nursing [92318] (MD)

- Guest lecturer
  - Evidence Based Practice [96008], Graduate School of Health (LL)
  - Foundations in Public Health [96702], Faculty of Health (LL)
  - Introduction to Specialty Practice: Aged Care [92339], Faculty of Health (XX)
  - Research Project 1 [96046], Graduate School of Health (LL)
  - Social Perspectives of Public Health [96704], Faculty of Health (MD, TL)

NEW GRANTS

1. **Agar, M., Currow, D**., Ely, W., Caplan, G., Lawlor, P., Bartlett, D., **Lam, L.T.**, McCaffrey, N., **Phillips, J.L., &** Nikles, J. Randomised, double-blind, placebo-controlled phase III trial of oral melatonin for the prevention of delirium in hospital in people with advanced cancer (APP1127727). *Cancer Australia Priority Driven Collaborative Cancer Research Scheme* 2017-2020: $599,820.
2. **Agar, M., Hosie, A., Phillips, J.L.,** Noble, B., **Lam, L.,** Brassil, M., Kurrrle, S., Cumming, A., Chye, R., Caplan, G., Le, B., Ely, W., Lawlor, P., Bush, S., & Davis, J.M. Phase II pilot cluster randomised controlled trial of a multicomponent multidisciplinary non-pharmacological intervention to prevent delirium for hospitalised people with advanced breast cancer. *National Breast Cancer Foundation Pilot Study Grant,* 2017-2018: $200,000.
3. **Agar, M., Phillips, J.L.,** Steer, C., Caplan, G., Gray, L., & Hovey, E. Phase II pilot cluster randomised controlled trial of a nurse-led triage and assessment system to optimize outcomes for older people with cancer. *SPHERE Cancer Clinical Academic Group Grant,* 2017- 2019: $200,000.
4. Braithewaite, J., Delaney, G., **Currow, D.C**., Bishop, J., & Ward, R. Systematically improving cancer outcomes. *National Health and Medical Research Council (NHMRC)* 2018-2022: $2,500,000.
5. **Brown. L**., **Currow, D.C., & Agar, M.R**. Advancing care for Japanese people with terminal illness (AJF2017089). *The Department of Foreign Affairs and Trade,* 2017: $20,000.
6. Clayton, J., Rhee, J., Tieman, J., Detering, K., Mitchell, G., **Phillips, J.L**., Halcomb, E., Morton, R., & Lewis, V. The Advance Project: Initiating palliative care and advance care planning through training and resources for primary and chronic/complex care clinicians. *Australian Government, Department of Health Public Health and Chronic Disease Grant Program*, 2017- 2020: $2,200,000.
7. **DiGiacomo, M., & Phillips, J.L**. Characteristics and well-being of Australian War Widows (ETH17-1479). *War Widows Guild of Australia (NSW),* 2017: $2,500. (contract research)
8. Hudson, P., **Parker, D.,** Tieman, J., & Carers Australia. Helping family carers to support a relative or friend with advanced disease: The Australian carer toolkit for advanced disease, *National Palliative Care Grants Department of Health and Ageing,* 2017-2020: $207,365.
9. Johnson, M., Macleod, U., Farrin, A., Meads, D., Wright-Hughes, A., Blenkinsopp, J., **Currow, D.C.,** Foy, R., Wilkes, S., Allgar, V., & Fraser, H. Reducing Inequalities in Cancer Outcomes in Yorkshire: Realising our potential for innovation in Patient Management, Survivorship and Palliative Care Research. Yorkshire Cancer Research (University of Hull Endowment HEND405), 2017-2021: £4,900,000.
10. **Parker, D**., **Agar, M.R**., & **Phillips, J.L**. Evaluation of HammondCare end-of-life residential homes project, *Sydney North Primary Health Network,* 2017-2018: $51,765.

11. **Phillips, J.L., Luckett, T., Lovell, M., Agar, M.R., &** Xu, X (R). Understanding cancer pain management experiences and needs of Chinese migrants in Australia: A mixed-methods study. *2016 Cancer Nurses Society of Australia Research Grant,* 2017: $9,499.
12. **Phillips, J.L.,** Shaw, T., Lovell, M., **Davidson, P.M**., Boyle, F., **Lam, L**., McCaffery, N., Harnett, P., & Krishnasamy, M. A phase III wait-listed RCT of a novel targeted inter-professional clinical education intervention to improve cancer patients' reported pain outcomes (PdCCRS 1127011). *Cancer Australia Priority Driven Collaborative Cancer Research Scheme*. 2017 -2020: $342,483.
13. Reymond, L., Tieman, J., & **Parker, D**. Aged Care Services Australia., Australian Primary Health Care Nurses Association., Leading Aged Services Australia., National Prescribing Service., Pharmaceutical Society of Australia & Royal Australian College of General Practitioners. Caring Safely for Australians at Home. *National Palliative Care Grants Department of Health and Ageing,* 2017-2020: $207,879.
14. Rose, L., Page, V., **Agar, M.R.,** Burry, L., Campbell, N., Clarke, M., Lee, J., Marshall, J., & Siddiqi, N. Core Outcome Set Development for Effectiveness Trials of Interventions to Prevent or Treat Delirium (Del-COrS). *Canadian Institutes of Health Project Grant*, 2017-2019: CAD 271,000.
15. Stevens, K., & **Parker, D.** Time travelling with technology: Google liquid galaxy for reminiscence for people with dementia. *Dementia Collaborative Research Centre Project Grant,* 2017-2018: $45,000.
16. **Visser, M**. Dementia, social interaction and communication: informing protocols for practice *UTS Early Career Researcher Grant,* 2017: $20,000.
17. **Xu, X.** Understanding dietary transition, diet and chronic diseases for older Australians. *UTS Faculty of Health Seed Grant Funding*, 2017-2018: $ 21,050
18. Yates, P., Tieman, J., & **Parker, D.** Specialist Palliative Care and Advance Care Planning Advisory Services. *National Palliative Care Grants Department of Health and Ageing*, 20172020: $1,753,065.

Palliative Care

Our program of research focuses on building the evidence at the patient, health professional and systems levels to better support people with chronic care needs transitioning into palliative care. We conduct this research in collaboration with the:

> Palliative Care Clinical Studies Collaborative (PaCCSC);

> Cancer and Supportive Care Clinical Studies Collaborative (CSCCSC); and

> Improving Palliative Care through Clinical Trials and Research (ImPaCCT:NSW).

Care-IS: Caregiver Intervention Study

Randomised controlled phase II trial of a structured nurse led home based support and education program for carers of people with high grade glioma.

Chief Investigators: A/Prof Georgia Halkett, Prof Anna Novak, Prof Elizabeth Lobb, ***Prof Meera Agar, Prof Jane Phillips,*** *Dr Lisa Miller, A/Prof Rachael Moorin and Dr Therese Shaw*

Project Manager: Ms Robyn Attwood

Funding: Cancer Australia

High Grade Glioma (HGG) is a rapidly progressive and significantly debilitating disease with a median survival of 12 months and a 5 year survival of 10%. The primary caregivers of people with this diagnosis experience significant levels of distress, anxiety and depression, which impact on their experience of caregiving, the quality of care received and the community in terms of the increased reliance on health care and potentially the development of complicated grief. This 12 month individually tailored supportive educational intervention aims to improve the experience of caregiving for carers of patients with HGG, through: regular assessment of the carers needs with coordination of care where required and provision of appropriate written resources; nurse led face to face home visit; personalised information resource folder tailored to individual carer needs; and ongoing telephone support for 12 months. The trial will evaluate whether the education and support intervention improves carer preparedness for the caring role, improve carers quality of life, reduces carer anxiety and depression and reduces unplanned use of health services.

This study is being coordinated collaboratively with Curtin University in Western Australia, where the study has been running since 2014. The New South Wales arm of the study has been recruiting since mid-2017 across five sites, with 32 referrals and 22 caregivers consenting to participate to date.

Publications:

- Halkett, G. K., Lobb, E. A., Miller, L., Shaw, T., Moorin, R., Long, A., King, A., Clarke, J., Fewster, S., & Nowak, A. K. (2017). Feasibility testing and refinement of a supportive educational intervention for carers of patients with high-grade glioma - a pilot study. Journal of Cancer Education, 1-9.

Conference presentations:

- Attwood, R., Halkett, G. et al. (2017). Care-IS: An RCT nurse-led supportive and educational intervention for carers of people with high grade glioma (poster). Australian Palliative Care Research Colloquium, Melbourne, VIC, 26-27 October 2017
- Halkett, G. et al. (2017). Unpacking the Care-IS intervention: What is covered during the structured nurse-led home based support and education programme for carers of people with high grade glioma (poster). Cooperative Trials Group for Neuro-oncology Annual Scientific Meeting, Melbourne, VIC, 23-24 October 2017.

Cough in lung cancer – a health professional survey

Chief Investigators: ***Dr Tim Luckett, Prof Jane Phillips, Prof Meera Agar, Prof David Currow*** *and Prof Alex Molassiotis*

Cough occurs in more than half of people with lung cancer and is associated with reduced quality of life. However, it is less researched than breathlessness and less commonly the focus of management in clinical practice. Work is being undertaken to describe current management of cough in lung cancer, in order to inform the need for further development and testing of nonpharmacological and pharmacological strategies. As a first step, a survey opened at the end of 2017 to canvass the perspectives of clinicians with a special interest in lung cancer regarding the clinical importance and management of cough. The study is a collaboration with Prof Alex Molassiotis at Hong Kong Polytechnic University, who led the development of guidelines for cough in lung cancer.

Melatonin for the prevention of delirium

Randomised, double-blind, placebo-controlled phase III trial of oral Melatonin for the prevention of delirium in hospital in people with advanced cancer

Chief Investigators: ***Prof Meera Agar, Prof David Currow, Prof Jane Phillips, Dr Annmarie Hosie*** *and* ***Dr Tim Luckett***

Funding: Cancer Australia

Despite being preventable in many cases, two thirds of people with advanced cancer will have a delirium episode at some point whilst in hospital. Delirium causes additional medical complications, excess mortality, high levels of patient and caregiver distress, and significant increases in health care costs. Delirium adversely affects cognition, awareness and communication ability at a critical time when being mentally aware and interacting with loved ones is crucial for quality of life. Among preventative strategies for delirium, most evidence is available for interventions that include exercise and cognitive components too demanding for

hospitalised people with advanced cancer. Recently, melatonin has been highlighted as a potential pharmacological alternative that has few side-effects and good potential for cost-effectiveness.

Through a phase III trial of oral melatonin versus placebo taken each night during inpatient oncology or palliative care admission, the current study will determine if oral prolonged release melatonin compared to placebo can increase the number of delirium-free days during hospitalisation for advanced cancer patients. The study will also determine whether oral prolonged release melatonin can reduce delirium severity and duration for those who develop a delirium episode; reduce delirium incidence; cause adverse effects such as sedation; positively influence adverse events associated with delirium episodes, and provide other symptom benefits in the form of improved sleep quality.

The study is being coordinated by the Palliative Care Clinical Studies Collaborative (PaCCSC), and being conducted in eight sites across Australia.

Who grieves? The patient perspective

Chief Investigators: ***Prof Jane Phillips****, Prof Elizabeth Lobb, A/Prof Richard Chye and* ***Prof David Currow***

Project Manager: Ms Frances Bellemore

Funding: CRN Project

This qualitative study aims to explore whether people with a life-limiting illness, who are expected to die within the next six months, are concerned about the bereavement needs of people other than their next of kin. This study evaluates if the diversity and complexity of modern families and kinship networks makes identifying ‘who’ the person with a life-limiting illness is most concerned about once they die, an important priority. If bereavement follow-up services continue to focus solely on contacting nominated next of kin, other family members, such as an offspring, sibling, grandchild or niece, along with friends, care givers and neighbours who have played a significant role in the person’s life and who may have unmet bereavement care needs, may be largely overlooked. Despite the inherent sensitivities, it is this unexplored aspect of bereavement care that this study proposes to explore.

Aged Care

Australia has an ageing population with the proportion of older people aged 65 more than tripling over the last fifty years. Over 80% of deaths in Australia are of people aged 65 and over, with dementia now the second leading cause of death. The need for and interactions with aged care services, primary care and acute services for older people increases as they approach end-of-life.

Research on palliative and end-of-life care is critical to understanding the holistic needs of older people with dementia and other life limiting illness, supporting family caregivers, addressing workforce challenges and understanding care needs across care settings. IMPACCT has three broad programs of research focused aged care:

> Improving palliative care for older people across care settings
> Workforce planning, education and support
> Family caregivers

Caring@home

Caring safely for Australians at home

Chief Investigators: Prof Elizabeth Reymond, Aged & Community Services Australia, Australian Primary Health Care Nurses Association, Prof Jennifer Tieman, Leading Age Services Australia, National Prescribing Service, Pharmaceutical Society of Australia, The Royal Australian College of General Practitioners and ***Prof Deborah Parker***

Funding: National Palliative Care Grants Department of Health and Ageing

The caring@home project aims to improve the quality of palliative care service delivery across Australia by upskilling community service providers to train lay carers to provide safe and effective breakthrough palliative symptom management to a family member/friend living at home.

End of Life Directions in Aged Care

Specialist palliative care and advance care planning advisory services

Chief Investigators: Prof Patsy Yates, Prof Jennifer Tieman, ***Prof Deborah Parker****, Palliative Care Australia, Leading Aged Care Services, Aged Care Services Australia, Catholic Healthcare, and Australian Healthcare and Hospitals Association*

Funding: Department of Health and Ageing, National Palliative Care Grants

End of Life Directions for Aged Care (ELDAC) brings together three Universities and five aged, palliative and primary care national bodies to improve the care of older Australians through advance care planning activities and palliative care connections. This aims to reduce avoidable hospital admissions, reduce length of stays, and improved quality of care for people supported in residential and community aged care programs by focusing on four streams of work: Capacity building through access to toolkits and to online and phone support; Improved care and service provision through technology solutions; Better understanding of issues through policy briefings and meetings; and Service and sector development through local and regional partnerships.

End of Life Residential Homes Project

Evaluation of the HammondCare end of life residential homes project

Chief Investigators: ***Prof Deborah Parker, Prof Meera Agar*** *and* ***Prof Jane Phillips***

Funding: Sydney North Primary Health Network

Evaluation of the HammondCare End of life Residential Homes Project aims to: 1) provide a multidisciplinary clinical consultation service to residents who require end of life care in 24 residential aged care facilities located in the SNPHN; Provide education for link nurses and careworker champions; and 2) establish communities of practice for the link nurses and careworker champions in the participating facilities. This mixed methods evaluation includes clinical audit, staff surveys and focus groups.

