

2019 Annual Report





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Centre Director's Message

The Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) takes real world problems and works collaboratively to develop feasible, affordable and effective solutions. Combining the input of our lived-experience advisors (consumers), with the insights from our clinical experts, industry partners and the depth and breadth of expertise within our academic group, ensures that our research and educational endeavours are grounded in improving what matters most to older people - those living with progressive chronic illnesses and people with palliative care needs.



This year, many of IMPACCT's academics were honoured with a variety of awards, highlighted below and showcased in the Annual Report. One of the most significant achievements was the world's first registration of a medication to manage optimally treated breathlessness, and its subsequent addition to the pharmaceutical benefits scheme list in early 2019 was a major highlight. This significant outcome was the end result of 20 years of breathlessness research led by Professor David Currow and undertaken by the Palliative Care Clinical Studies Collaborative (PaCCSC). On the back of the extensive program of research work, Professor Currow was recognised as Australia's Research Field Leader in Hospice and Palliative Care for 2019.

IMPACCT, in partnership with the Wolfson Palliative Care Research Centre, University of Hull, was successful in securing an inaugural Research England i3 grant funding to strengthen palliative and supportive care research collaborations between our two Centres. Over the next five years, this funding will strengthen our palliative international research endeavours in the areas of breathlessness; delirium; geriatric oncology, palliative care and physical exercise, and social isolation. Most importantly, it will provide numerous collaborative opportunities for the two centres' emerging and mid-career researchers.

During 2019, IMPACCT on-boarded four new postgraduate researchers, including a joint health economics personal research fellow working across the Centre for Health Economics and Research and Evaluation (CHERE) and IMPACCT; and four doctoral students. Each of these postdoctoral research fellows and doctoral students are focussed on an area of scholarship aligned to the Centre's priorities.

We also extended our reach through the addition of a new stream of research focused on cancer survivorship led by Professor Suzanne Chambers AO, Dean Faculty of Health.

As a fully integrated research and education Centre, during 2019 IMPACCT welcomed 26 clinicians from across Australia into our newly created Master of Palliative Care. This new interdisciplinary online course is the first palliative care Masters degree to be offered in New South Wales. The input of our External Advisory Board and wide-ranging consultation has enabled us to develop a suite of palliative care courses that address the needs of industry.

I continue to be in awe of the dedication, commitment and talent of the entire IMPACCT team, who work collaboratively to make a difference to the many people living with a progressive chronic illness and those facing the last year of life. The 2019 Annual Report demonstrates the way in which collectively this team is working to deliver on our promise to ensure best care, every place, and any time.

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



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 health care 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 well-being.
- **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 care settings.

IMPACCT AT A GLANCE

RESEARCH PRODUCTIVITY & CAPACITY BUILDING

144
PUBLICATIONS

141
Peer reviewed manuscripts & publications



3
Book chapters

RESEARCH GRANTS AWARDED





\$2,470,512 IMPACCT-led grants

\$4,379,656 Collaborative grants led by other institutions

41 

HIGHER DEGREE RESEARCH STUDENTS

23 Current 5 Submitted
4 New 9 Other universities

5  UTS academic international collaborative visits 

IMPACCT TEAM

- ▶ 11 Academics
- ▶ 8 Postdoctoral Research Fellows
- ▶ 36 Research Assistants
- ▶ 16 Adjunct Professors
- ▶ 18 Honorary Associates
- ▶ 5 Visiting Scholars



SERVICES TO THE UNIVERSITY & COMMUNITY

32

Editorial roles on peer reviewed journals

114
COMMITTEES



17 International



59 National



23 NSW



15 University

TEACHING & LEARNING



NEW

3 Delivered

Postgraduate Palliative Care

2 Developed

Masters subjects

6

NSW Palliative Care Masterclasses



159

Health Professionals



- ▶ Postgraduate teaching and subject coordination: 2 subjects
- ▶ Undergraduate teaching: 1 subject
- ▶ Guest lectures: 4 subjects

AWARDS & ACHIEVEMENTS

ACHIEVEMENTS



Professor Meera Agar elected as the Palliative Care Australia Board Chair



Professor David's Currow investigator driven research which enabled Mayne Pharmaceuticals to secure Australian Registration of Kapanol for breathlessness and its subsequent PBS listing



Professor David Currow recognised as Australia's Research Field Leader in Hospice and Palliative Care for 2019



Dr Anna Green commenced as Postdoctoral Research Fellow as part of the NHMRC Centre for Research Excellence in Prostate Cancer Survivorship



The combined **Palliative Care Clinical studies collaborative and Cancer Symptom Trials Group Annual Forum** – celebrated its 10th Annual forum



Professor Deborah Parker appointment to the European Associate for Palliative Care (EAPC) Task force on Advanced Care Planning in Dementia



Professor Meera Agar (second left) receiving award at OPCC from Dr Jane Fisher (second right)



Professor David Currow

AWARDS



Professor Meera Agar awarded the Outstanding Teamwork award - Palliative Care Australia's National Palliative Care Awards for her role in the Palliative Care Home Support Packages (PEACH) Program Care Team at South Western Sydney Local Health District



Professor David Currow awarded the University Partnership Award at the Hull University Teaching Hospitals NHS Trust's annual Golden Hearts awards, where he was part of the team taking forward work in chronic breathlessness.



Ms Ingrid Amgarth-Duff awarded an Australian Delirium Associate Award for her delirium related doctoral research



Dr Nicole Heneka awarded the Emerging Research - Palliative Care Australia's National Palliative Care Awards



A/Professor Sally Inglis awarded the Heart Foundation Future Leadership Fellowship



Dr Irina Kinchen's awarded a palliative care health economic Postdoctoral Research Fellowship with CHERE and IMPACCT, plus a 12 month Global Brain Health Institute Atlantic Fellowship, Trinity College, Dublin



Dr Tim Luckett Poster Exhibition Award at the International Association for Hospice and Palliative Care International Palliative Care Network Conference, November 2019.



Dr Luna Xu awarded NSW Cardiovascular Research Network 2019 Travel scholarship to attend 67th Annual Scientific Meeting of the Cardiac Society of Australia and New Zealand and Heart Foundation Postdoctoral Fellowship.



Dr Nicole Heneka receiving Palliative Care Australia's National Care Award – Emerging Researcher



Combined PaCCS and CST 10th Annual Forum: Professor Annmarie Hosie and Andrea Cross, IMPACCT Consumer Advisor

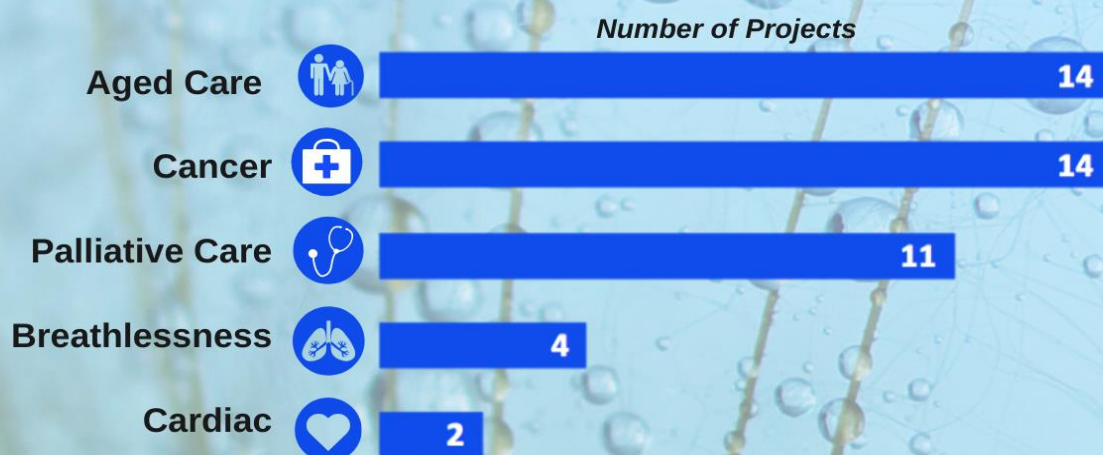
RESEARCH PROJECTS

44

ACTIVE RESEARCH PROJECTS

 **9** New  **35** Continuing

RESEARCH AREAS



WORLD FIRST - MEDICATION LISTED FOR MANAGEMENT OF CHRONIC BREATHLESSNESS

250,000

Living with chronic breathlessness



Crossover study begins

1998

2003

Crossover study published

CLINICAL OBSERVATION

People with breathlessness seem to improve with



MORPHINE

2008

Burden of chronic breathlessness defined

maynepharma



INDUSTRY PARTNERSHIP

5 YEAR STUDY

14 AUSTRALIAN HOSPITALS



2010

Phase 3 clinical trial begins



284 PATIENTS

Dose ranging study published

2011

2014

Phase 3 clinical trial closes

Submission

2018



TGA

Therapeutic Goods Administration

Approval

2019

MEDICINE AVAILABLE

MEDICINE AFFORDABLE

2019

Subsidy

PBS

Pharmaceutical Benefits Scheme



WORLD FIRST REGISTRATION



PUBLICATIONS

144

PUBLICATIONS

141 Peer reviewed manuscripts and publications

3 Book chapters



34

IN TOP 10%
IN TOP
JOURNALS

22

IMPACCT led publications across
9 high impact journals

- > British Medical Journal
- > Cochrane Database of Systematic Reviews
- > European Respiratory Journal
- > Journal of Biomedical Informatics
- > Journal of Pain and Symptom Management
- > Medical Education
- > Nurse Education Today
- > Palliative Medicine
- > Social Science and Medicine

POSTGRADUATE PALLIATIVE CARE COURSE

This course commenced in 2019, and is designed for registered health professionals at any practice level, from any specialty area, wanting to extend their palliative care capabilities. The course prepares students to build clinical performance capabilities, critical decision-making and leadership skills to make a meaning difference to patients and their families anywhere in the world.

We are delivering the course with global leading clinical academic researchers in palliative care at Australia's #1 Uni for Nursing. Students have the flexibility of online teaching, and to learn alongside health professionals from a range of clinical backgrounds to deliver truly multidisciplinary palliative care.

Our external advisory group and industry engagement ensure we are aligning our curriculum to advance the skills to support palliative care needs across a range of health and medical organisations where it is needed most.



Subjects & Number of Students Completed



Delivering Best Palliative Care Any Place Every Time
(21 students)

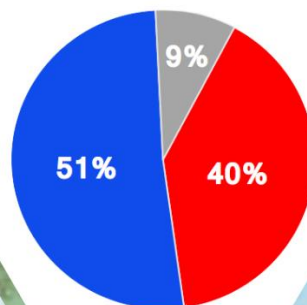


Complex Symptom Management
(38 students)



Communicating and Collaborating for Optimal Person Centred Care
(25 students)

Course Enrolments



- Masters **(18 Students)**
- Graduate Diploma **(14 Students)**
- Graduate Certificate **(3 Students)**

New Subjects Developed

- Immersive Palliative Care Futures 
- Optimising wellbeing for people living with advanced disease