Reminiscence therapy using Google liquid galaxy

Knowledge Translation and Time Travelling with Technology (KT-TTT): Google Liquid Galaxy for Reminiscence for people with dementia

Chief Investigators: Prof Kate Stevens, ***Prof Deborah Parker*** *and Mr Andrew Leahy*

Funding: Dementia Collaborative Research Centres and in-kind contribution from BaptistCare

The 'Time Travelling with Technology' (TTT) during 2016-17 investigated the feasibility and effectiveness of new Google Liquid Galaxytechnology as an intervention to reduce the behavioural and psychosocial symptoms of people with dementia. Building on the feasibility and overwhelming popularity of the TTT Liquid Galaxy immersive installation in two residential aged care facilities, knowledge gained from the two experiments will be translated into a KT-TTT to develop a portable and more automated version of the technology and resource. This studies includes two phases focused on resource development, and includes: 1) software and hardware streamlining and simplification for general ease of use; and 2) developing an implementation guide for care staff to understand the theoretical and evidence-based framework that underlies reminiscence therapy and TTT, including a reminiscence therapy guide for a six-week program, guide to using the technology, and evaluation of the usability of the platform and the guide.

The Australian Carer Toolkit for Advanced Disease

Helping family carers to support a relative or friend with advanced disease: The Australian carer toolkit for advanced disease

Chief Investigators: Prof Peter Hudson, ***Prof Deborah Parker****, Prof Jennifer Tieman and Carers Australia*

Funding: National Palliative Care Grants Department of Health and Ageing

The purpose of the Australian carer toolkit for advanced disease is to help Australian family carers to support a person with advanced disease by providing free access to high quality information via a national e-health toolkit.

Chronic Care

Chronic conditions, such as cardiovascular disease, diabetes, cancer, and arthritis have a significant impact on the lives of individuals, their families and communities. Living with a chronic illness commonly requires people to make difficult decisions about treatment options, lifestyle changes, and engage in self-management strategies.

At IMPACCT, we undertake research and health services planning to help individuals and their families cope with these challenges. The research includes the design, implementation and management of clinical trials focusing on health services, symptom management and evaluation of interventions to improve outcomes for individuals with chronic illness.

Cancer

Cancer Pain Assessment Study

A phase III wait-listed randomised controlled trial (RCT) of a novel targeted interprofessional clinical education intervention to improve cancer patients' reported pain outcomes.

Chief Investigators: ***Prof Jane Phillips****, Prof Tim Shaw, Prof Melanie Lovell,* ***Prof Patricia Davidson,*** *Prof Frances Boyle,* ***Prof Lawrence Lam****, Dr Nikki McCaffery, Prof Paul Harnett and Prof Mei Krishnasamy*

Funding:Cancer Australia

Cancer pain is experienced by 30–75% of patients in high income countries. Variations in care contribute to cancer pain being under-recognised and under-treated in 50% of patients. This project addresses a priority identified at the Australian National Pain Summit to reduce unrelieved cancer pain by improving cancer and palliative clinicians' pain assessment capabilities through a targeted mHealth inter-professional training and support intervention which combines: an online spaced learning module that delivers authentic case-based cancer pain assessment scenarios directly to a clinician's mobile device; real-time site-specific pain assessment audit and feedback, providing de-identified peer to peer comparisons; and online links to evidence-based pain assessment decision supports. The intervention will be delivered via the online QStream platform directly to clinicians' emails and will be accessible from their mobile devices.

The wait-listed randomised controlled trial (RCT) is being conducted in six sites across Australia, and is coordinated by IMPACCT.

Conference presentations:

- Phillips, J.L., Lovell, M., Davidson, P., Boyle, F., Lam, L., McCaffrey, N., Heneka, N. and Shaw, T. A Phase III wait-listed RCT of a novel targeted inter-professional clinical education intervention to improve cancer patients' reported pain outcomes: Protocol (poster). European Association for Palliative Care 10th World Research Congress, Bern, 24-26 May 2018.

Chinese Migrant Cancer Pain Management Study

Understanding Cancer Pain Management Experiences and Needs of Chinese Migrants in Australia: a mixed-method study

Chief Investigators: Ms Xiangfeng Xu, ***Prof Jane Phillips****,* ***Dr Tim Luckett*** *and Prof Melanie Lovell*

Funding: Cancer Nurse Society of Australia 2016 Annual Research Grant

Cancer related chronic pain is a common and often complex symptom experienced by the majority of cancer patients. Cultural factors can significantly influence cancer patients' pain experience, coping behaviours and adherence to pain treatment. Understanding cultural diversity and providing culturally appropriate care is an essential element of effective cancer pain management for patients from culturally and linguistically diverse backgrounds. Chinese migrants form one of the largest cultural and linguistically diverse communities in Australia. Cultural diversity may inadvertently act as a barrier to effective pain management for Chinese migrant cancer patients. The project employs a sequential mixed-method research design to explore cultural related facilitators and enablers at the levels of patient, oncology nursing professional and health system in relation to providing culturally congruent cancer pain management for the largest Australian migrant population other than the UK and New Zealand – people born in China.

The project is being led by PhD candidate Ms Xiangfeng Xu and includes two sub-studies. Study 1: Focus Group to Chinese Migrant Cancer Patients is being conducted in 2 sites in NSW. Study 2: Survey of Cancer and Palliative Care Nurses are undertaken via the peak bodies (e.g. Cancer Nurse Society of Australia and Palliative Care Nurses Australia) with members across Australia and 5 sites in NSW.

Publications:

- Xu, X.(R)., Luckett, T., Wang, A., Lovell, M., & Phillips, J.L**.** (2017). Cancer pain management needs and perspectives of patients from Chinese backgrounds: A systematic review of the Chinese and English literature. *Asia-Pacific Journal of Clinical Oncology*, [Epub] doi: 10.1017/S1478951517001171.

Conference presentations:

- Xu, X.(R)., Phillips, J.L., Luckett, T., Lovell, M., & Wang A. (2017). Cultural influences on pain-related perspectives, beliefs & needs of cancer patients from Chinese backgrounds: A systematic review of Chinese & English language research literature (poster). Clinical Oncological Society of Australia Annual Scientific Meeting, Sydney, NSW, 13-15 November 2017.
- Xu, X.(R)., Phillips, J.L., Luckett, T., & Lovell, M. (2017). Implementing culture care theories and models in practice and research (poster). Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.
- Xu, X.(R)., Phillips, J.L., Luckett, T., & Lovell, M. (2017). Implementing culture care theories and models in practice and research (oral). Cancer Nurses Society of Australia 20th Annual Congress, Adelaide, SA, 15-17 June 2017.

Geriatric Oncology Trial

Chief Investigators: ***Prof Meera Agar*** *and* ***Prof Jane Phillips***

Funding: SPHERE Cancer Academic Group Grant

More than half of newly diagnosed people with cancer are 65 years and older, and this number is expected to increase as the population ages. It has been demonstrated that chronological age alone is insufficient to plan cancer treatment and supportive care for this patient group, and more comprehensive assessment is needed to avoid poor outcomes. In the Australian context, a system is needed which can ensure older people with cancer who require comprehensive geriatric assessment and the subsequent care for any problems identified, have access to this; and that oncologists are equipped with skills to use these assessments in decisions about cancer treatments.

The first stage of this study will develop a model of care, which includes: a screening assessment for all older people with cancer, comprehensive geriatric assessment by a trained nurse for those who have issues identified on screening, and an education package for oncologists to equip them with skills to use these assessments in cancer care planning. The second stage will implement this model in cancer centres and compare it to the usual approach to care of older cancer patients, in a randomized trial.

The Cannabis Study

Evaluation of oromucosal nabiximols and vaporised botanical leaf cannabis in cancerrelated anorexia cachexia syndrome in palliative care: A pharmacokinetic study and Phase III double-blind RCT

Chief Investigators: ***Prof Meera Agar, Prof Jane Phillips, Prof David Currow, Dr Tim Luckett,*** *and* ***Ms Linda Brown***

Funding: NSW Health

Up to 80% of advanced cancer patients suffer debilitating loss of appetite, taste problems, and weight loss causing distress to both patients and families. Cancer-anorexia-cachexia-syndrome (CACS) is an international palliative care research priority because of the great distress, morbidity and mortality it causes. Cannabis, reported to stimulate appetite in recreational users, may impact multiple symptoms and improve the quality of life of people living with cancer.

This study evaluates the effects of two types of cannabis, oromucosal spray and cannabis leaf, in people with CACS to determine whether cannabis can improve their appetite, ability to feel hungry and enjoyment of meals. The study will also explore the impact of cannabis on other distressing symptoms like fatigue, altered taste and smell, low mood, weight loss, nausea and insomnia that often co-exist with poor appetite.

Rigorous trials of oromucosal spray and cannabis leaf are cutting edge in palliative care, and will advance the science of medicinal cannabis as a basis for policy over and above the vicissitudes of current politicised debate. If effective, cannabis will be a useful addition to the medications available in Australia for the treatment of advanced cancer symptoms.

Conference presentations:

- Minichiello, V., Phillips, J.L., Agar, M.R, & Scott, J. (2017). Setting an agenda for social science research on medicinal cannabis in palliative care. Crime and Justice in Asia and the Global South, Cairns, QLD, 10-13 July 2017.

The PRESERVE Pilot Study

Phase 2 (pilot) cluster randomised controlled trial of a multi-component nonpharmacological intervention to prevent delirium for hospitalised people with advanced cancer

Chief Investigators: ***Prof Meera Agar, Dr Annmarie Hosie,*** *and* ***Prof Jane Phillips***

Funding: National Breast Cancer Foundation

Delirium during hospitalisation is a significant medical complication for up to two in every three people with advanced cancer. Delirium adversely affects cognition, awareness and communication ability at a critical time when being mentally aware and interacting with loved ones is crucial. An episode also can lead to many adverse consequences: distress, increased falls, physical and mental decline, longer hospital stay, increased mortality and higher health care costs.The aim of the PRESERVE pilot study is to determine if a tailored multi-component nonpharmacological delirium prevention intervention is feasible and acceptable for people with advanced cancer in hospital.

The study will develop a multi-component non-pharmacological delirium prevention intervention for the inpatient palliative care and oncology setting and people with advanced cancer. All four participating sites will introduce delirium screening and diagnostic assessment; two intervention sites will also introduce the multi-component intervention (preserve natural sleep; maintain optimal vision and hearing; optimise hydration; promote communication, orientation and cognition; optimise mobility and function; and family partnership). Patient, family caregivers, staff and volunteer feedback about the feasibility and acceptability of the intervention will be obtained using interviews and surveys. The study will inform the feasibility and design of a phase 3 trial to determine if delirium is prevented in people with advanced cancer to the extent achieved for older people in hospital. *Conference presentations:*

- Hosie, A., Phillips, J., Kochovska, S., Lam, L.T, Brassil, M., Noble, B., Kurrle, S., Cumming, A., Caplan, G.A., Chye, R., Le, B., Ely, E.W., Lawlor, P.G., Bush, S.H., Davis, J.M, Lovell, M., Brown, L., Fazekas, B., Cheah, S.L. Edwards, L., & Agar, M.R. (2017). Multicomponent nonpharmacological intervention to prevent delirium for hospitalised people with advanced cancer: a phase II cluster randomised waitlist controlled trial (poster). Palliative Care Nurses New Zealand Conference, Wellington, New Zealand, 9-10 October 2017.
- Hosie, A., Amgarth-Duff. I, Edwards, L., Siddiqi, N., Featherstone, I., Boland, J., Johnson, M., Lawlor, P., Bush, S., Agar, M.R, & Phillips, J.L. (2017). Non-pharmacological delirium interventions for adult inpatients with advanced, progressive illness: a systematic review (poster). American Delirium Society 7th Annual Meeting, Nashville, USA, 4-6 June 2017.

The Stop Cancer PAIN Trial

Translating evidence into practice: Implementing a national clinical pathway for pain to ensure equitable, cost-effective, evidence-based, person-centred care for people with advanced cancer

Chief Investigators: Dr Melanie Lovell, ***Dr Tim Luckett, Prof Patricia Davidson, Prof Jane Phillips, Prof Meera Agar,*** *Prof Fran Boyle, Mr John Stubbs, Ms Anna Green, Prof Tim Shaw, Prof David Currow, Prof Louise Ryan and Dr Nikki McCaffrey*

Project Manager: Ms Alison Read

Funding: National Breast Cancer Foundation

Cancer pain continues to be a major problem experienced by cancer and palliative care patients. Under-identification, under-management and poor coordination of care contribute to the burden of pain experienced by people living with advanced cancer. The Stop Pain Pathway aims to ensure better access to evidenced based care for advanced cancer patients living with pain.

This project ensures minimum standards are met through the implementation, evaluation and dissemination of a national clinical pain pathway that provides step-by-step instructions on pain screening, assessment and management. The pathway is supported by a suite of resources, including: a patient-held “Managing Cancer Pain” resource for people with cancer and their families that supports self-management, communication and coordination between different healthcare providers; quality improvement resources and audit tools to record service level pain scores and adherence to cancer pain indicators; and an online training program called 'QStream' for health professionals which combines gaming with scientifically proven methodology that increases long-term knowledge retention.

The pathway and resources are regularly updated and available free-of-charge on the Cancer Council Australia Cancer Guideline Wiki. They will be accessible to services and patients in regional and rural areas and translated for non-English speaking patients and their medical teams.Better management of pain has the potential to reduce healthcare costs, reduce caregiver distress and improve quality of life for people living with cancer.

Conference presentations:

- Lovell, M., Phillips, J.L., Agar, M.R., Luckett, T., & Read, A. (2017). Stop Cancer PAIN Trial Lessons learned on implementing best-practice pain care (poster). Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.
- Lovell, M., Agar, M., Phillips, J.L., Luckett, T., & Read, A. (2017). ‘Touching the void’: Bridging the chasm between clinical guideline development and local site implementation (poster). Asia Pacific Hospice Conference, Singapore, 26-29 July 2017.
- Phillips, J.L., Lovell, M., Agar, M.R., Boyle, F., Davidson, P.M., Luckett, T., Currow, D.C, Lam, L.T., McCaffrey, N., Shaw, T., & Read, A. (2017). Preliminary site evaluation of the stop cancer pain trial using the PARIHS framework (oral). International Conference on Cancer Nursing, Anaheim, USA, 9-12 July 2017.

- Phillips, J.L., Lovell, M., Agar, M.R., Boyle, F., Davidson, P.M., Luckett, T., Currow, D.C., Lam, L.T., McCaffrey, N., Shaw, T., & Read, A. (2017). From PARHIS with love - measuring successful evidence-based guideline implementation (oral). Cancer Nurses Society of Australia 20th Annual Congress, Adelaide, SA, 15-17 June 2017.

Cardiovascular Disease

Heart Disease in Women

Title: Strategies to improve heart disease outcomes in Australian women

Chief Investigators: ***Dr Michelle DiGiacomo****,* ***Prof Phillip Newton*** *and* ***Prof Patricia Davidson***

Funding: Australian Research Council Discovery Project

Heart disease is the major killer of Australian women, yet many women remain unaware and underestimate their risk. Heart disease occurs more commonly in older women who face numerous other health and social life changes. Building on previous work of the project team, this project tests a novel cardiac rehabilitation program designed specifically for women.