Jane Phillips



Meera Agar



David Currow



Louise Hickman



Michelle DiGiacomo



Deborah Parker



Tim Luckett



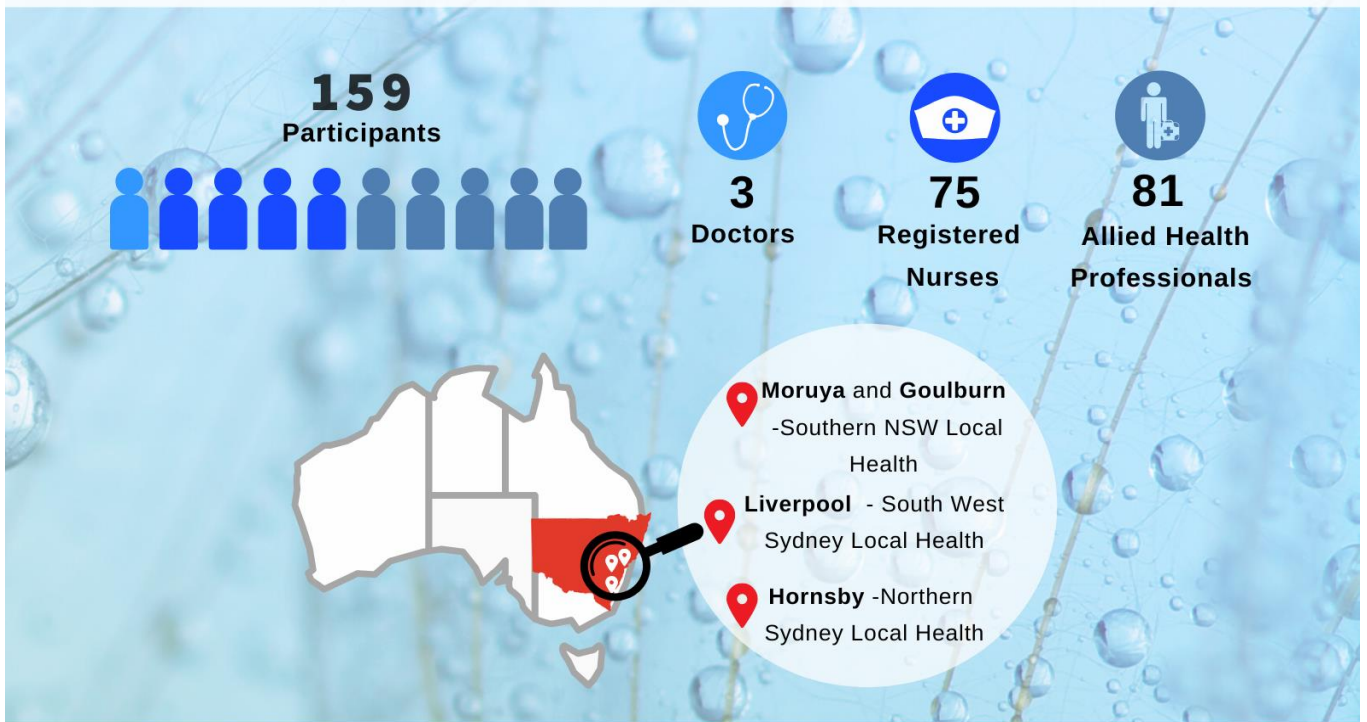
Josh Cohen

Clinical Academic Research Teaching Team

ITERATIVE INDUSTRY ENGAGEMENT HIGHLY CONNECTED INTERDISCIPLINARY EXTERNAL ADVISORY GROUP





MASTERCLASSES


Designed to build palliative care workforce capacity to regional and district areas. The Masterclasses have been developed in consultation with industry leaders from Local Health Districts, with educational content targeted specifically to meet local need.




Masterclasses led by IMPACCT clinical academic team delivering targeted expertise

Classes Delivered


-  Introduction to Palliative Care
-  Advanced Communication Skills in Palliative Care
-  Complex Symptom Management
-  Social Justice Law and Ethics in Aged Palliative Care



Professor Jane Phillips



Professor Meera Agar



A/Prof Nola Ries

OUR COLLABORATIONS

IMPACCT collaborates with a broad range of universities, hospitals and organisations to deliver world class research and clinical trials. Our partnerships are from all over Australia and the world that help develop our student learning and research capacity.

Through this engagement, IMPACCT has the opportunity to translate research in the area of Palliative, Aged and Chronic Care and produce better outcomes for the community.

We are proud of our network of partners and collaborators, and always welcome new opportunities to work with hospitals, research institutes, local health districts, government and international partners.



NSW



National



International

NSW



National



International



OUR EXTERNAL ENGAGEMENT

Our IMPACCT team contribute to many committees, both within UTS and more broadly throughout education and health communities nationally and internationally.

This external engagement provides an opportunity for our staff to work and contribute collaboratively with many of the government, university and health professional organisations that design and guide policy decisions in the Palliative, Aged and Chronic care sector.

IMPACCT Team

Professors

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

IMPACCT Director and Professor of Palliative Nursing



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

Professor Phillips research aims to improve care outcomes for people in the last year of their life by strengthening the nexus between research, education, policy and practice. She has led complex health service reforms, including a number of cancer and palliative care initiatives at local and national levels. She has evaluated non-pharmacological interventions to improve pain, breathlessness and delirium; and health services research designed to improve the care of older people with cancer. Professor Phillips is leading a national project to develop a new model of care for people with palliative care needs in Australian prisons and developing a new rapid response model of care, that better support people with palliative care needs to spend more days at home. She is in the final stages of completing several translational research cancer pain management projects. She has developed and evaluated nurse-coordinated models of palliative care and has extensive experience in cancer and chronic disease nursing and research.

Professor Phillips has been instrumental in establishing UTS and NSW's first online Palliative Care Master, in partnership with IMPACCT clinical academics.

Professor Phillips is a Fellow of the Australian College of Nursing and the current President of Palliative Care Nurses Australia (PCNA). 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. She also holds several academic appointments in the UK, China and Australia and is an Editor as well as on the Editorial Board of several international journals.

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

Professor of Palliative Medicine



Professor Meera Agar is a palliative medicine physician with particular interests in delirium, supportive care needs of people with brain tumours and geriatric oncology. Professor Agar leads a clinical research portfolio at UTS, including clinical trials and health services evaluation in cancer and palliative care. She led a world-first clinical trial of antipsychotics in delirium and is leading New South Wales Government-funded clinical trials of medicinal cannabis for anorexia in people with advanced cancer. A Fellow of the Royal

Australasian College of Physicians, Fellow of the Australasian Chapter of Palliative Medicine, and a clinician scientist, she holds a Masters in Palliative Care. Her doctorate was awarded in the area of delirium in advanced illness.

Professor Agar's research and teaching have won numerous awards, including an Australian Learning and Teaching Council (ALTC) Citation, an Australian Award for University Teaching,

European Associate for Palliative Care (EAPC) Early Career Researcher Award and Dean's Academic Excellence Award for Research Excellence. In 2019, she was also awarded the National Palliative Care Award for *Outstanding Teamwork* for her role in the Palliative Care Home Support Packages (PEACH) Program Care Team at South Western Sydney Local Health District.

Professor Agar is Chair of the ImPaCCT: NSW Advisory Committee and Chair of Cancer Symptom Trials. Professor Agar is on the scientific committees of the Cooperative Trials Group for Neuro-oncology (COGNO), the Psycho-oncology Cooperative Research Group (PoCoG) and the National Health and Medical Research Centre (NHMRC) Cognitive Decline Partnership Centre. She is a Board Member of the European Delirium Association, committee member of the Australasian Delirium Association, on the Clinical Advisory Group for NPS MedicineWise, Chair of the Geriatric Oncology Group for the Clinical Oncological Society of Australia, a member of the Australian Advisory Council on the Medicinal Use of Cannabis and TGA Opioid Regulatory Advisory Group. She is the immediate past President of the Australian and New Zealand Society (ANZSPM) for Palliative Medicine.

In December 2019, Professor Agar was appointed as Chair of the Palliative Care Australia Board.

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 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 with contributions in clinical trials, population-based planning and codifying the evidence base underpinning palliative care. He has published more than 600 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 and a foundation partner in the Australian Palliative Care Outcomes Collaborative (PCOC).

Professor Currow's research track record includes: better understanding and treating chronic breathlessness; Phase II, III and IV clinical trials; population-based planning for palliative care; and codifying the evidence base underpinning palliative care. His success in securing competitive funding has included the National Health and Medical Research Council (NHMRC) and the National Institutes of Health (NIH).

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 co-investigator 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 of Palliative Care NSW, Board Director of Carrington Care and Board Director of Leigh Place. She is an active member of professional organisations supporting palliative care and aged care, a 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 of Cardiovascular Nursing



Professor Patricia Davidson is the Dean of the Johns Hopkins School of Nursing. 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 health and quality of life of underserved populations through the development of innovative, acceptable, and sustainable initiatives. 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.

Lawrence Lam, PhD, MAppPsy, MPH, Grad Dip Biostats, BSc (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 Behavioural Health, which is an affiliated body of the International Society of Behavioural Medicine.

Associate Professors

Michelle DiGiacomo, PhD, MHSc (Hons), BA

Associate Professor (Research)



Associate Professor Michelle DiGiacomo has a background in psychology and her program of research centres on the ways in which people adjust to living with chronic conditions. She primarily uses qualitative and mixed methods approaches that are focused on carers, gendered approaches to health, Aboriginal and Torres Strait Islander peoples and underserved populations. In 2019, she taught into the Masters of Palliative Care and continued to develop subjects that focus on communication. She was a chief investigator on two successful tenders, and began a new collaboration with the Carers Research Centre within the Institute for Public Policy and Governance.

Louise Hickman, PhD, MPH, BN, RN

Associate Professor, Director of Studies, Palliative Care Programs



Associate Professor Louise Hickman current research focus on improving care of vulnerable frail older populations, CVD, chronic disease, cognitive decline, dementia, aged palliative care and translational research that improves care between the acute care sector, community and residential aged care. She brings to her Director of Palliative Care Studies role her in-depth knowledge of the healthcare industry and significant understanding of pedagogy and research in the real-world setting. These attributes enable her to redesign educational opportunities to better address the needs of patients, clinicians and students in contemporary healthcare organisations across and within sectors. Associate Professor Hickman holds leadership positions in four professional associations; National Advisory Group Palliative Care Education and Training Collaborative; the Joanna Briggs Institute, Cardiovascular Expert Reference group; elected executive Palliative Care Nurses Australia; elected committee member of the Xi

Omicron Chapter at Large Sydney STTI International. Associate Professor Hickman is the Editor in Chief of Contemporary Nurse.

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

Associate Professor, Principal Research Fellow

Currently supported by NSW Cardiovascular Research Network Life Sciences Fellowship supported by the Heart Foundation and the NSW Office for Health and 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 heart failure, and the use of mHealth education interventions for people with heart failure, as well as, the epidemiology, management and outcomes of people with peripheral arterial disease. Associate Professor Inglis' research into the use of telemonitoring and structured telephone support has been incorporated into several national and international heart failure guidelines.

Associate 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 Health and Medical Research which is supporting her to continue her program of research to improve outcomes for Australians with chronic cardiovascular disease.

Senior Research Fellows

Sungwon Chang, PhD, MS, BScBM

Senior Research Fellow: Biostatistician



Dr Sungwon Chang is a biostatistician who is building a track record in methodological contribution to statistics and epidemiology. Her methodological skill sets include ensuring soundness of each phase of an epidemiological study to obtain valid answers to the proposed questions. She has more than twenty years of experience in the design and analysis of large epidemiological studies, including health data linkage studies. Sungwon has been a chief or associate investigator on research grants in excess of \$2M in a NHMRC project funding. She is on the editorial board of the Journal of Cardiology and Therapy, and the Critical Care Journal. She is also a statistical reviewer for the Journal of Clinical Nursing. Sungwon is currently teaching epidemiology and global health to undergraduate students.

Tim Lockett, PhD, BSc (Hons)

Senior Research Fellow / Senior Lecturer (Research)



Dr Tim Lockett is a Senior Lecturer in the Faculty of Health at UTS. Dr Lockett's research is aimed at informing improvements to self-management of symptoms including breathlessness and pain. In 2019, Dr Lockett led research projects in the areas of opioid misuse in the cancer context, respiratory symptoms in COPD and lung cancer, wellbeing in carers, and palliative care in residential aged care. Dr Lockett also served as a member of the UTS Human Research Ethics Committee and coordinated a subject for the new Master of Palliative Care.

Irina Kinchin, PhD (Econ), MSc (Health Econ)

Senior Research Fellow: Health Economist



Dr Irina Kinchin is a Senior Research Fellow with a joint appointment at the Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) and the Centre for Health Economics Research and Evaluation (CHERE). The underlying aim of Dr Kinchin's work is to ensure that committed investments are cost-effective and spent in ways leading to greatest improvements in target populations' health and wellbeing. She collaborates extensively with academics, clinicians and decision makers in

building capacity in the knowledge, use and translation of health economics.

In September 2019, Dr Kinchin was awarded an Atlantic Fellowship at the Global Brain Health Institute to join a unique cohort of leaders who are developing the critical skills and brain health knowledge to make transformative change around the globe. She is currently based in Dublin.

Postdoctoral Research Fellows

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.

Dr Anna Green, PhD, MDev, BSocSci

Postdoctoral Research Fellow



Dr Anna Green is a Postdoctoral Research Fellow in the NHMRC Centre for Research Excellence in Prostate Cancer Survivorship (CRE-PCS), based within IMPACCT.

Anna's research interest is health services research for priority populations living with chronic conditions. Her postdoctoral fellowship is focused on better understanding the psychosocial needs of female partners of prostate cancer survivors to inform service design and delivery to support their health and well-being. Her doctoral research focused on access to services and support for Aboriginal children with a disability and their families as part of the ARC Linkage project 'Doubly Disadvantaged'.

Anmarie Hosie, PhD, RN, MPallCareAgeCare, BHlthSc

PaCCSC Postdoctoral Research Fellow



Dr Anmarie Hosie is Postdoctoral Research Fellow, Palliative Care Clinical Trials Collaborative (PaCCSC). From 1999 to 2015, Dr Hosie worked as a clinician in acute, sub-acute, community and residential aged care settings, including in advance nursing practice and coordination roles. Her doctoral research, completed in 2015, contributed to knowledge of delirium epidemiology and the need for interdisciplinary systems to improve its recognition and assessment in inpatient palliative care units. Dr Hosie's postdoctoral research is focused on delirium recognition, prevention and management in advanced illness, and strategies to promote ethical research participation by older people with cognitive impairment. In 2017-18, she co-led the PRESERVE pilot study, a phase II cluster randomised clinical trial of a multi-component non-pharmacological intervention to prevent delirium in people with advanced cancer in four palliative care units. Dr Hosie is a committee member of Palliative Care Nurses Australia and the Australian Delirium Association.