The project investigates the use of a gendered approach to healthcare through developing strategies to improve women's heart health in Australia through a randomised controlled trial (RCT), with the benefit of a group-based tailored program. Women were randomised to a standard cardiac rehabilitation program or a standard cardiac rehabilitation program plus a gendered specific mutual support group. This study was conducted in the Western Sydney Local Health District and completed recruitment and interventions in December 2017.

Publications in press:

- Rao, A., Newton, .P, DiGiacomo, M., Hickman, L., Hwang, C., & Davidson, P.M. Optimal gender specific strategies for the secondary prevention of cardiovascular disease in women: a systematic review, accepted by *Journal of Cardiopulmonary Rehabilitation and Prevention* August 2017.

Publications under review:

- Rao, A., DiGiacomo, M., Newton, P., Phillips, J.L., & Hickman L. Meditation for the secondary prevention of depression and anxiety in heart disease: A systematic review, submitted to *Mindfulness*.

Remote monitoring and mHealth interventions for people with heart failure

Chief Investigator: ***A/Prof Sally Inglis***

Funding: Cardiovascular Research Network Life Science Research Fellow, supported by the Heart Foundation and the NSW Office for Medical Research

This research examines the use of eHealth and mHealth technologies to support and educate people with heart failure to better self-manage their condition. This research includes Cochrane Reviews and quantitative surveys of clinician attitudes towards these interventions.

Conference presentations:

- Inglis, S.C. (2017). The controversy of remote monitoring in heart failure: What does the evidence say? Cardiac Society of Australia and New Zealand Annual Scientific Meeting, Perth, WA, 10-13 August 2017

Understanding the Needs of People with Peripheral Arterial Disease

Understanding needs of people with Peripheral Arterial Disease and developing and evaluating interventions to address those needs

Chief Investigators: ***A/Prof Sally Inglis*** *and* ***Dr Michelle DiGiacomo***

Funding: Cardiovascular Research Network Life Science Research Fellow, supported by the Heart Foundation, the NSW Office for Medical Research and NHMRC Centre of Research Excellence for Peripheral Arterial Disease.

Peripheral arterial disease is a debilitating form of chronic cardiovascular disease which leads to poor quality of life and increased risk of events such as heart attack and stroke. Unlike other forms of cardiovascular disease, people with peripheral arterial disease have limited access to specialised support services such as rehabilitation services and self-management programs.

These projects examine the needs for additional support and services which people with peripheral arterial disease themselves identify. They also examine the current evidence to support self-management for people with peripheral arterial disease and look to develop new interventions to support self-management for people with peripheral arterial disease.

- C*ochrane Review*: Disease management interventions for improving self-management in lower-limb peripheral arterial disease.
- *Living with peripheral arterial disease in Australia: patient experiences and unmet needs*: Nine face-to-face and telephone semi-structured interviews were conducted with individuals who have peripheral arterial disease in 2017. Interviews were transcribed and have undergone thematic analysis.

Respiratory Conditions

Breathlessness Self-Management

Developing self-management strategies to reduce avoidable Emergency Department presentations for chronic refractory breathlessness: a strengths-based approach using qualitative methods

Chief Investigators: ***Dr Tim Luckett, Prof Jane Phillips, Dr Phillip Newton****, Dr Rebecca Disler,* ***Prof Patricia Davidson, Prof David Currow****, Prof Miriam Johnson, Prof Ginger CarrieriKohlman, A/Prof Richard Chye, Dr Caitlin Sheehan,* ***Prof Meera Agar****, Ms Bridget Whelan and* ***Prof Lawrence Lam***

Funding: UTS Health Futures Development

This study aimed to inform development of self-management strategies for reducing avoidable breathlessness-related Emergency Department (ED) presentations via a better understanding of

the natural history of such presentations and strategies that ‘expert’ patients and families have found useful in avoiding them.

Semi-structured interviews with 20 patients and 3 carers included questions on decision-making about whether or not to go to ED, perceptions of what helped avoid presentation, and use of selfmanagement strategies more generally.

The study gathered insights into important factors in avoiding ED presentation, including: perceived control over breathlessness, self-efficacy in coping with a crisis and desire not to be hospitalised. Effective coping strategies appeared to include: taking a project management approach that involved goal setting, monitoring and risk management; managing the affective dimension of breathlessness separately from the sensory perceptual, and building three-way partnerships with primary care and respiratory services.

Publications:

- Luckett, T., Phillips, J., Johnson, M., Garcia, M., Bhattarai, P., Carrieri-Kohlman, V., Hutchinson, A., Disler, R.T., Currow, D.C. Agar, M.R. & Ivynian, S. (2017). Insights from Australians with respiratory disease living in the community with experience of self-managing through an emergency department ‘near miss’ for breathlessness: a strengths-based qualitative study. *BMJ open*, *7*(12), e017536.

Conference presentations:

- Disler, R., Luckett, T., Phillips, J.L., Johnson, M., Garcia, M., Bhattarai, P., Hutchinson, A., Currow, D.C., Carrieri-Kohlman, V., Whelan, B., Newton, P.J., Agar, M.R., Chye, R., Sheehan, C., Ivynian, S., & Davidson, P.M. (2017). Respiratory patient experiences in selfmanaging emergency department 'near-miss' for breathlessness: A strengths-based qualitative study (poster). American Thoracic Society, Washington DC, USA, 19-24 May 2017.

- Luckett, T., Phillips, J.L., Johnson, M., Garcia, M., Bhattarai, P., Hutchinson, A., Currow, D., Disler, R., Carrieri-Kohlman, V., Whelan, B., Newton, P., Agar, M., Chye, R., Sheehan, C., Ivynian, S., & Davidson, P.M. (2016). Self-management to reduce avoidable emergency department presentations for breathlessness: A strengths-based approach using qualitative methods (poster). Palliative Care Nurses Australia Conference, Canberra, ACT, 11-12 September.
- Luckett, T., Phillips, J.L., Johnson, M., Garcia, M., Bhattarai, P., Hutchinson, A., Currow, D., Disler, R., Carrieri-Kohlman, V., Whelan, B., Newton, P.J., Agar, M., Chye, R., Sheehan, C., Ivynian, S., & Davidson, P.M. (2016). Self-management to reduce avoidable emergency department presentations for breathlessness: A strengths-based approach using qualitative methods. Palliative Care NSW Biennial State Conference 2016, Broken Hill, NSW, 13-15 October.

Evaluation of a new Breathlessness Clinic at Westmead Hospital

Randomised controlled trial of a non-pharmacological integrated care intervention to reduce breathlessness in patients with moderate to very severe chronic obstructive pulmonary disease (COPD)

Chief Investigators: Prof John Wheatley, Dr Tracy Smith, Ms Mary Roberts, Dr Jin Gun-Cho, Dr Nikki McCaffrey, ***Dr Tim Luckett*** *and Dr Adrienne Kirby*

Funding: NSW Health Translational Research Grant

This project will address the question of whether an integrated care approach using nonpharmacological interventions in patients with COPD can reduce breathlessness, with consequent improvement in quality of life and reduction in health care utilisation and hospital admissions. An RCT (single blind, parallel group with wait list control) is underway of a combination of short term (8 weeks) intensive non-pharmacological interventions added to standard care in 88 patients with COPD and refractory breathlessness. The primary outcome is mastery of breathlessness as measured by the Chronic Respiratory Questionnaire (CRQ), with secondary outcomes of quality of life, breathlessness intensity, anxiety and depression, and health care utilisation.

IMPACCT is leading a qualitative sub-study that will contribute to interpretation of outcome data. Participants are interviewed immediately after completing the 8 week program and again at 6 months to see if any intervention effects have been sustained. Data collection began in June 2017 and will continue into 2018.

Publications under review:

- Smith,T., Roberts, T., Cho, J., Klimkeit, E., Luckett, T., McCaffrey, N., Kirby, A. & Wheatley, J. Protocol for a single-blind, randomized parallel group study of a non-pharmacological integrated care intervention to reduce the impact of breathlessness in patients with chronic obstructive pulmonary disease (COPD). Submitted to *Contemporary Clinical Trials*.

South Australian Carer Study

Health status of people who have provided informal care or support to an adult with chronic disease over the past 5 years: a population-based cross-sectional survey in South Australia

Chief Investigators: ***Prof Jane Phillips, Prof Meera Agar, Dr Michelle DiGiacomo, Prof Lawrence Lam, Dr Tim Luckett, A/Prof Phillip Newton, Dr Caleb Ferguson***

In Australia in 2015, 2.7 million (11.6%) of the population were informal carers. The financial value of informal caregiving to Australia includes cost savings both from reduction in the need for community care from the healthcare system (estimated to equal $60.3 billion in 2015) and decreased likelihood of care recipients being admitted to long-term care. However, the societal value of informal caregiving comes at a personal cost to carers themselves. In the 2012 National Survey of Disability, Ageing and Carers, the majority (54%) of Australian carers reported negative impacts on their wellbeing as a result of caregiving.

To better understand the impacts on carers' mental and physical health status, IMPACCT is analysing data collected in September to November 2017 via the South Australian Health Omnibus. The Health Omnibus is an annual, cross-sectional survey that uses a multi-stage, systematic approach to ensure its sample is representative of the South Australian population. Respondents were asked whether they had experience in the last 5 years of providing care or support to an adult with one or more of the following chronic diseases: cancer, heart disease (e.g. heart failure), respiratory disease (e.g. emphysema), mental illness (e.g. depression, schizophrenia), neurological disease (e.g. Parkinson's, stroke) or dementia. These six diseases were selected because they confer a high burden of disability that requires carer input and support over an extended period across the illness trajectories. Other items asked of carers included the hours spent caring, the types of tasks undertaken, and the Carer Experience Scale (CES) (Hoefman et al, 2015), a validated scale that assesses perceived level of social support, activities outside caring, support from family and friends, assistance from organisations and the government, fulfilment from caring, control over caring, and ability to 'get on' with the person being cared for. Analyses are underway.

Conference presentations:

- Luckett T, Agar M, DiGiacomo M, Ferguson C, Lam L, Newton P, Phillips J**.** Predictors of health status in South Australians caring for people with cancer: a population-based study (poster). Clinical Oncological Society of Australia Annual Scientific Meeting, Adelaide, 13th15th November 2017.

Priority Populations

Characteristics and wellbeing of Australian War Widows

Chief Investigators: ***Dr Michelle DiGiacomo*** *and* ***Prof Jane Phillips***

Funding: War Widows' Guild of Australia (NSW)

Older women are particularly at risk for a range of chronic health conditions and economic deprivation, have higher rates of severe disability and increased rates of depression, anxiety, and loneliness. Australian society faces major challenges as women age and have fewer options for social and financial support. To better understand the needs and characteristics of older women to inform the planning of social, health, and financial services we collaborated with the War Widows' Guild of Australia (NSW) and Legacy to ascertain current and future needs of Australian war widows and better meet the needs of this group and the next generation.

In this study, we developed a postal questionnaire that was pilot tested and discussed in focus groups and interviews with 30 Guild members between July-August 2017. The final questionnaire was a 95-item (closed and open-ended items) survey that asked about demographics, perceptions of and engagement with the Guild and Legacy (if applicable) and services provided by these organisations. Other topics included related to living arrangements, physical and mental health, social and financial wellbeing, service use, and caregiving/care recipient status. Results will be used to help to design services and supports or facilitate links to meet the needs of a

declining membership, to inform services offered for Guild members, and to ensure its sustainability in longer term.

Doubly Disadvantaged

Doubly Disadvantaged: harnessing elements of resilience and establishing information for systems change

Chief Investigators: ***Dr Michelle DiGiacomo****,* ***Prof Patricia Davidson****, Prof Rosemary Johnston and Ms Anna Green*

Funding: Australian Research Council Linkage Project

Aboriginal and Torres Strait Islander families with children with a disability experience higher disadvantage than other Australian families due to a number of health, social and economic inequities. Aboriginal caregivers are twice as vulnerable to poor health, face difficulties accessing services and lack support in addressing the physical and developmental challenges in the critical early years of a child's life. This disproportionate burden can have long term effects on the child's health, education and employment opportunities, contributing to a life-long cycle of disadvantage for Aboriginal children with disability, their carers, family, and community.

This community-driven research, in partnership with the formerly named Aboriginal Medical Service Western Sydney (AMSWS), evaluated the current availability of Aboriginal early childhood disability services, the family journey to accessing support and the acceptability and utility of support services. Using qualitative research methods, including the data collection of PhD student Anna Green, the project aimed to understand the perspectives and experiences of Aboriginal families of children with a disability as well as health, education and social service providers within the socio-cultural and environmental context of Western Sydney. The partnership represents an opportunity to develop strategies to facilitate non-Aboriginal and Aboriginal professionals working together to develop a solution-based pathway to reduce health disparities faced by Aboriginal Australians.

The project has informed the design and delivery of services and led to the development of educational resources for parents, children, and health services, providing practical, tangible and measureable means to improve access to care for Aboriginal children and support for families and the community. In 2017, the project concluded and the PhD thesis entitled "Families with an Aboriginal and Torres Strait Islander child with disability: System, service and provider perspectives" was submitted by Anna Green, and is currently under examination.

Publications:

- DiGiacomo, M., Green, A., Delaney, P., Delaney, J., Patradoon-Ho, P., Davidson, P.M. & Abbott, P. (2017). Experiences and needs of carers of Aboriginal children with a disability: a qualitative study. BMC family practice, 18(1), 96.

Publications under review:

- Green, A., Abbott, P. Davidson, P.M., Delaney, J., Delaney, P. &, DiGiacomo, M.

  Intersectionality and cultural competence in Aboriginal carers of children with disability. Submitted to Qualitative Health Research (revisions submitted).

Conference presentations:

- Green, A., Henry, V., Abbott, P., Davidson, P.M., Delaney, J., Delaney, P., & DiGiacomo, M. (2017). Re-imagining the service landscape for Aboriginal children with a disability. NH&MRC & Lowijita Institute Symposium on Research Translation, Brisbane, QLD, 14-15 November 2017.

HIGHER DEGREE RESEARCH STUDENTS

PhD Completions (2017)

Sabine Allida

Title: Randomised controlled trial of chewing gum to relieve thirst in chronic heart failure study.
Supervisors: Phillip Newton, Sally Inglis, Patricia Davidson, Christopher Hayward

Leanne Hunt

Title: The nurses' role in intra-abdominal pressure monitoring in the critical care setting.
Supervisors: Patricia Davidson, Phillip Newton, Ken Hillman

Skye Dong (University of Sydney)

Title: Symptom clusters in palliative care.

Supervisors: Phyllis Butow, Melanie Lovell, Meera Agar

Della Maneze (Western Sydney University)

Title: Acculturation and health-seeking behaviours among Filipinos living in Australia.