In October 2019, Dr Hosie left IMPACCT to take up a role as Associate Professor, Palliative Care Nursing, The University of Notre Dame, Sydney Australia.

Slavica Kochovska, PhD, MA (Hons 1), BA (Hons)

PaCCSC Postdoctoral Research Fellow



Dr Slavica Kochovska is the inaugural Postdoctoral Research Fellow with the Palliative Care Clinical Studies Collaborative (PaCCS) at IMPACCT. She is an early career researcher whose research focuses on improving the quality of patient-clinician communication at the end of life and the science of consenting in palliative care clinical research. Her research aims to improve communication in the clinical setting by developing novel assessment methods that would facilitate an earlier recognition of the impact of advanced symptoms on people's everyday lives and help facilitate a more systematic and effective recognition of advanced symptom burden on patients, caregivers and the community at large.

Dr Kochovska has an academic background in theoretical linguistics and over ten years' research and teaching experience at both undergraduate and postgraduate level. Her research interests also include health literacy in palliative care, and consumer involvement in healthcare research.

Rayan Saleh Moussa, BMedSci (Hon 1), PhD

CST Postdoctoral Research Fellow (commenced Sep 2019)



Dr Rayan Saleh Moussa is a Cancer Symptom Trials (CST) Postdoctoral Research Fellow. Rayan's research aims to identify cancer symptom interventions that may offer benefit to people living with cancer. She has a strong understanding of drug development from the pre-clinical to clinical phase. Her doctoral degree focused on identifying the molecular mechanisms involved in the regulation of cell cycle proteins in response to novel anti-cancer agents, namely Iron Chelators. Rayan has also managed a range of projects that had clinical implications, specifically in the areas of health promotion, disease prevention, and disease management, in her capacity as a medical writer.

Mandy Visser, PhD, MSc, BSc

Postdoctoral Research Fellow



Dr Mandy Visser 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, Dr Visser 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.

In December 2019, Dr Visser left IMPACCT to take up a Fellowship position, Leiden University, The Netherlands (European Union, co-funded by Horizon 2020 and Marie Curie).

Xiaoyue (Luna) Xu, PhD, MPH, MSc, BN

Postdoctoral Research Fellow, Nursing (Aged care)



Dr Luna Xu is a postdoctoral 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 was awarded a nursing degree in China (2009), Masters by Research in Advanced Nursing study in the United Kingdom (2011), Master of Public Health (2012) and PhD (2016) at the University of Newcastle, Australia.

Dr Xu is an executive member of NSW, Australian Association of Gerontology (AAG), a member of the 2019 AAG Conference planning committee, a member of the 2019 Emerging Researchers in Ageing (ERA) Conference planning committee; and an ECR representative on the UTS Faculty of Health Research Committee. Dr Xu is also an affiliate member of the Cardiovascular Society of Australia and New Zealand (CSANZ), an executive member of the CSANZ Cardiovascular Nursing Council, and she is active in the NSW Cardiovascular Research Network's Rising Stars Network for Early and Mid-Career Researchers.

Dr Xu has attracted \$401,000 of research funding through a combination of funders including: The National Heart Foundation fellowship, Uniting, University of Technology Sydney, University of Newcastle and SPHERE - Age and Ageing Clinical Academic Group. Dr Xu has been working on numbers of projects include the ARC Linkage-funded project and NHMRC Partnership Project-funded projects. Dr Xu has also contributed to various government and non-government report, such as: United Nations, Department of Economic and Social Affairs; World Health Organization, Chinese Center for Disease Control and Prevention and Uniting

Holly Mack, PhD, BS

Postdoctoral Research Fellow



Dr Holly Mack is a Research Fellow in the UTS Faculty of Health working with Professor Deborah Parker. She is currently working on the End of Life Directions for Aged Care (ELDAC), a nationally funded program to improve palliative care and advance care planning for older Australians. Dr Mack has an interdisciplinary research background in Biobehavioural Health focusing on adult development and ageing. She has extensive research experience in Aboriginal health and ageing, cognitive performance, dementia risk factors, genetic epidemiology, quantitative methods, and project management of longitudinal cohort studies.

Ian Flaherty (BA MA PhD)

Postdoctoral Research Fellow



Dr Ian Flaherty is a postdoctoral research fellow in the UTS Faculty of Health working with Professor Deborah Parker. He has been working in health research, mainly investigating the experiences of marginalised groups, injection drug users for example, in navigating the health care system. He has experience in quantitative and qualitative methods, and an interest in participatory action research.

Visiting Adjuncts on Sabbatical

Hiromichi Matsuoka, MBBS, PhD

Adjunct Professor, Honorary



Dr Hiromichi (Hiro) Matsuoka is Associate Professor in the Department of Psychosomatic Medicine, Palliative Care Center, Kindai University Faculty of Medicine, Japan. Dr Matsuoka undertook a sabbatical with the Palliative Care Clinical Studies Collaborative (PaCCSC), IMPACCT, UTS Faculty of Health, from September 2017 to January 2019. During Hiro's sabbatical, his work program included:

- Attachment to the national Palliative Care Clinical Studies Collaborative
- Attachments to the University of Technology Sydney; St Vincent's Hospital and Sacred Heart Health Service
- Working on key sub-studies from the existing program of work from the clinical trials unit
- Working on the project titled: Development of standard medical therapy based on evidence for refractory neuropathic pain in cancer patients.

This has been an exciting opportunity for Dr Matsuoka to broaden his research experience, build collaborations between the Collaborative and our Japanese colleagues at Japanese Organization for Research and Treatment of Cancer (JORTC), and ensure we are taking forward high-quality science in the management of cancer pain.

Thomas Fischer PhD, MPH, Diplom Pflegewirt (FH)

Adjunct Professor, Honorary



Dr Thomas Fischer's work is focused on pain and delirium. His connection with the UTS Faculty of Health was established in 2016 when he was an Endeavour Research Fellow at the former Centre for Cardiovascular and Chronic Care. He is currently Professor of Aged Care Nursing at [Evangelische Hochschule \(ehs\) Dresden](#), University of Applied Sciences in Dresden, Germany. At ehs, Dr Fischer is head of nursing study programs, leads several research projects with a focus on pain and impaired cognition and he is instrumental in developing the

health-related research portfolio at ehs.

He is also chair of the German Pain Society's special interest group on pain in older persons. He is also an editor for the international journal, *Contemporary Nurse*.

IMPACCT Research Support

- > Ingrid Amgarth-Duff, BSc (Hons), PhD candidate, Research Assistant
- > Robyn Attwood, RN, MHM, Clinical Research Nurse, Care-IS
- > Priyanka Bhattarai BNursing (Hons), PhD thesis submitted, Research Assistant
- > Molly Cao, RN, MHM, Research Assistant, Stop PAIN project
- > Kerry Clifford, Project Officer
- > Divya Priya Dakshinamurthy M.Tech Biopharma, Research and Administrative Assistant
- > Domenica DiSalvo, BMedSci (Hons), PhD thesis under review, Research Assistant
- > Layla Edwards, BAppPH, Research Assistant
- > Sally Fielding, RN, MPH, Research Assistant
- > Maja Garcia, BIntSt.BMedSci (Hons), Research Assistant
- > Nicole Heneka, MHumNutr, PhD candidate, Research Assistant
- > Serra Ivynian, BMedSci(Hons), Research Assistant, working with Professor Deborah Parker
- > Michelle Kaczurowski, BSc, Data Assistant
- > Catherine Lambert, GCBA, Executive Assistant
- > Vanessa Moore, (JP NSW), Centre Manager/EA (commenced December 2019)
- > Yinyin Phyo, BBioTech, BBus (Marketing)
- > Linda Richards, BPharm, Project Manager
- > Simone Simonetti, Research Assistant working with Professor Deborah Parker
- > Mariana S. Sousa, BMed, PhD, Research Assistant
- > Charmain Strauss BMedSci (Hons), PhD, Research Assistant
- > Therese Schroeder, BBus, Administrative Assistant
- > Zac Vandersman, Data Manager working with Professor Deborah Parker
- > Claudia Viridun, BN (Hons), MSc, PhD candidate, Research Officer

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 Meer Agar and the Project Officer is Dr Valentina Naumovski.

Valentina Naumovski, GCULT (UNSW), PhD (USYD), BSci (Chem- UNSW), BE Hons (Manuf. Mgt-UNSW)

Senior Research Fellow, University of New South Wales and Honorary Fellow at IMPACCT



Dr Valentina Naumovski is a researcher in the fields of pharmaceutical sciences and pharmacology, with expertise in complementary medicines. She is one of very few researchers in the world with a multidisciplinary approach spanning the cultivation and preparation, analytical (isolating and identifying compounds), pharmacological (mechanism of action, drug interactions, pharmacokinetics) and clinical research of plant material. Currently, she provides organisational leadership as the program coordinator/associate investigator of clinical trials using medicinal cannabis for anorexia in advanced cancer. She is the inaugural Chair of the Appetite and Cachexia Symptom Node Subcommittee under PaCCSC/CST tasked with mapping a program of work to improve anorexia-cachexia syndrome, thus making her research career truly original and translational. She is based at the School of Medicine, University of New South Wales, is a sessional lecturer at the Western Sydney University.

Clinical Trials

IMPACCT is home to two clinical trials collaboratives, the Palliative Care Clinical Studies Collaborative (PaCCSC) and Cancer Symptom Trials (CST). PaCCSC and CST clinical trials are provided with infrastructure support through the IMPACCT Clinical Trials Coordination Centre (ITCC).

PaCCSC is an Australia-wide research network that aims to improve the wellbeing of people with life-limiting illness through:

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

CST is one of fourteen Cancer Cooperative Trials Groups (CCTGs) funded by Cancer Australia. Through clinical trials, CST researchers options for improved management of cancer symptoms by identifying accessible, affordable and appropriate medicines and therapies for people with cancer.

The ITCC supports research teams to undertake high quality clinical-studies and/or clinical-trial support for drugs, non-pharmacological interventions and medical devices. The ITCC will offer University clients the expertise of moving a new drug, intervention, device or health service(s) reform intervention trial from conception to start up, conduct, completion, and dissemination/translation without the research team having to maintain a specialist trial team

PaCCSC and CST Team

Linda Brown MBus, BBus (Mgmt)

PaCCSC/CST National Manager



Linda leads the ITCC and PaCCSC/CST teams to implement the PaCCSC and CST strategic and operational plans working closely with Chairs of the various committees, members, consumers, investigators and staff. She provides professional leadership and management of the research network as well as ongoing development of the research program and oversight of the trials coordination unit. Linda plays a key role in the strategic and operational planning, project management, quality oversight of studies, financial management, governance support, and stakeholder engagement.

PaCCSC and CST Research Support

- > Christine Bassiri, CST Executive Assistant (departed Jun 2019)
- > Louise Fazekas-Giles, Administration Officer (departed September 2019)
- > Linda James, CST Project Officer
- > Debbie Marriot, Executive Assistant
- > Melanie Mora, CST Research Assistant - Writer (departed Sep 2019)

PaCCSC Governance

PaCCSC has been governed by a Management Advisory Board (MAB), a Scientific Committee (SC), a Trials Management Committee (TMC) and study-specific Data and Safety Monitoring Committees. At the end of 2019, it was decided that the MAB and SC would be dissolved, and the responsibilities of these committees would be taken up by a new IMPACCT Committee. The MAB and SAC memberships for 2019 are included below.

Engagement with health professionals, researchers and the general community is a high priority for PaCCSC. We have a diverse national membership and encourage active participation in our research from colleagues and the community.

Management Advisory Board (MAB)

The Management Advisory Board was responsible for the strategic governance of PaCCSC.

- > Emeritus Professor Lloyd Sansom - Chair
- > Professor Meera Agar – Chair, CST
- > Dr Peter Allcroft – ANZSPM Representative
- > Ms Meg Brassil – Consumer Representative
- > Dr Leigh Claase – Therapeutic Guidelines Limited Representative
- > Professor David Currow – PaCCSC Chief Investigator
- > Professor Katy Clark – Site Investigator Representative
- > Emeritus Professor Richard Head – Chair, Scientific Committee
- > Professor Deborah Parker – Chair, Trials Management Committee
- > Professor Jane Phillips – Director, IMPACCT
- > Dr John Primrose – Principal Medical Adviser, Medical Benefits

Scientific Committee (SC)

The Scientific Committee is responsible for the overall review of clinical study proposals and associated ethics applications, publication, dissemination and implementation of study outcomes.