Supervisors: Yenna Salamonson, Bronwyn Everett, Michelle DiGiacomo, Patricia Davidson

PhD Submissions (2017)

Anna Green

Title: Families with an Aboriginal and Torres Strait lslander child with disability: System, service and provider perspectives.
Supervisors: Michelle DiGiacomo, Tim Luckett, Penelope Abbott, Patricia Davidson. Cultural mentors: Pat Delaney, John Delaney

Serra Ivynian

Title: Care-seeking behaviours for worsening symptoms in heart failure.
Supervisors: Phillip Newton, Michelle DiGiacomo

Sunita Jha

Title: Frailty in patients with advanced heart failure referred for heart transplantation.
Supervisors: Phillip Newton, Louise Hickman, Peter Macdonald, Sungwon Chang

John Rihari-Thomas
Title: Risk management of the deteriorating patient in the Acute Care Setting (RACS study): A single centre case study
Supervisors: Patricia Davidson, Phillip Newton, David Sibbritt

Sajad Sheehab
Title: The use of biventricular assist devices in end stage chronic heart failure.
Supervisors: Phillip Newton, Patricia Davidson, Sally Inglis, Christopher Hayward

Lisa Wong
Title: Help seeking behaviour of Chinese carers of people living with dementia.
Supervisors: Jane Stein-Parbury, Lynnette Chenoweth, Michelle DiGiacomo

Current PhD students

Commenced 2017

Ingrid Amgarth-Duff
Title: Understanding the biological and clinical correlates of cognitive problems and delirium in advanced cancer: A mixed methods study. Supervisors: Meera Agar, Annmarie Hosie

Tony Noun
Title: Understanding medical professional - to - professional social exchange relationship drivers: Implications for referral practices and patient outcomes
Supervisors: Carla Saunders, Meera Agar

Lachlan Pasch
Title: Pharmacotherapy in heart failure
Supervisors: Phillip Newton, Sasha Bennett

Bronwyn Raymond
Title: Supporting self-management of breathlessness
Supervisors: Tim Luckett, Jane Phillips, Melanie Lovell

Christine Sanderson
Title: A mixed methods study investigating moral distress of doctors in relation to end of life medical decision-making, using the case of patients with cognitive impairment dying in the acute hospital setting
Supervisors: Meera Agar

Continuing PhD Candidates

Humood Albughami
Title: Interventions to promote positive health behaviours in Saudi boys schools aged 9-15 in Jeddah city.
Supervisors: David Sibbritt, Patricia Davidson, Phillip Newton

Adam Beaman
Title: Health systems strengthening in global service-learning: a mixed-methods investigation
Supervisors: Patricia Davidson, Phillip Newton**,** David Sibbritt

Nicola Brown
Title: Family based interventions for a smoke free home: A mixed methods approach to intervention development & pilot implementation.
Supervisors: Michelle DiGiacomo, Tim Luckett, Patricia Davidson

Taryn Chalmers (Science, UTS)
Title: Professional drivers: Assessing cardiovascular associations to affective states. Supervisors: Sara Lal, Tim Luckett

Cleo Crossley
Title: Breathlessness measurement in chronic heart failure.
Supervisors: Phillip Newton, Sally Inglis, Tim Luckett, Patricia Davidson

Domenica DiSalvo
Title: Improving the safety and quality of prescribing for aged care residents with advanced dementia.
Supervisors: Tim Luckett, Patricia Davidson, Meera Agar, Sasha Bennett

Andrew Donker
Title: Overview of cancer care services in Ghana.
Supervisors: Jane Phillips, Tim Luckett, Sanchia Aranda

Jaymen Elliot (Science, UTS)
Title: Cardiovascular health, stress and sleep of shift working police officers: A physiological assessment
Supervisors: Sara Lal, Phillip Newton, Patricia Davidson

Janet Forber
Title: Appreciating complexity, context and continuum in undergraduate nurse clinical education: English and Australian perspectives.
Supervisors: Michelle DiGiacomo, Debra Jackson, Bernie Carter, Patricia Davidson, Jane Phillips

Kyoungrim Kang
Title: Health-related quality of life in patients with myocardial infarction: trends and predictors.
Supervisors: Leila Gholizadeh, Sally Inglis, Hae Ra Han

Jessica Lee
Title: Improving outcomes for patients with neuropathic cancer pain.
Supervisors: Meera Agar, Jane Phillips, Melanie Lovell

Ty Lees (Science, UTS)
Title: The Impact of stress and anxiety on the neurocognitive performance of Australian Nurses: Electroencephalographic and psychometric assessment.
Supervisors: Sara Lal, Phillip Newton, Patricia Davidson

Julee McDonagh
Title: Frailty measurement in heart failure: a prospective cohort study.
Supervisor: Phillip Newton, Caleb Ferguson

Elyn Montgomery
Title: Impact of frailty in people undergoing lung transplantation.
Supervisors: Phillip Newton

Pauline Murray-Parahi
Title: Preparing nurses for roles in primary health care.
Supervisors: Patricia Davidson, Debra Jackson, Michelle DiGiacomo, Jane Phillips

Glenn Paull
Title: Care resynchronisation: A nursing delivery platform for coordinated cost efficient inpatient management of chronic heart failure in Australia. Supervisors: Patricia Davidson, Phillip Newton

Roslyn Prichard
Title: Advanced heart failure management with ventricular assist therapy: evaluating Australian costs of care and effectiveness from implant to transplant or end of life.
Supervisors: Patricia Davidson, Christopher Hayward, Phillip Newton, Stephen Goodall

Angela Rao
Title: Implementing meditation in heart disease clinical settings: The MENTOR Study
Supervisors: Louise Hickman, Michelle DiGiacomo, Jane Phillips

Sara Shishegar
Title: Health and sociocultural needs of Iranian refugee and asylum seeker women living in Metropolitan Sydney, Australia.
Supervisors: Leila Gholizadeh, Michelle DiGiacomo, Patricia Davidson

Gusharan Singh
Title: The role of palliative care in heart failure.
Supervisor: Phillip Newton, Patricia Davidson

Olutoyin Sowole
Title: West African migrant women in Australia: Stories of resilience and strength.
Supervisors: Michelle DiGiacomo, Tamara Power, Debra Jackson, Patricia Davidson

Claudia Virdun
Title: Developing and pilot-testing person-centred quality improvement measures to improve endof-life care in Australia's acute care system.
Supervisors: Jane Phillips, Tim Luckett, Patricia Davidson, Karl Lorenz

Jeffrey Vongmany
Title: Exploring clinically effective and ineffective family interactions to improve chronic disease management in non-communicable diseases. Supervisor: Jane Phillips, Tim Luckett

Paul Warner
Title: Community based screening program: Impact on healthy utilisation and cardiovascular risk perception.
Supervisors: Patricia Davidson, Phillip Newton

Aileen Wyllie
Title: The early career academic nurse: using a customised self-directed program as a mechanism for critical reflection and career planning.
Supervisors: Michelle DiGiacomo, Tracy Levett-Jones, Patricia Davidson

Xiangfeng Xu
Title: Developing a cultural diversity care model for Chinese-Australian cancer patients on cancer pain management: a mixed methods study.
Supervisors: Jane Phillips, Tim Luckett, Melanie Lovell

Other universities

Priyanka Bhattarai (UNDA)
Title: Using digital health technology to optimise older people's pain self-management capabilities: a mixed methods project. Supervisors: Jane Phillips, Toby Newton-John

Philippa Cahill (UNDA)
Title: Family meetings in palliative care.
Supervisors: Jane Phillips, Liz Lobb, Chris Sanderson

Helen Dick (UQ)
Title: Grief and loss for staff working in residential aged care facilities
Supervisors: Neil Pembroke, Deborah Parker

Diana Ferreria (Flinders)
Title: Building the evidence for the use of regular, low-dose, extended-release morphine for chronic breathlessness in Chronic Obstructive Pulmonary Disease. Supervisors: David Currow, Jane Phillips

Megan Jeon (UNSW)
Title: Sleep disturbance in patients with brain tumours and their family caregivers: Building evidence for an effective intervention.
Supervisors: Meera Agar, Haryana Dhillon, Lawrence Lam

Nicole Heneka (UNDA)
Title: Knowledge translation intervention to reduce opioid medication errors in adult oncology and palliative care.
Supervisors Jane Phillips, Tim Shaw, Debra Rowlett, Sam Lapkin

Helen Holloway (UQ)
Title: Pain identification, assessment and management in residential aged care
Supervisors: Helen McCutcheon, Deborah Parker

Kirstin Maltby (UNDA) (on leave)
Title: Sleep in palliative care patients and their caregivers.
Supervisors: Jane Phillips, Liz Lobb

Nikki Mellor (WSU)
Title: Personal and professional grief of nurses working in acute care
Supervisors: Deb Hatcher, Athena Sheehan, Deborah Parker

Emily Stone (USYD)
Title: Multi-disciplinary care planning for people newly diagnosed with lung cancer.
Supervisors: Tim Shaw, Jane Phillips, Nicole Rankin, David Currow

Ninik Yunitri (UMJ)
Title: Mental Health intervention among high school students in Indonesia.
Supervisors: Lawrence Lam, Mary K Lam

Masters completion (2017)

Elizabeth Lewis
Title: Dyspnoea: Design for the coxswain in the mind.
Supervisors: Vasilije Kokotovich, Tim Luckett, Patricia Davidson, Rebecca Disler

Honours Completions (2017): First Class

Kevin Koo

Title: Evidence and patient and clinician perspectives on invasive transthoracic telemonitoring in heart failure

Supervisors: Sally Inglis, Caleb Ferguson, Sara Lal

NSW Health PhD Scholarship Program

In 2017 Three PhD Candidates were awarded a NSW Health PhD Scholarship. The Program aims to: Develop the capability and skill of the PhD candidate: build capacity in areas of identified need; improve efficiencies in the delivery of population health, health services and clinical care in NSW; provide support to projects that transfer and scale best practice processes in the health system; and enhance health and medical research capability within the NSW health system.

Jessica Lee: Improving outcomes for people living with neuropathic cancer pain

The project will develop a cohesive strategy to enable people living with cancer, their carers and health providers to use proven methods to better manage cancer nerve pain. Cancer nerve pain stops people from participating in society by causing worse physical, cognitive and social function.

Even for those who see a doctor, cancer pain is inadequately controlled over half the time. Half of all people in NSW will be diagnosed with cancer by age 85. Over two-thirds of people with advanced cancer experience pain. This project will involve meeting with key people and organisations to effect health service change. Research will be conducted into the patient and carer experience of having poorly controlled cancer nerve pain and whether their care was evidence-based.

Use of drug and non-drug methods will be explored. A clinical trial will be conducted to explore a promising treatment of lignocaine, a local anaesthetic, used as an infusion for cancer nerve pain. The project will use a national database with over 100,000 encounters to target interventions where greatest impact is expected. Priority populations such as people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander communities, older Australians, carers, people experiencing socio-economic disadvantage, those living in rural locations and those living with a mental illness will be intentionally included. These populations have traditionally not been well captured within research due to additional logistical requirements. The findings will be put into practice and shared through media, consumer organisations and government.

Julee McDonagh: The frailty measurement in heart failure (FRAME-HF) study

The frailty measurement in heart failure (FRAME-HF) project aims to improve the care of heart failure patients. It has been discovered in the last decade that a large proportion of heart failure patients are also frail. Frailty is defined as a syndrome of an increased vulnerability to acute stressors such as; infection, falls or hospitalisation. An individual who is frail is less able to overcome these stressors than an individual who is non-frail.

Frailty in heart failure patients is linked to a significantly higher rate of hospitalisation and death. If heart failure patients who are frail can be identified earlier, solutions can be put in place to try and improve their frailty.

The project will compare four different measurement tools used to assess frailty in the form of a clinical study currently taking place at St Vincent's Hospital Sydney. The aim is to find out which is the most accurate and reliable tool for use in patients with heart failure. This study aims to provide a reliable and validated measurement tool to assess frailty in individuals with heart failure.

Christine Sanderson: Mixed methods investigation of doctors' moral distress in end-of-life decision-making: the case of patients dying with cognitive impairment in acute hospital settings

Doctors often care for dying patients who are cognitively impaired, and cannot make their own decisions. Impairment may be due to dementia, to delirium which is very common when people are extremely sick, or other medical conditions. This situation is common in hospitals, especially when dying older people are transferred from nursing homes. Hospital care processes are complex, involving many different teams, with intense emotions for families when their relative is dying.

This results in competing pressures on individual doctors. Understanding how doctors deal with this, and how it affects their decision-making, may provide a better understanding of why particular treatment decisions are made for such patients, and why things sometimes seem to go wrong.

A national online survey of doctors will assess this problem from doctors' own perspectives. A longitudinal study will follow up a group of doctors from early in their careers, exploring their experiences with in-depth interviews. The same doctors will be reinterviewed 2 - 3 years later, to see how they have adapted and coped, what support they have wanted or used, and what they have learnt. Finally, a series of case studies will be done, where the researcher follows individual patients in real time as they go through the hospital system, observing decision-making processes and conversations as they unfold, in order to provide an accurate depiction of end of life decision-making for these very vulnerable patients.

Improving care for cognitively impaired dying patients in hospitals may require culture change. This study will help to inform that change, contributing to education and support for doctors, to support them in providing best care for their most vulnerable patients.

PUBLICATIONS

Book Chapters

1. **Phillips, J.L.,** Virdun, C, Bhattarai, P., & Fraser, C. Nursing and palliative care. In MacLeod, R., & Van den Block, L. (Eds.), *Textbook of Palliative Care*, Springer. (Accepted, 24 Nov 2017, in press).
2. **Lam LT**. (2017). Mental Health Literacy of Internet Addiction. In Adams, M. (Ed), *Computer and Internet Use: Attitudes, Impacts and Current Issues.* New York: Hauppauge.
3. **Lam LT.** Parental Mental Health and Internet Addiction in Adolescents. In K.S. Young & C Nabuco de Abreu (Eds), *Internet Addiction in Children and Adolescents: Risk Factors, Treatment, and Prevention,* New York*:* Springer. (Accepted 2017, in press).
4. **Luckett, T**., **Agar, M**., & **Phillips, J.L**. Palliative care in chronic illness and multimorbidity. In MacLeod, R., & Van den Block, L. (Eds.), *Textbook of Palliative Care*, Springer. (Accepted, 6 June 2017, in press).

Journal Articles

5. Aapro, M., Scotte, F., Bouillet, T., **Currow, D.C**., & Vigano, A. (2017). A practical approach to fatigue management in colorectal cancer. *Clinical Colorectal Cancer, 16*(4), 275-285.
6. **Agar, M.R.**, Lawlor, P., Quinn, S., Draper, B., Caplan, G., Rowett, D., Sanderson, C., Hardy, J., Le, B., Eckermann, S., Mccaffrey, N., **Devilee, L., Fazekas, B.**, Hill, M., & **Currow, D.C.** (2017). Efficacy of oral risperidone, haloperidol, or placebo for symptoms of delirium among patients in palliative care a randomized clinical trial. *JAMA Internal Medicine, 177*(1), 34-42.
7. **Agar, M.R.**, **Luckett, T.**, Luscombe, G., **Phillips, J.L.**, Beattie, E., Pond, D., Mitchell, G., **Davidson, P.M.,** Cook, J., Brooks, D., Houltram, J., Goodall, S., & Chenoweth, L. (2017). Effects of facilitated family case conferencing for advanced dementia: A cluster randomised clinical trial. *PLoS ONE, 12*(8), e0181020.
8. **Agar, M.R.**, Draper, B., & Caplan, G.A. (2017). Neuroleptics for delirium: More research is needed Reply. *JAMA Internal Medicine, 177*(7), 1055-1056.
9. **Agar, M.R.**, Lawlor, P.G., Quinn, S., Draper, B., Caplan, G.A., Rowett, D., Sanderson, C., Hardy, J., Le, B., Eckermann, S., McCaffrey, N., **Devilee, L**., **Fazekas, B.**, Hill, M., & **Currow, D.C.** (2017). Efficacy of oral risperidone, haloperidol, or placebo for symptoms of delirium among patients in palliative care: A randomized clinical trial. *JAMA Internal Medicine 177*(1), 34-42.
10. Ahmadi, Z., **Currow, D.C**., & Ekstrom, M. (2017). The need for greater opioid pharmacovigilance in COPD -Reply. *International Journal of Chronic Obstructive Pulmonary Disease, 12*, 191-192.

11. Ahmadi, Z., **Currow, D.C**., & Ekström, M. (2017a). Palliative oxygen for chronic breathlessness: What new evidence? *Current opinion in supportive and palliative care, 11*(3), 159-164.

12. Barbetta, C., **Currow, D.C**., & Johnson, M.J. (2017). Non-opioid medications for the relief of chronic breathlessness: Current evidence. *Expert Review of Respiratory Medicine, 11*(4), 333-341.

13. Blay, N., Roche, M., Duffield, C., & **Xu, X.** (2017). Intra-hospital transfers and adverse patient outcomes: An analysis of administrative health data. *Journal of Clinical Nursing, 26*(23-24), 4927–4935.

14. Bhattarai, P., Newton-John, T., & **Phillips, J.L.** (2017). Quality and usability of arthritic pain self-management apps for older adults: A systematic review. *Pain medicine* [Epub] doi:10.1093/pm/pnx090.

15. Bhattarai, P., & **Phillips, J.L.** (2017). The role of digital health technologies in management of pain in older people: An integrative review. *Archives of Gerontology and Geriatrics, 68*, 1424.

16. Boland, J.W., Allgar, V., Boland, E.G., Oviasu, O., **Agar, M.R.**, **Currow, D.C**., & Johnson, M.J. (2017). Effect of opioids and benzodiazepines on clinical outcomes in patients receiving palliative care: An exploratory analysis. *Journal of Palliative Medicine*, *20*(11), 1274-1279.

17. Boyce, M., **Lam, L.,** Chang, F., Mahant, N., Fung, V., & Bradnam, L. (2017). Validation of fear of falling and balance confidence assessment scales in persons with dystonia. *Journal of Neurologic Physical Therapy*, *41*(4), 239-244.

18. Brown, N., **Luckett, T.**, **Davidson, P.M., & DiGiacomo, M.** (2017). Family-focussed interventions to reduce harm from smoking in primary school-aged children: A systematic review of evaluative studies. *Preventive Medicine, 101*, 117-125.

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118. Tervonen, H.E., Morrell, S., Aranda, S., Roder, D., You, H., Niyonsenga, T., Walton, R., Baker, D., & **Currow, D.C.** (2017). The impact of geographic unit of analysis on socioeconomic inequalities in cancer survival and distant summary stage - a population based study. *Australian and New Zealand Journal of Public Health, 41*(2), 130-136.

119. Tervonen, H.E., Roder, D., Morrell, S., You, H., & **Currow, D.C.** (2017). Does exclusion of cancers registered only from death-certificate information diminish socio-demographic disparities in recorded survival? *Cancer Epidemiology, 48*, 70-77.

120. Tervonen, H.E., Walton, R., You, H., Baker, D., Roder, D., **Currow, D.C**., & Aranda, S. (2017). After accounting for competing causes of death and more advanced stage, do Aboriginal and Torres Strait Islander peoples with cancer still have worse survival? A population-based cohort study in New South Wales. *BMC Cancer, 17*(1), 398-398.

121. To, T.H.M., Leblanc, T.W., Eastman, P., Neoh, K., **Agar, M.R.**, To, L.B., Rowett, D., Vandersman, Z., & **Currow, D.C.** (2017). The prospective evaluation of the net effect of red blood cell transfusions in routine provision of palliative care. *Journal of Palliative Medicine, 20*(10), 1152-1157.

122. To, T.H.M., Tait, P., Morgan, D.D., Tieman, J.J., Crawford, G., Michelmore, A., **Currow, D.C**., & Swetenham, K. (2017). Case conferencing for palliative care patients - a survey of South Australian general practitioners. *Australian Journal of Primary Health, 23*(5), 458-463.

123. Virdun, C., **Luckett, T.**, Lorenz, K., **Davidson, P.M., & Phillips, J.L.** (2017). Analyzing consumer priorities for hospital end-of-life care using a systematic review to inform policy and practice. *SAGE Research Methods Cases*. [Epub] doi:10.4135/9781526424884

124. Virdun, C., **Luckett, T.**, Lorenz, K., **Davidson, P.M., & Phillips, J.L.** (2017). Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliative Medicine, 31*(7), 587-601.

125. Vongmany, J., **Luckett, T.**, **Lam. L.T., & Phillips, J.L.** (2017). Family behaviours that have an impact on the self-management activities of adults living with type 2 diabetes: A systematic review and meta-synthesis. *Diabetic Medicine,* [Epub] doi:10.1111/dme.13547.

126. Walczak, A., Butow, P.N., Tattersall, M.H.N., **Davidson, P.M.,** Young, J., Epstein, R.M., Costa, D.S.J., & Clayton, J.M. (2017). Encouraging early discussion of life expectancy and end-of-life care: A randomised controlled trial of a nurse-led communication support program for patients and caregivers. *International Journal of Nursing Studies, 67*, 31-40.

127. Xu, X.(R)., **Luckett, T.,** Wang, A., Lovell, M., & **Phillips, J.L.** (2017). Cancer pain management needs and perspectives of patients from Chinese backgrounds: A systematic review of the Chinese and English literature. *Asia-Pacific Journal of Clinical Oncology*, [Epub] doi: 10.1017/S1478951517001171.

128. Xu X., Hall JJ., Byles JE., Shi Z. (2017). Dietary patterns, dietary lead exposure and hypertension in the older Chinese population. *Asia Pacific Journal of Clinical Nutrition*, [Epub] doi:10.6133/apjcn.032017.20

129. **Xu, X.**, **Parker, D., Ferguson, C**., & Hickman, L. (2017). Where is the nurse in nutritional care? *Contemporary Nurse, 53(3),* 267-270.

130. Zwar, N., Hermiz, O., Halcomb, E., **Davidson, P.M., &** Bodenheimer, T. (2017). Improving blood pressure control in general practice: A pilot study of the impress intervention. *Australian Family Physician, 46*(5), 306-311.

In press

131. Cahill, P.J., **Phillips, J.L.,** Lobb, E.A., & Sanderson, C. (2018). The VOICE study, valuing opinions, individual communication and experience: Building the evidence base for undertaking patient-centred family meetings in palliative care: A mixed methods study. *Pilot and Feasibility Studies,* (In press, accepted Dec 2017).

132. Heneka, N., Shaw, T., Rowett, D., Lapkin, S., & **Phillips.J.L**. (2018). Opioid errors reported in Australian inpatient palliative care services: a retrospective review. *BMJ Supportive and Palliative Care,* (In press, accepted Dec 2017).

133. Ferreira, D., **Currow, D.C**., Lam, L., Boland, J., & **Phillips, J.L**. (2018). The impact of therapeutic opioid agonists on driving-related psychomotor skills assessed by a driving

simulator or an on-road driving task: a systematic review. *Palliative Medicine*, (In press, accepted Nov 2017).

134. Liu H., Hall JJ., **Xu X.,** Zhang M., Wu X., Mishra G., Byles J. (2017) Differences in food and nutrient intakes between Australia- and Asia-born women living in Australia: Results from Australia Longitudinal Study on Women' Health. *Nutrition & Dietetics,* (In press, accepted Dec 2017).

135. Smith, A., Rutherford, C., Butow, P., Olver, I., **Luckett, T.,** Grimison, P., Toner, G, Stockler, M., & King, M. (2018). A systematic review of quantitative observational studies investigating psychological distress in testicular cancer Survivors. *Psycho-Oncology*, (In press, accepted Nov 2017).

136. Virdun, C., **Luckett, T.,** Lorenz, K., & **Phillips, J.L**. (2018) National quality indicators and supporting policies from 15 countries leading in end-of-life care provision for adult populations: A systematic environmental scan. *BMJ Supportive & Palliative Care,* (In press, accepted Dec 2017).

137. Yee, J., Davis, G., Hackett, D., Beith, J., Wilcken, N., **Currow, D.C**., Emery, J., **Phillips, J.L.,** Martin, A., Harrison, M., Segelov, E., Kilbreath, S. (2018). Safety and efficacy of a physical activity program for women with metastatic breast cancer: A randomized controlled trial. *Archives of Physical Medicine and Rehabilitation,* (In press, accepted June 2017).

CONFERENCE PRESENTATIONS

Keynote speaker / Plenary sessions

1. **Currow, D.C.** (2017). *Gaps and the need for evidence-based research in hospice / palliative care***.** International Palliative Care Network Conference, online, 15 November - 15 December 2017.
2. **Currow, D.C.** (2017). *Palliative care, surgery and palliative surgery. Three worlds collide?* Annual Australasian Symposium of Perioperative Medicine, Sydney, NSW, 2-4 November 2017.
3. **Parker, D**. (2017). *Engaging people living with dementia in palliative care research*. Australian Palliative Care Research Colloquium, Melbourne, VIC, 26-27 October 2017.
4. **Phillips, J.L.** (2017). *All you need to know about the methodological insights when conducting palliative care research involving complex populations,* Australian Palliative Care Research Colloquium, Melbourne, VIC, 26-27 October 2017.
5. **Phillips, J.L**. (2017). *Exemplary nursing leadership central to improving care of the dying*, International Nursing Conference 2017, Hong Kong, 19 October 2017.
6. **Phillips, J.L**. (2017). *Translating evidence into practice: the role of the clinical nurse.* Palliative Care Nurses New Zealand Conference, Wellington, New Zealand, 9-10 October 2017.
7. **Currow, D.C**. (2017). *Good clinical governance in cancer care.* International Society of Oncology Pharmacy Professionals Australasian Symposium, 26-27 August 2017, Melbourne, VIC.
8. **Currow, D.C.** (2017). *Measuring what counts: impact, benchmarking and policy*. Asia Pacific Hospice Conference, Singapore, 26-29 July 2017.
9. **Currow, D.C.** (2017). *The evidence for opioids in chronic breathlessness – are we convinced yet?* Asia Pacific Hospice Conference, Singapore, 26-29 July 2017.
10. **Phillips, J.L.** (2017*). Research Collaboration: Lessons from Palliative Care*, Catholic Health Care Australia, Research Conference, 30 June 2017
11. **Phillips, J.L**. *Intersection of policy and practice and how nurses can contribute to this agenda.* Sigma Theta Tau International, Sydney, NSW, 29 June 2017**.**
12. **Currow, D.C.** (2017*). Management of malignant bowel obstruction.* Sapporo Conference for Palliative and Supportive Care in Cancer, Sapporo, Japan, 16-17 June 2017.
13. **Phillips, J.L.** (2017). *From PARHIS with love – measuring successful evidence based guideline implementation*, Cancer Nurses Society of Australia Annual Congress, Adelaide, SA, 17 June 2017.

14. **Phillips, J.L.** (2017*). Giving voice to nursing.* Business and Professional Women's Forum, Coffs Harbour, NSW, 13 June 2017.
15. **Phillips, J.L.** (2017*). Cultural diversity and end of life care.* Diversicare Multicultural Advisory Service Annual Forum, Cairns, QLD, 25 May 2017.
16. **Phillips, J**.**L** (2017*). Projecting our voices – leading the way in shaping the future of patient care.* Nepean Blue Mountains Local Health District Nursing and Midwifery Research and Practice Development Conference, Sydney, NSW, 12 May 2017.
17. **Phillips, J.L**. (2017). *End of Life Care: Promoting dignity and choice,* Australian College of Nursing Policy Summit, Canberra, ACT, 21 April 2017.
18. **Currow, D.C**. (2017). *Why we are not applying what we know?* Innovative Approaches to Optimal Cancer Care in Canada Conference, Toronto, Canada, 7-8 April 2017.
19. **Phillips, J.L.** (2017). *End of life nursing*. Indian Palliative Care Association Conference, Coimbatore, India, 11 February 2017.
20. **Phillips, J.L.** (2017). *Education in palliative care*. Indian Palliative Care Association Conference, Coimbatore, India, 11 February 2017
21. **Phillips, J.L**. (2017). *Research as part of education*. Indian Palliative Care Association Conference, Coimbatore, India, 9 February 2017

Oral

1. Kabir, M., Boland J, Spiller, J., **Agar, M.R.,** Johnson, M., Bush, S., & Lawlor P.G. (2017). *Delirium management by specialists in palliative medicine: A survey of eligible members of the Association of Palliative Medicine (APM) of Great Britain and Ireland.* European Delirium Association 12th Annual Meeting, Oslo, Norway, 16-17 November 2017.
2. Sands, M., Sharma, S., Lujic, S., Carpenter, L., Lee, J.T., Congdon, M., Buchanan, A., **Agar, M.R**., & Vardy, J. (2017). *SQiD: How useful is a single question in helping clinicians detect delirium in hospitalized cancer patients?* European Delirium Association 12th Annual Meeting, Oslo, Norway, 16-17 November 2017.
3. Green, A., Henry, V., Abbott, P., **Davidson, P.M**., Delaney, J., Delaney, P., & **DiGiacomo, M.** (2017). *Re-imagining the service landscape for Aboriginal children with a disability*. NH&MRC & Lowijita Institute Symposium on Research Translation, Brisbane, QLD, 14-15 November 2017.
4. Smith, B., **Agar, M.R**., Delane, G., Descallar, J., Dobell-Brown, K., Grand, M., Aung, J. Patel, P., Kaadan, N., & Girgis, A. (2017). *Cancer research participation by culturally and linguistically diverse patients in south west Sydney from 2006-2016: A retrospective analysis*. Clinical Oncological Society of Australia Annual Scientific Meeting, Sydney, NSW, 13-15 November 2017.
5. **Xu, X.,** Liu H., Byles J.E., Wu, X., Zhang, M., & Hall, J. (2017) *Association between night time sleep and successful aging among Chinese people*. Australian Association of Gerontology. Australian Association of Gerontology, Perth, WA, 8-10 November 2017.