- > Emeritus Professor Richard Head - Chair
- > Professor Meera Agar – Chair, CST
- > Belinda Butcher – Biostatistician
- > Professor David Currow – PaCCSC Chief Investigator
- > Winston Liauw – Clinical Pharmacologist
- > Melanie Lovell – Site Investigator
- > Nikki McCaffrey – Health Economist
- > Professor Deborah Parker – Chair, Trials Management Committee
- > Professor Jane Phillips – Director, IMPACCT
- > Jennifer Philip – Site Investigator and Chair, Qualitative Research Committee
- > Debra Rowett – Clinical Pharmacist
- > Caitlin Sheehan – Site Investigator (Early Career)

Trials Management Committee (TMC)

The Trials Management Committee is responsible for the development, review and oversight of issues specific to each study, including recruitment, outcomes and milestones.

Site representation

- > Sutharsha Kanathigoda, Calvary Bruce, Clare Holland House, ACT
- > Michael Chapman, The Canberra Hospital, ACT
- > Jennifer Philip, St Vincent's Hospital Melbourne, VIC
- > Anu Krishnan, Sir Charles Gairdner Hospital (Perth), WA
- > Peter Allcroft, Southern Adelaide Palliative Care Service, SA
- > Christine McDonald, Austin Health, VIC
- > Caitlin Sheehan, Calvary Health Care Kogarah, NSW
- > Jessica Lee, Concord Hospital, NSW
- > Kwun Fong, The Prince Charles Hospital, QLD
- > Louise Welch, Sunshine Coast University Hospital (Nambour), QLD
- > Melanie Lovell, Greenwich Hospital, NSW
- > Peter Eastman, Barwon Health, VIC
- > Philip Good, Mater Health/St Vincent's Private Hospital (Brisbane), QLD
- > Richard Chye, St Vincent's Hospital Sydney, NSW
- > Katherine Clark, Northern Sydney LHD, NSW
- > Brian Le, Royal Melbourne Hospital, VIC
- > Raj Aggarwal, Liverpool Hospital, NSW
- > Fiona Stafford Bell, Braeside Hospital, NSW

Other members

- > Deborah Parker, Chair, NSW (Deborah stepped down from the role in September, and Jane Phillips took on role)
- > Douglas Bellamy, Nurse Representative (Cancer), NSW
- > <Vacancy>, Nurse Representative (Palliative Care)
- > Richard McNeill, Advanced Trainee Representative, NZ

- > David Currow, PaCCSC Lead Investigator, NSW
- > Meera Agar, CST Chair, NSW
- > Jane Phillips, IMPACCT Director, NSW
- > Annmarie Hosie, PRESERVE Principal Investigator, NSW
- > Linda Brown, PaCCSC/CST National Manager, NSW

Data and Safety Monitoring Committees are independent contracted committee responsible for safety evaluation and determination and reporting of adverse events for all studies conducted by PaCCSC and CST.

CST Governance

CST is governed by a Management Advisory Committee, a Scientific Advisory Committee, study-specific Trial Management Committees and a Data and Safety Monitoring Committee. Engagement with the community is a high priority for CST and consumers play a vital role in ensuring our research is relevant and meaningful to people living with cancer. Management Advisory Committee (MAC)

Management Advisory Committee (MAC)

The Management Advisory Committee is responsible for the strategic governance of CST.

- > Professor Meera Agar – Chair
- > Professor Jane Phillips – IMPACCT Director
- > Professor Jennifer Philip – CST external investigator
- > Dr Katherine Clark – CST external investigator
- > Professor David Currow – PaCCSC Chief Investigator
- > Professor Lloyd Sansom – PaCCSC Management Advisory Board Chair
- > Professor Richard Head – PaCCSC/CST Scientific Committee Chair
- > Dr Phillip Lee – Cancer survivorship expert
- > Dr Purnima Sundaresan – Radiation oncologist expert
- > Professor Bogda Koczwara – Medical oncologist expert
- > Professor Meinir Krishnasamy – Cancer nursing expert
- > Professor Janette Vardy – Primary care expert
- > Associate Professor Prue Cormie – Allied Health expert
- > Dr Christopher Steer – Regional Australia cancer trials expert

Ex officio members

- > Linda Brown – PaCCSC/CST National Manager
- > Linda James – PaCCSC/CST Project Officer (secretariat)

Scientific Advisory Committee (SAC)

The Scientific Advisory Committee is responsible for the overall review of clinical study proposals and associated ethics applications, publication, dissemination and implementation of study outcomes.



Membership

- > Professor Richard Head – Chair
- > Professor Meera Agar – CST MAC Chair
- > Professor Rosalie Viney – Health Economist
- > Professor Madeleine King – Quality of Life National Technical Service (nominee)
- > Dr Belinda Butcher – Biostatistician
- > Associate Professor Joel Rhee – Primary Care expert
- > Professor Dorothy Keefe (vacated position June 2019) – medical oncologist with supportive care/symptom expertise
- > Professor Phyllis Butow – Psycho-oncology expert
- > (vacancy) – Radiation oncologist with supportive care/symptom expertise
- > Dr Michael Chapman – Geriatric oncology expert
- > Associate Professor Brian Le – Palliative care representative
- > Dr Aaron Wong – Early- to mid-career representative
- > Andrea Cross – Consumer representative

Ex officio members

- > Linda Brown – PaCCSC/CST National Manager
- > Linda James – PaCCSC/CST Project Officer
- > Dr Rayan Saleh Moussa – CST Postdoctoral Research Fellow
- > Dr Vanessa Yenson - CST Research Assistant-Writer

Trials Management Committees

A Trial Management Committee will be nominated for each clinical study. These committees are responsible for the development, review and oversight of issues specific to each study, including applications for external funding, recruitment, outcomes and study milestones.

Data and Safety Monitoring Committee

The Data and Safety Monitoring Committee is an independent contracted committee responsible for the safety evaluation and determination and reporting of adverse events for all studies conducted by CST.

IMPACCT Trials Coordination Unit (ITCC) team

Belinda Fazekas, BN

National Project Officer



Belinda has worked with PaCCSC since its commencement and her role has expanded across CST and IMPACCT within the ITC. She is integral in the implementation of clinical trial protocols including protocol and form design, data management, ethics submissions, and reporting. Belinda is responsible for ensuring that all clinical trials are conducted within the principles of Good Clinical Practice, Australian Regulations, and ethics and governance requirements, irrespective of the interactions of study populations. Belinda provides site-specific support from study initiation to study closure, including safety and data monitoring.