6. **Xu, X.,** Liu H., Byles J.E., Wu, X., Zhang, M., & Hall, J. (2017) *Evaluation of successful aging among older people in China.* Australian Association of Gerontology, Perth, WA, 8-10 November 2017.
7. **Lam, L.T**., Lam, M., & Browne, G. (2017). *Childhood mild traumatic brain injury and mental health service utilisation in New South Wales, Australia: A prospective cohort data-linkage study.* International Federation of Psychiatric Epidemiology Congress. Melbourne, VIC, 17-20 October 2017.
8. Stevens, K., **Parker, D.,** Leahy, A., & Watson, K. (2017). Time Travelling with Technology (TTT): Applying and Evaluating Behavioural and Psychosocial Benefits of Liquid Galaxy-Based Reminiscence Therapy for People with Dementia, *National Institute of Dementia Forum*, Melbourne, VIC, 15-17 October 2017.
9. **Xu, X.,** Perry, L., Gallagher, R., Nicholls, R., Sibbritt, D., & Duffield C. (2017) *Lifestyle health behaviours of nurses: The 'Fit for the Future' survey*. Australian Nursing and Midwifery Conference, Newcastle, NSW, 14-15 September 2017.
10. **Xu, X.,** Perry, L., Dunbabin, J., Lowe, J., Acharya, S., & Steinbeck K. (2017) *Young adult diabetes services usage after transition from paediatric diabetes services.* Australian Nursing and Midwifery Conference, Newcastle, NSW, 14-15 September 2017.
11. **Agar, M.R., Luckett, T.,** Luscombe, G., **Phillips, J.L.,** Beattie, E., Pond, D., Mitchell, G., **Davidson, P.M.,** Cook, J., Brooks, D., Houltram, J., Goodall, S., & Chenoweth, L. (2017). *Case conferencing for aged care residents with advanced dementia*. Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.
12. Clayton, J., Nagarajan, S., Gavin, J., Stokes, J., Rhee, J., **Phillips, J.L.,** Tierman, J., Halcomb, E., Mitchell, G., Detering, K., Morton, R., Lewis, V., Livingston, A., & Shaw, T. (2017). *The Advance Project: Initiating palliative care by training general practice nurses.* Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.
13. Virdun, C., **Luckett, T**., & **Phillips, J.L.** (2017). *Quality measurement of end-of-life care: a review of international approaches.* Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.
14. Tieman, J., & **Parker, D**. (2017). *palliAGED: evidence and practice.* Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017
15. **Ferguson, C.,** Hickman, L., **Phillips, J.L., Newton, P.J., Inglis, S., Lam, L.T., &** Bajorek, B. (2017). *An mhealth intervention to improve nurses' atrial fibrillation and anticoagulation knowledge and practice: The EVICOAG study.* Stroke Society of Australasia 27th Annual Scientific Meeting, Queenstown, New Zealand, 23-25 August 2017.
16. Virdun, C., **Luckett, T**., & **Phillips, J.L.** (2017). *End-of-life care in hospitals: Utilising patient and family identified areas of importance as the foundation to make change happen*. Australian College of Nursing National Nursing Forum, Sydney, NSW, 21-23 August 2017.
17. Sands, M., Sharma, S., Carpenter, L., Lee, J.T., Congdon, M., Buchanan, A., Lujic, S., **Agar, M.R**., & Vardy, J. (2017). *SQiD: Can a single question help clinicians identify delirium in*

people in hospital with cancer? World Congress of Psycho-Oncology, Berlin, Germany, 14-18 August 2017.

18. **Inglis S.C.** (2017). *The controversy of remote monitoring in heart failure: What does the evidence say?* Cardiac Society of Australia and New Zealand Annual Scientific Meeting, Perth, WA, 10-13 August 2017.
19. **Newton P.J.,** Reid, C., Si, S., **Davidson, P.M**., Macdonald, P. (2017). *30-day and 12-month outcomes from the NSW Heart Failure Snapshot*. Cardiac Society of Australia and New Zealand Annual Scientific Meeting, Perth, WA, 10-13 August 2017.
20. Halcomb, E., Gavin, J., Stokes, J., Rhee, J., **Phillips, J.L.,** Tieman, J., Mitchell, G., Detering, K., Morton, R., Lewis, V., Livingston, A., Nagarajan, S., Shaw, T., & Clayton, J. (2017). *Initiating palliative care and advance care planning in general practice: The Advance Project.* Primary Health Care Research Conference, Brisbane, QLD, 7-9 August 2017.
21. **Agar, M**., **Hosie, A., &** Lobb, L. (2017). *An interdisciplinary approach to delirium*. Asia Pacific Hospice Conference, Singapore, 26-29 July 2017.
22. **Visser, M**., Kim, J., & Davis, C. (2017). *Emotion recognition and ageing: Comparing a sorting task and a labeling task.* International Society for Research on Emotion Conference, St. Louis, USA, 26-29 July 2017.
23. **Parker, D**. (2017). *Knowledge into practice: Improving advance care planning for older people in Australia.* International Association of Gerontology and Geriatrics 21st World Congress of Gerontology and Geriatrics, San Francisco, USA, 23-27 July 2017
24. Rawlings, D., Miller-Lewis, L., Tieman, J., Sanderson, C., & **Parker, D.** (2017). *MOOCs: Principles, pedagogy and partnering.* Australian & New Zealand Association for Health Professional Educators Conference, Adelaide, SA, 11-14 July 2017.
25. **Phillips, J.L.,** Lovell, M., **Agar, M.R**., Boyle, F., **Davidson, P.M**., **Luckett, T**., **Currow, D.C, Lam, L.T.,** McCaffrey, N., Shaw, T., & Read, A. (2017). *Preliminary site evaluation of the stop cancer pain trial using the PARIHS framework*. International Conference on Cancer Nursing, Anaheim, USA, 9-12 July 2017.
26. **Phillips, J.L., Luckett, T., & Kochovska, S.** (2017). *Employment and financial needs of working age people facing an expected premature death and their families: A systematic review*. International Conference on Cancer Nursing, Anaheim, USA, 9-12 July 2017.
27. Virdun, C., **Phillips, J.L., & Luckett, T.** (2017). *Hospital end-of-life care: Using consumer identified areas of importance to improve practice.* International Conference on Cancer Nursing, Anaheim, USA, 9-12 July 2017.
28. **Phillips, J.L.**, Lovell, M., **Agar, M.R**., Boyle, F., **Davidson, P.M., Luckett, T**., **Currow, D.C., Lam, L.T.,** McCaffrey, N., Shaw, T., & Read, A. (2017). *From PARHIS with love - measuring successful evidence-based guideline implementation*. Cancer Nurses Society of Australia 20th Annual Congress, Adelaide, SA, 15-17 June 2017.
29. Rawlings, D., Tieman, J., Sanderson, C., **Parker, D**., & Miller-Lewis L. (2017). *Never Say Die: Euphemisms and misunderstandings at the end of life.* Cancer Nurses Society of Australia 20th Annual Congress, Adelaide, SA, 15-17 June 2017.

30. Xu, X.(R)., **Phillips, J.L., Luckett, T**., & Lovell, M. (2017). *Implementing culture care theories and models in practice and research.* Cancer Nurses Society of Australia 20th Annual Congress, Adelaide, SA, 15-17 June 2017.

31. Mileshkin, L., Yoong, J., Nowak, A., Philip, J., Le, B., **Agar, M.R., Phillips, J.L**., Goodall, S., Schofield, P., Ulgade, A., Ball, D., **Currow, D.C,** Stubbin, I., Temel, J., Clark, K., Lorgelly, P., Donoghoe, M., Tognela, A., Livingstone, A., & Stockler, M. (2017). *A randomised phase 3 trial of early referral to palliative care for patients with advanced thoracic malignancies: The PEARL study.* American Society of Clinical Oncology Annual Meeting, Chicago, USA, 2-6 June 2017.

32. **Luckett, T.** (2017). *Case conferencing for aged care residents with advanced dementia.* BaptistCare Aged Care Palliative Care Conference, Sydney, NSW, 25 May 2017.

33. Collier, A., Ward, P., Clark, K., Mccaffrey, N., **Phillips, J.L**., **Currow, D.C**., Kelly, B., & Waller, A. (2017). *The use of benzodiazepines in a specialist palliative care unit: A focused ethnography study.* European Association for Palliative Care 15th World Congress, Madrid, Spain, 18-20 May 2017.

34. **Currow, D.C.,** Ekstrom, M., Fazekas, B., Plummer, J., Quinn, S., McDonald, C., **Agar, M.R.,** Clark, K., Eckermann, S., & Abernethy, A. (2017). *A Phase III, multi-site, randomised, double blind, placebo controlled parallel arm study of daily extended release (ER) morphine for chronic breathlessness.* (Winner, Best Abstract) European Association for Palliative Care 15th World Congress, Madrid, Spain, 18-20 May 2017.

35. Johnson, M., & **Currow, D.C.** (2017). *A new syndrome of chronic breathlessness: Implications for services, research, and health policy.* European Association for Palliative Care 15th World Congress, Madrid, Spain, 18-20 May 2017.

36. Clayton, J., Halcomb, E., Gavin, J., Stokes, J., **Phillips, J.L**., Tierman, J., Mitchell, G., Detering, K., Morton, R., Lewis, V.L., A., Shaw, T., & Rhee, J. (2017). *The Advance Project: Initiating palliative care and advance care planning: Training and resources for general practice nurses.* Australian Primary Health Care Nurses Association Conference, Hobart, TAS, 4-6 May 2017.

37. Forber, J., **DiGiacomo, M.,** Carter, B., **Davidson, P.M**., **Phillips, J.L., &** Jackson, D. (2017). *Undergraduate nurse clinical education: an appreciative dialogue to explore innovative approaches.* Royal College of Nursing International Nursing Research Conference, Oxford, UK, 5-7 April 2017.

38. Jha, S., Hannu, M., **Newton, P.J**., Wilhelm, K., Hayward, C., Kotlyar, E., Keogh, A., Dhital, K., Connellan, M., Montgomery, E., Smith, A., Harkess, M., **Davidson, P.M., &** Macdonald, P. (2017). *Reversibility of Fried's frailty domains post-intervention among patients with advanced heart failure.* European Society of Cardiology Heart Failure Conference, Paris, France, 29 April-2 May 2017.

39. Maneze, D., Ramjan, L., **DiGiacomo, M**., Everett, B., **Davidson, P.M., &** Salamonson, Y.

(2017). *Negotiating health and chronic illness in Filipino-Australians: A qualitative study with implications for health promotion*. World Congress on Public Health, Melbourne, VIC, 3-7 April 2017

40. Stone, E., Rankin, N., Bewes, T., Kerr, S., **Phillips, J.L.,** Fong, K., **Currow, D.C., &** Shaw, T. (2017). *MDT v non-MDT care in lung cancer: does co-morbidity status have an impact?* Thoracic Society of Australia and New Zealand Annual Scientific Meeting, Canberra, ACT, 25-28 March 2017.

41. **Newton, P.J.** (2017). *Heart failure snapshot.* Australasian Cardiovascular Nursing Council Conference, Brisbane, QLD, 10-11 March 2017.

42. **Visser, M**., Kim, J., & Davis, C. (2017). *The effect of ageing on the perception of cues for uncertainty*. Society for Applied Research in Memory and Cognition Conference, Sydney, NSW, 3-6 January 2017.

Posters

1. **Luckett, T, Phillips, J.L,** Johnson, M., Farquhar, M., Swan, F., Assen, T., Bhattarai, P., & Booth, S. (2017). *Contributions of a hand-held fan to self-management of chronic breathlessness*. International Palliative Care Network Conference, online, 15 November - 15 December 2017. (Best poster award)

2. **Kochovska, S., Luckett, T., Agar, M.R., & Phillips, J.L.** (2017) *Impacts on employment, finances and lifestyle for working age people facing an expected premature death: A systematic review.* Clinical Oncological Society of Australia Annual Scientific Meeting, Sydney, NSW, 13-15 November 2017.

3. **Luckett, T., Agar, M.R, DiGiacomo, M., Ferguson, C., Lam, L., Newton, P.J,** & **Phillips, J.L**. (2017) *Predictors of health status in South Australians caring for people with cancer: a population-based study.* Clinical Oncological Society of Australia Annual Scientific Meeting, Sydney, NSW, 13-15 November 2017.

4. Xu, X.(R)., **Phillips, J.L**., **Luckett, T**., Lovell, M., & Wang A. (2017). *Cultural influences on pain-related perspectives, beliefs & needs of cancer patients from Chinese backgrounds: A systematic review of Chinese & English language research literatures.* Clinical Oncological Society of Australia Annual Scientific Meeting, Sydney, NSW, 13-15 November 2017.

5. Halkett, G., Lobb, E., **Phillips, J.L.,** Miller, L., Hudson, P., Tsoi, D., Long, A., King, A., Clarke, J., Attwood, R., & Nowak, A. (2017). *Unpacking the CARE-IS intervention: what is covered during the structured nurse-led home based support and education programme for carers of people with high grade glioma*. Cooperative Trials Group for Neuro-Oncology Annual Scientific Meeting: Tailoring Therapies for Brain Tumours: Challenges and Opportunities, Melbourne, VIC, 23-24 October 2017.

6. **Hosie, A., Phillips, J., Kochovska, S**., **Lam, L.T,** Brassil, M., Noble, B., Kurrle, S., Cumming, A., Caplan, G.A., Chye, R., Le, B., Ely, E.W., Lawlor, P.G., Bush, S.H., Davis, J.M, Lovell, M., Brown, L., Fazekas, B., Cheah, S.L. Edwards, L., & **Agar, M.R.** (2017). *Multicomponent non-pharmacological intervention to prevent delirium for hospitalised people with advanced cancer: a phase II cluster randomised waitlist controlled trial*, Palliative Care Nurses New Zealand Conference, Wellington, New Zealand, 9-10 October 2017.

7. Rhee, J., Nagarajan, S., Gavin, J., Stokes, J., Detering, K., Halcomb, E., **Phillips, J.L.,** Tieman, J., Mitchell, G., Morton, R., Lewis, V., Livingston, A., Shaw, T., & Clayton, J. (2017). *The Advance Project: Training general practice nurses to initiate advance care planning.* International Society of Advance Care Planning & End of Life Care Conference, Banff, Canada, 6-9 September 2017.

8. Lovell, M., **Phillips, J.L., Agar, M.R., Luckett, T**., Read, A. (2017). *Stop Cancer PAIN Trial Lessons learned on implementing best-practice pain care.* Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.

9. **Luckett, T**., **Phillips, J.L.,** Chenoweth, L., Brooks, D., Cook, J., Mitchell, G., Pond, D., Beattie, E., **Davidson, P.M**., Luscombe, G., Goodall, S., & **Agar, M.R**. (2017). *Implementing facilitated case conferencing for people living in aged care with advanced dementia - benefits, barriers and facilitators*. Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.

10. **Luckett, T**., **Phillips, J.L.,** Johnson, M., Farquhar, M., Swan, F., Bhattarai, P., Assen, T., & Booth, S. (2017). *Contributions of a hand-held fan to self-management of chronic breathlessness.* Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.

11. Virdun, C., **Luckett, T**., & **Phillips, J.L.** (2017) *Hospital end-of-life care: Strengthening improvements through connecting with consumers.* Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.

12. Virdun, C., **Luckett, T**., & **Phillips, J.L.** (2017) *Quality measurement of end-of-life care: a review of international approaches.* Australian Palliative Care Conference, Adelaide, SA, 6-8 September 2017.

13. **Ferguson, C.,** Hickman, L., **Phillips, J.L.**, **Newton, P.J., Inglis, S., Lam, L.T., &** Bajorek, B. (2017). *Exploring the acute care registered nurses' contribution in anticoagulation decision making for stroke prevention in atrial fibrillation*. Stroke Society of Australasia 27th Annual Scientific Meeting, Queenstown, New Zealand, 23-25 August 2017.

14. Lovell, M., **Agar, M.R., Phillips, J.L., Luckett, T**., Read, A. (2017). *Touching the void: Bridging the chasm between clinical guideline development and local site implementation.* Asia Pacific Hospice Conference 2017, Singapore, 26-29 July 2017.

15. Durepos, P., Sussman, T., Kaasalainen, S., Ploeg, J., **Parker, D., &** Thompson, G. (2017). *Assessing family care conferences in long term care: Lessons learned from content analysis.* International Association of Gerontology and Geriatrics 21st World Congress of Gerontology and Geriatrics, San Francisco, USA, 23-27 July 2017.

16. Durepos, P., Sussman, T., Kaasalainen, S., Ploeg, J., **Parker, D., &** Thompson, G. (2017). *Characteristics of residents in need and family perception of family care conferences in long term care.* International Association of Gerontology and Geriatrics 21st World Congress of Gerontology and Geriatrics, San Francisco, USA, 23-27 July 2017.

17. Laver, K., Gnanamanickam, E., Ratcliffe, J., Shulver, W., Cameron, I., **Agar, M.R., &** Crotty, M. (2017). *A Citizens Jury to inform policy on rehabilitation for people in residential care for*

hip fracture. International Association of Gerontology and Geriatrics 21st World Congress of Gerontology and Geriatrics, San Francisco, USA, 23-27 July 2017.

18. Minichiello, V., **Phillips, J.L**., **Agar, M.R,** & Scott, J. (2017). *Setting an agenda for social science research on medicinal cannabis in palliative care.* Crime and Justice in Asia and the Global South, Cairns, QLD, 10-13 July 2017.
19. **Currow, D.C**. Temel, J. S., Abernethy, A. P., Friend, J., & Giorgino, R. (2017). *Pooled analysis of two phase III trials: body weight response with anamorelin in advanced non-small cell lung cancer (NSCLC) patients with anorexia / cachexia*, Multinational Association of Supportive Care in Cancer Annual Conference, Washington DC, USA, 22-24 June 2017.
20. Vongmany, J., **Luckett, T., Lam, L.T., & Phillips, J.L**. (2017). *Family behaviours that impact on the capacity of adults living with type 2 diabetes to adhere to their self-management plan: A systematic review and meta-synthesis.* American Diabetes Association 77th Scientific Sessions, San Diego, USA, 9-13 June 2017.
21. **Hosie, A.,** Amgarth-Duff. I, Edwards, L., Siddiqi, N., Featherstone, I., Boland, J., Johnson, M., Lawlor, P., Bush, S., **Agar, M.R,** & **Phillips, J.L.** (2017). *Non-pharmacological delirium interventions for adult inpatients with advanced, progressive illness: a systematic revie*w. American Delirium Society 7th Annual Meeting, Nashville, USA, 4-6 June 2017.
22. Sands, M., Sharma, S., Lujic, S., Carpenter, L., Lee, J.T., Congdon, M., Buchanan, A., **Agar, M.R**., & Vardy, J. (2017). *SQiD: can a single question help clinicians identify delirium in cancer patients?* American Delirium Society 7th Annual Meeting, Nashville, USA, 4-6 June 2017.
23. Disler, R., Cui, Y., **Luckett, T**., Smith, T., Donesky, D., Irving, L., **Currow, D.C.,** Horsfall, L., & Smallwood, N. (2017). *Palliative care nurses' attitudes and perceived barriers to COPDrelated advance care planning: preliminary findings from a cross-sectional survey study*. American Thoracic Society, Washington DC, USA, 19-24 May 2017.
24. Disler, R., Cui, Y., **Luckett, T.,** Smith, T., Donesky, D., Irving, L., **Currow, D.C.,** Horsfall, L., & Smallwood, N. (2017). *Respiratory nurses' knowledge and practice behaviours in COPDrelated advance care planning: preliminary findings from a cross-sectional survey study*. American Thoracic Society, Washington DC, USA, 19-24 May 2017.
25. Disler, R., **Luckett, T**., **Phillips, J.L.,** Johnson, M., Garcia, M., Bhattarai, P., Hutchinson, A., **Currow, D.C**., Carrieri-Kohlman, V., Whelan, B., **Newton, P.J., Agar, M.R.,** Chye, R., Sheehan, C., Ivynian, S., & **Davidson, P.M.** (2017). *Respiratory patient experiences in selfmanaging emergency department 'near-miss' for breathlessness: A strengths-based qualitative study.* American Thoracic Society, Washington DC, USA, 19-24 May 2017.
26. Johnson, M., Allgar, V., Chen, H., Richfield, E., **Currow D.C., &** Macleod, U. (2017). *Construct validation of a palliative care needs assessment tool for use in primary care.* European Association for Palliative Care 15th World Congress, Madrid, Spain, 18-20 May 2017.
27. Lawlor, P., Bush, S., McNamara-Kilian, M., Momoli, F., Tierney, S., Lacaze-Masmonteil, N., Dasgupta, M., **Agar, M.R.,** Periera, J., & **Currow, D.C.** (2017). *Efficacy of melatonin to*

prevent delirium in advanced cancer: Feasibility of a double blind, randomised, controlled trial. European Association for Palliative Care 15th World Congress, Madrid, Spain, 18-20 May 2017.

28. Rihari-Thomas, J., **DiGiacomo, M., Phillips, J.L., Newton, P.J., & Davidson, P.M**. (2017). *Physicians' and nurses' perspectives of a rapid response system in an academic health centre: A focus group study* Rapid Response Systems and Medical Emergency Teams 13th International Conference, Chicago, USA, 11-12 May 2017.
29. Prichard, R., **Newton, P.J., Davidson, P.M.,** Goodall, S., Macdonald, P., Zhao, F., & Hayward, C. (2017). *Quality of life in advanced heart failure – disconnect between patients' and clinicians' perceptions, independent of clinician experience.* European Society of Cardiology Heart Failure Conference, Paris, France, 29 April-2 May 2017.
30. Jha, S., Hannu, M., **Newton, P.J.,** Wilhelm, K., Hayward, C., Kotlyar, E., Keogh, A., Dhital, K., Connellan, M., Montgomery, E., Smith, A., Harkess, M., **Davidson, P.M., &** Macdonald, P. (2017). *Changes in Fried's frailty domains post- ventricular-assist device implantation and heart transplantation.* International Conference on Sarcopenia and Frailty, Barcelona, Spain, 27-29 April 2017.
31. Disler, R., Cui, Y., **Luckett, T**., Smith, T., Donesky, D., Irving, L., **Currow, D.C**., Horsfall, L., & Smallwood, N. (2017). *Respiratory nurses' knowledge and practice behaviours in COPDrelated advance care planning: preliminary findings from a cross-sectional survey study* Thoracic Society of Australia and New Zealand Annual Scientific Meeting, Canberra, ACT, 24-28 March 2017.
32. Disler, R., Cui, Y., **Luckett, T**., Smith, T., Donesky, D., Irving, L., **Currow, D.C**., Horsfall, L., & Smallwood, N. (2017). *Palliative care nurses' attitudes and perceived barriers to COPDrelated advance care planning: preliminary findings from a cross-sectional survey study*. Thoracic Society of Australia and New Zealand Annual Scientific Meeting, Canberra, ACT, 24-28 March 2017.

COLLABORATIONS

Stakeholder Engagement

Local (State)

> Australian Cancer Research Foundation Oncology Alliance for the Science of Integrated Survivorship (ACRF OASIS) Centre (MA)
> Blacktown & Mt Druitt Hospitals Sydney (MD, PJN)
> Calvary Health Care Sydney (AH, MA, MD,)
> Cancer Institute NSW (DC)
> Cancer Institute NSW – Translational Cancer Research Network (JLP)
> Camden Palliative Care Unit (AH, JLP, MA)
> Caresearch, Flinders University (DC, DP)
> Central Adelaide Palliative Care Service (AH, JP, MA)
> Flinders University (DC)
> Greater West Aboriginal Health Service (MD)
> Griffith University (AH, MA)
> HammondCare (AH, JLP, MA)
> LiveBetter Community Services (DP).
> Melbourne University (DP)
> NSW Cardiovascular Research Network (PJN, SCI)
> NSW Ministry of Health (MA)
> NSW Nurses Association (CF)
> Palliative Care Outcomes Collaboration (DC)
> Palliative Care Council of South Australia (DC)
> Queensland University of Technology (DP)
> Research in Implementation Science and eHealth (RISe), Sydney University (JLP)
> Rotary Club of Sydney (XX)
> South Eastern Sydney Translational Cancer Research Network, University of New South Wales (MA)
> Southern Adelaide Palliative Care Service (DC, JLP, MA)
> SPHERE - Sydney Partnership for Health, Education, Research and Enterprise
    - Aboriginal Health & Wellbeing Clinical Academic Group (MD)
    - Age and Ageing Clinical Academic Group (DP, JLP, MA)
    - Early Life Determinants of Health Clinical Academic Group (MD)
    - Cancer Clinical Academic Group (JLP, MA)
    - Mindgardens Clinical Academic Group (MA)

> St Vincent's Hospital and/or Sacred Heart Health Service Sydney (AH, JLP, MA, PJN, SCI, TL)
> South Western Sydney Local Health District Palliative Care Service (MA)
> Translational Cancer Research Network, University of New South Wales (JLP)
> Uniting (DP, MV, XX)
> University of NSW
    - Early life determinants of health: Invest early to make a life time difference (MD)
    - South Western Sydney Clinical School (MA)
> University of Sydney
    - Brain and Mind Centre (MV)
    - School of Medicine (DC, LL)
> War Widows' Guild of Australia (NSW) (MD)
> Western Sydney University
    - MARCS Institute for Brain, Behaviour and Development (DP, MV)
    - School of Nursing and Midwifery (DP)
> Westmead Hospital Sydney (DC, JLP, PJN, TL)

National

> Aged Care Services Australia (DP)
> Alzheimer's Australia (DP)
> Australian Association of Gerontology (XX)
> Australasian Delirium Association (AH, MA)
> Australian and New Zealand Society of Palliative Medicine (DC)
> Australian Commission on Safety and Quality in Health Care (AH, JLP, MA)
> Australian Healthcare and Hospital Association (DP)
> Cancer Council Australia (including NSW) (JLP, TL)
> Cardiac Society of Australia & New Zealand (PJN, SCI)
> Carers Australia (DP)
> Caresearch, Flinders University (DP)
> Catholic Health Australia (DP)
> Leading Aged Services Australia (DP)
    - NHMRC Centre for Research Excellence Cardiovascular Outcomes Improvement (PJN)
    - Peripheral Arterial Disease (SCI)
    - Reduce Inequality in Heart Disease (PJN)
> Palliative Care Australia (DP)
> Palliative Care Clinical Studies Collaborative (AH, DP, JLP, LL, MA, MD, TL)
> Palliative Care Nurses Australia (AH, JLP)
> Stroke Society of Australasia (CF)

PACCSC Clinical Trials Sites

- Barwon Health, Geelong
- Braeside Hospital, Sydney Calvary Health Care Kogarah, Sydney
- Calvary Mater Newcastle Hospital, Newcastle
- Concord Repatriation General Hospital, Sydney
- Flinders Medical Centre, Adelaide
- Hammondcare Greenwich Hospital, Sydney
- Liverpool Hospital, Sydney
- Mater Health Services, Brisbane
- Nambour General Hospital, Sunshine Coast
- Prince Charles Hospital, Brisbane
- Royal Melbourne Hospital, Melbourne
- Sacred Heart Health Service, St Vincent's Hospital, Sydney
- Sir Charles Gairdner Hospital, Perth
- St Vincent's Hospital, Brisbane
- St Vincent's Hospital, Melbourne
- The Austin Hospital, Melbourne
- The Queen Elizabeth Hospital, Adelaide
- Westmead Hospital, Sydney

International

- Asia Pacific Hospice and Palliative Care Network (DC)
- Bruyère and Ottawa Hospital Research Institutes (AH, JLP, MA)
- Bengbu Medical College, Anhui, China (XX)
- Chinese University of Hong Kong, Hong Kong (LL)
- Cochrane Collaboration (SCI)
- Evangelische Hochschule Dresden (EHS), Germany (AH, JLP, MA, TL)
- Guangxi Medical University, Nanning, China (LL)
- Hong Kong Health Authority
- Hong Kong Polytechnic University, Hong Kong (JLP, TL)
- Huazhong University of Science and Technology, Wuhan, China (LL, JLP)
- Hull York Medical School, University of Hull, UK (DC)
- International Association for the Study of Lung Cancer (DC)
- International Association for Hospice and Palliative Care (DC)
- International Council of Women's Health Issues (MD, PD)
- International Network for Doctoral Education in Nursing (PD)

- Johns Hopkins University, Baltimore, USA (MD, PJN)
- Lancaster University, UK (DP)
- Leiden University Medical Centre, Netherlands (DP)
- Mental Health Association of Hong Kong (LL)
- Mahidol University, Salaya, Thailand (PD)
- McGill University, Montreal, Canada (DP)
- McMaster University, Hamilton, Canada (DP)
- Multinational Association of Supportive Care in Cancer (DC)
- Queens University Belfast, Ireland (DP)
- Stanford Primary Care and Population Health, USA (JLP, TL)
- Sun Yat-sen University, Guangzhou, China (JLP, LL)
- The Education University of Hong Kong, China (LL)
- Tilburg University, The Netherlands (MV)
- University of Basel, Basel, Switzerland (JLP, PJN)
- University of California, San Francisco, USA (JLP, TL)
- University of Cambridge, UK (DC, JLP, TL)
- University of Hertfordshire, UK (JLP, MA, TL)
- University of Ottawa, Canada (AH, MA)
- University of Manitoba, Canada (DP)
- Vanderbilt University, Nashville, USA (AH, MA)
- Vrije Universiteit Brussel, Brussels, Belgium (DP)
- Wolfson Palliative Care Research Centre, University of Hull, UK (AH, DC, JLP, MA, TL)

Adjunct Professors

International

- Prof Sabina De Geest, Professor of Nursing, Institute of Nursing Science, Department Public Health, Faculty of Medicine, University of Basel, Switzerland
- A/Prof Cheryl Dennison Himmelfarb, Health Systems and Outcomes, School of Nursing and
- Director, Office of Science and Innovation, Johns Hopkins University, Baltimore, USA
- Prof Laura Gitlin, Director, Center for Innovative Care in Aging, School of Nursing, Johns Hopkins University, Baltimore, USA
- Prof Thomas Fischer, Prof of Nursing, Evangelische Hochschule Dresden (University of Applied Sciences for Social Work, Education and Care), Dresden, Germany
- Prof Martha Hill, Dean Emerita, School of Nursing, Johns Hopkins University, Baltimore, USA
- Prof Sonja McIlfatrick, Prof in Nursing and Palliative Care, Head of School of Nursing, Ulster University, Newtownabbey, UK

- Prof Cynda Rushton, Prof of Clinical Ethics, Prof of Nursing and Paediatrics, Johns Hopkins University, Baltimore, USA
- Prof Sarah Szanton, Director PhD Program, School of Nursing, Johns Hopkins University, Baltimore, USA
- A/Prof Anne Tetitelman, School of Nursing, University of Pennsylvania, Philadelphia, USA
- Professor Cheryl Westlake, Associate Dean, International and Community Program, Azusa Pacific University, San Diego, USA

National

- Prof Sanchia Aranda, CEO, Cancer Council Australia, Sydney, NSW
- A/Prof Richard Chye, Director, Sacred Heart Health Service, St Vincent's Hospital Sydney, NSW
- A/Prof Katherine Clark, Clinical Director of Palliative Care, Northern Sydney Local Health District, NSW
- Prof Jonathan Golledge, Director, Queensland Research Centre for Peripheral Vascular Disease, James Cook University, Cairns, QLD
- Prof Christopher Hayward, Consultant Cardiologist, St Vincent's Clinic and St Vincent's Private Hospital Sydney, NSW
- Dr Melanie Lovell, Palliative Medicine Physician, Greenwich Hospital, HammondCare, Sydney, NSW
- Prof Peter Macdonald, Medical Director, Heart Transplantation, Senior Staff Cardiologist, St Vincent's Hospital Sydney, and Victor Chang Cardiac Research Institute, Sydney, NSW
- Prof Phillip Newton, Professor of Nursing, Director, Nursing Research Centre, Western Sydney University and Western Sydney Local Health District, NSW
- Prof Abdullah Omari, Head of Vascular Medicine and Staff Specialist, St Vincent's Hospital Sydney, NSW
- Prof Tim Shaw, Prof of eHealth, Director Research in Implementation Science and eHealth Charles Perkins Centre, University of Sydney, NSW

Honorary Associates

- Dr Penelope Abbott, General Practitioner, Sydney West Aboriginal Health Service (SWAHS), Mt Druitt, NSW
- Ms Kimberley Bardsley, Nurse Practitioner, St Vincent's Hospital Sydney, NSW
- Dr Chakra Budhathoki, Assistant Professor, Department of Acute and Chronic Care, School of Nursing, Johns Hopkins University, Baltimore, USA
- Dr Christopher Steer, Medical Oncologist, Border Medical Oncology, NSW

- Dr Michael Chapman, Director of Palliative Care, Canberra Regional Cancer Centre, The Canberra Hospital, ACT
- Mr Joshua Cohen, Palliative Care Transitional Nurse Practitioner, Calvary Health Care Kogarah, NSW
- Mrs Patricia Delaney, Senior Policy Officer, Sydney West Aboriginal Health Service Mt Druitt, NSW
- Dr Huiyun Du, Lecturer, School of Nursing and Midwifery, Flinders University, Adelaide, SA
- Dr Peter Eastman, Palliative Care Consultant, Barwon Health, Melbourne Health, VIC
- Dr Magnus Ekstrom, Consultant, Department of Medicine, Blekinge Hospital, Sweden
- Ms Aine Greene, Clinical Trials Manager, Southern Adelaide Palliative Service, SA
- Dr Terrence Hays, PhD, Associate Professor, Faculty of the Professions (retired), NSW
- Dr Mehrdad Heydari, Research Assistant, Collaborating on projects in Peripheral Arterial Disease, NSW
- Dr Brian Le, Director Palliative Care, Victorian Comprehensive Cancer Centre - The Royal Melbourne Hospital and Peter MacCallum Cancer Centre, VIC
- Dr Peter Martin, Clinical Director, Palliative Care, Barwon Health, VIC
- Dr Valentina Naumovski, Research Fellow/Program Coordinator ImPaCCT, University of New South Wales, Sydney, NSW
- Dr Eugene Salole, Principal, Value-Based Access (Specialists in Market Access and HTA for medical devices & diagnostics), Sydney, NSW
- Dr Caitlin Sheehan, Staff Specialist, Palliative Care, Calvary Health Care, NSW
- Dr Tracy Smith, Staff Specialist, Respiratory Medicine, Westmead Hospital, Sydney, NSW
- Prof Elizabeth (Ibby) Tanner, Geriatrics and Gerontology, Schools of Nursing and Medicine, Johns Hopkins University, Baltimore, USA
- Dr Timothy To, Senior Staff Specialist, Rehabilitation, Aged Care & Palliative Care, Repatriation General Hospital, Adelaide, SA
- Dr Amy Waters, Staff Specialist, Palliative Care, St George Hospital, NSW
- Ms Carol Whitfield, Nurse Practitioner, St Vincent's Hospital Sydney, NSW
- Mr Robert Zecchin, Nursing Unit Manager, Area Cardiac Rehabilitation, NSW

Visiting Scholars

The Centre hosted a number of renowned international visiting scholars and students from collaborating institutions during 2017, further strengthening our ties with our international collaborators. International collaboration is a key aspect of maximising the impact of the research generated by the Centre.

International visitors to the Centre in 2017 were:

A/Prof Hiromichi Matsuoka
Associate Professor, Department of Medicine, Kindai University, Osaka
PaCCSC Visiting Fellow: 1 August 2017 to January 2019 Research

Dr Nathan Davies, Post-Doctoral Research Fellow, National Institute for Health Research (NIHR), School for Primary Research, University College London, UK. 7 March 2017.
Presentation: Managing uncertainty in end-of-life care for people with dementia

A/Prof Tessa Watts, Associate Professor, College of Human and Health Science, Swansea University, Wales; Centre for Ageing and Dementia Research, UK. 31 March 2017.
Presentation: 'They have given me my life back': The impact of access to local multi-professional lymphoedema clinics in Wales, UK.

Prof Marie Bakitas, Marie L. O'Koren Endowed Chair and Professor, School of Nursing and Associate Director, Center for Palliative and Supportive Care, Division of Geriatrics, Gerontology & Palliative Care, University of Alabama at Birmingham, USA. 14 June 2017.

Prof Stein Kaasa, Professor II, Department of Oncology, University of Oslo; Director of the European Palliative Care Research Centre, Faculty of Medicine, Norwegian University of Science and Technology, Trondheim (NTNU), 1 August 2017.
Journal Club for HDR Students and Clinicians

Prof Claire Goodman, Professor of Health Care Research, Centre for Research in Primary and Community Care, University of Hertfordshire, UK. 11 - 15 December 2017.
Presentation: Living and dying with dementia in long term care settings

UTS Academic Collaborative Visits

> Eindhoven University of Technology (TU/e), The Netherlands, 19 December 2017 (MV)

> Tilburg University, The Netherlands, 20 December 2017 (MV)

> Leiden University, The Netherlands, 21 December 2017 (MV)

EXTERNAL ENGAGEMENT

NSW Committees

- Agency for Clinical Innovation, Renal Palliative Care Working Group (JLP)
- Australian Learning and Teaching Council Leadership Capacity Building Project Advisory Group, School of Nursing, Western Sydney University (JLP)
- Cancer Institute NSW, Communities of Practice Working Group (JLP)
- Carrington Care, Board Director (DP)
- Leigh Place, Board Director (DP)
- Heart Foundation NSW Cardiovascular Research Network (MD, PJN, SCI)
- Improving Palliative Care through Clinical Trials (ImPaCCT), Management Advisory Committee (TL, JLP)
- Palliative Care NSW
  - Executive Management Committee (DP)
  - Acting President (July 17-present) (DP)
- SPHERE (Sydney Partnership for Health, Education, Research and Enterprise)
  - Aboriginal Health & Wellbeing Clinical Academic Group (MD)
  - Age and Ageing Clinical Academic Group - Quality of Life, Co-chair (MA)
  - Cancer Clinical Academic Group - Living With and After Cancer, Chair (MA)
  - Early Life Determinants of Health (ELDoH): Invest Early to make a difference Clinical Academic Group (MD)
  - Mindgardens Clinical Academic Group - Steering Committee (MA)
- SWSLHD, PROMPT-Care Clinical Advisory Group (TL)
- Sydney Catalyst, T2 Advisory Group (JLP)
- Translational Cancer Research Network
  - TCRN Executive (JLP)
  - Workforce 2025 Flagship, Co-chair (JLP)

National Committees

- ANZUP Cancer trials group, Quality of Life Subcommittee (TL)
- Australasian Cardiovascular Nurses College
  - Executive Committee (PJN)
  - Scientific Committee (PJN)
- Australian Association of Gerontology
  - Culturally and Linguistically Diverse Special Interest Group (XX)
  - Student and Early Career Professional Development and Events Group (XX)
- Australasian Delirium Association, Management Committee (MA, AH)
- Australasian Palliative Link International, Executive Committee (MA, JLP)
- Australian Adult Cancer Pain Management Guidelines
  - Organising Committee (MA, TL)
  - Working Party (MA, TL, JLP)
- Australian Diabetic Educators Association, Diabetes Research Foundation Council (DC)
- Australian Hartford Consortium of Gerontological Nursing Excellence -Foundation Member (DP, JLP)
- Australian Lung Foundation, national advisory board Supportive and Palliative Care (DC)
- Australian New Zealand Society of Palliative Medicine
  - President (MA)
  - 2019 ASM Conference Committee (Scientific and Organising), Chair (MA)
- Australian Palliative Care Conference 2017, Program Committee (JLP)
- Australian Palliative Care Research Colloquium 2016, Scientific Committee (MA)
- Cancer Australia, National Lung Cancer Steering Committee (JLP)
- Cardiac Society of Australia & New Zealand
  - Board (SCI)
  - Cardiovascular Nurses Council (PJN)
  - Cardiovascular Nurses Council, Chair (SCI)
  - Continuing Professional Development Committee (PJN)
  - Heart Failure Council, Chair (PJN)
  - Professional and Ethical Standards Committee (SCI)
  - Scientific Committee (SCI)
  - Scientific Programming Committee (SCI)
- Caresearch
  - palliAGED National Advisory Group, Chair (DP)
  - National Advisory Group (DP)
- Choosing Wisely Australia, Advisory Committee (MA)
- Clinical Oncology Society Australia Council

- Palliative Care Special Interest Group, Chair (JLP)
- Geriatric Oncology Guideline Working Group, Chair (JLP)
- Geriatric Oncology Research Working Group, Chair (MA)

> Cooperative Trials Group in Neuro-oncology
- Management Advisory Committee (MA)
- Scientific Committee (MA)

> European Delirium Association Board Member (MA)

> Heart Foundation Atrial Fibrillation Guideline Working Group (CF)

> Lung Cancer Foundation, Kylie Johnston Lung Cancer Network Committee (JLP)

> Palliative Care Australia
- National Policy Advisory Committee (DP, JLP, MA)
- National Standards Review Group (MA)
- Review Guide to Palliative Care Service Development Steering Committee (DC, JLP)

> Palliative Care Clinical Studies Collaborative
- Management Advisory Board, Member (JLP)
- Member (AH, DP, JLP, LL, MA, MD)
- Mood and Cognitive Disorder Symptom Node Sub-Committee (AH, Chair - MA)
- Qualitative Sub-committee (MD, JLP)
- Scientific Committee, Member (JLP)
- Trials Management Group, (AH, Chair - JLP)

> Palliative Care Nurses Australia
- President (JLP)
- Committee member (AH, JLP)
- 2018 PCNA Conference Committee & Chair Scientific Committee (JLP)
- Aged Care Special Interest Group, Chair (DP)

> Primary Care Collaborative Cancer Clinical Trials Group, Scientific Committee (AH)

> Psycho-Oncology Cooperative Research Group
- ADAPT Implementation & RCT Working Group (TL)
- Depression Working Group (MA)
- Scientific Committee (MA)

> Royal Australasian College of Physicians
- Adult Medicine Division Council (DC)
- Medicinal Cannabis Reference Group (MA)

> Tele-Trial Project Cancer Cooperative Trials Groups Advisory Committee (JLP)

International Committees

- Asia Pacific Hospice Conference 2017, Scientific Committee (MA)
- iDelirium, Committee Member (AH)
- International Association Hospice Palliative Care, Board member (DC)
- Essential Medications Working Group (DC).
- International Cancer Benchmarking Program Board, Deputy Chair (DC).
- International Conference of Alzheimer's Disease International 2017, Advisory Board (MA)
- International Conference of Indian Association of Palliative Care, Scientific Committee (MA, JLP)
- International Council of Women's Health Issues, Board (MD)
- International Palliative Care Family Carer Research Collaborative, Advocate (DP)
- International Society Nursing Cancer Care
  - Communications Committee (JLP)
  - Policy and Advocacy Committee (JLP)
- Johns Hopkins University, Wellness Steering Committee subgroup on Tobacco Cessation Strategy, Subject matter expert (MD)
- Lien Centre, Duke-National University of Singapore, Scientific Advisory Committee (DC)
- National Health Service, Public Health England, Palliative Care data program Expert Reference Group (DC)
- Sigma (Global Excellence in Nursing) – previously Sigma Theta Thau International (JLP)
- Wellness Steering Committee subgroup on Tobacco Cessation Strategy, Subject matter expert (MD)
- Scientific Committee Wolfson Palliative Care Research Centre, University of Hull, in the UK (DC and JLP - Chair)

APPROVALS & OVERALL COMMENTS – CENTRE ANNUAL REPORT

We wish to acknowledge the support of all our collaborators who have contributed to the work of the Centre and in particular to Professor John Daly, Dean of the Faculty of Health, UTS.

Professor Jane Phillips, RN PhD, FACN
Professor Palliative Nursing, Director IMPACCT
IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation

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UTS

Editor, Journal of Chronic Illness
Editor, Collegian: The Australian Journal of Nursing Practice, Scholarship & Research Editorial Board, International Journal of Palliative Care

Visiting Professor, School of Medicine, Sydney University
Adjunct Professor, School of Nursing, University of Notre Dame Australia - Sydney
Honorary Professor, School of Nursing, Hong Kong Polytechnic University, Hong Kong
Visiting Professor, School of Nursing, Sun Yat-sen University, Guangzhou, China

President, Palliative Care Nurses Australia

30 March 2018