Diana Ferreira, MD MPC

Project Officer



Diana is a medical doctor and PhD candidate with an interest in chronic and palliative care. She is particularly interested in chronic breathlessness in advanced disease and is an associate investigator in the Breathlessness, Exertion and Morphine Sulphate (BEAMS) trial. Diana assists with clinical trials implementation across various sites. She provides clinical trials data monitoring and safety reporting as well as assisting study sites while ensuring that trials-related activities are compliant with protocol and ethical requirements.

Jane Hunt, RN

Project Officer



Jane has a background in palliative care nursing. When the first PaCCSC clinical trials started, she worked as a site coordinator/clinical trials nurse. Jane now works within the ITCC as a research assistant, providing assistance with the RAPID pharmacovigilance study. She assists with the development and day-to-day running of the RAPID series.

Sandra Kent, BSc, GradCertDrugDev, MSc

PaCCSC Research Assistant-Writer



Sandra assists clinical trial researchers to develop clinical trial protocols, generate literature reviews and prepare grant applications and ethics submissions. She provides research, writing and editing support to help convert new study ideas into clinical trials. Sandra has ten years' industry experience in Australia and the United Kingdom with clinical trials expertise in project management, medical writing, monitoring, coordination, and administration. She has a Master of Science and completed her dissertation in lung pharmacokinetics.

Jessie Lourdesamy BSc(Hons)

Research Assistant-Trials



Jessie assists with the coordination of Phase II and Phase III clinical trials conducted across multiple sites within Australia. She undertakes study monitoring responsibilities, provides infrastructure support and assists with devising recruitment strategies for local sites. Jessie has a background in Biomedical Science with a keen focus on pharmacology. She is experienced in the pre-clinical trials industry, with expertise in project management and resource development for data management systems. She has also contributed to research on novel/emerging therapies for various chronic pain states and diabetic foot ulcers.

Manraaj Sidhu BMedSc, BSc(Hons)

Research Assistant-Data



Manraaj is part of the PaCCSC data management team and is the national ITCC research assistant responsible for managing data. With a background in medical sciences and sciences, he brings a researcher's expertise to data management. Specifically, he is focused on building new case report forms as well as considering new ways to analyse previously collected ITCC data.

Charmain Strauss, B.BiomedSci, PhD

Research Assistant- Trials



Charmain supports the National Project Officer with the provision of coordinated trial management and processes including the development of clinical trial implementation resources, providing education and study protocol training to clinical sites, completing case reports and data entry. She collaborates with study and site investigators to implement new studies, assists with local recruitment and undertakes study monitoring to ensure trials are conducted in compliance with the ICH Guidelines for Good Clinical Practice and other local regulations.

Charmain has over seven years' laboratory and academic experience, having completed her PhD in molecular biology and genetics and having previously worked as a technical officer and casual academic at UTS.

Dr Vanessa Yenson, BHealth Sci, BBMSc (Hons), PhD

Research Assistant-Data



Vanessa assists clinical trial researchers to develop clinical trial protocols, generate literature reviews, and prepare grant applications and ethics submissions. She provides research, writing and editing support to help convert new study ideas into clinical trials. Vanessa has nine years' experience in laboratory research, having completed her PhD in Reproductive Immunology in Sydney before embarking on a postdoctoral position in the US. Prior to working with CST, Vanessa worked in clinical trials for almost five years, including as a Clinical Research Associate with full-cycle monitoring experience in Phase 1-4 students



Consumer Advisory Group

Our Consumer Advisory Group (CAT) is made up of consumers with extensive knowledge and experience across a large range of life-limiting illnesses. 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.

We thank them for their contributions and active participation in design, implementation, evaluation of research projects, guidance on strategic directions, and feedback on current practices in the healthcare system to identify effective practices and areas for improvement

- > Meg Brassil
- > Dea Close
- > Andrea Cross
- > Imelda Gilmore
- > Padman Karamil
- > Carmela Kendrick-Smith
- > Philip Lee
- > Ted Moors
- > Bev Noble
- > John Stubbs
- > Noelene Trotter

External Academic Appointments

Professor 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

Professor David Currow

- > Matthew Flinders Distinguished Professor, Palliative and Supportive Services, Flinders University
- > Professor, Palliative Care Research, Hull York Medical School, University of Hull,
- > Associate Director (Research), Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull
- > Honorary Professor, School of Medicine, University of Sydney
- > Honorary Senior Associate, Sax Institute

Associate Professor Michelle DiGiacomo

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



Professor Deborah Parker

- > Adjunct Associate Professor, School of Nursing and Midwifery, University of Queensland
- > Adjunct Professor, School of Nursing and Midwifery/Centre for Applied Nursing Research, Western Sydney University

Professor Jane Phillips

- > Adjunct Professor, School of Nursing, University of Notre Dame Australia, Sydney, NSW
- > Honorary Professor, School of Nursing, Hong Kong Polytechnic University
- > Visiting Professor, School of Medicine, University of Sydney, NSW
- > Visiting Professor, School of Nursing, Sun Yat-sen University, Guangzhou, China
- > Visiting Professor, Oxford Brookes University, Faculty of Health and Life Sciences, Oxford, United Kingdom
- > Adjunct Research Fellow, Australian National University, Institute for Communication in Health Care, Australian National University, Canberra

Dr Sungwon Chang

- > Adjunct Fellow, Western Sydney University, NSW

Professor Laurence Lam

- > Honorary Professor, Discipline of Paediatrics and Child Health, Sydney Medical School, University of Sydney

Editorial Roles

Professor David Currow

- > Associate Editor, Journal of Pain and Symptom Management
- > Editorial Board, Current Opinions in Palliative and Supportive Care
- > Editorial Board, Indian Journal of Palliative Care
- > Editorial Board, Journal of Opioid Management
- > Editorial Board, Journal of Palliative Medicine

Dr Seong Cheah

- > Editorial Board, International Journal of Healthcare
- > Editorial Board, Journal of Alternative, Complementary & Integrative Medicine
- > Editorial Board, Journal of Cardiology and Therapy

Professor Patricia Davidson

- > Editor, Collegian
- > Associate Editor, International Journal of Nursing Studies
- > Editorial Boards, European Journal of Cardiovascular Nursing
- > Editorial Board Journal of Cardiovascular Nursing
- > Editorial Board Heart Lung and Circulation



Associate Professor Michelle DiGiacomo

- > Associate Editor, BMC Health Services Research
- > Deputy Editor, Journal of Smoking Cessation

Associate Professor Louise Hickman

- > Editor in-Chief, Contemporary Nursing

Dr Annmarie Hosie

- > Editorial Board, Journal of Gerontological Nursing

Associate Professor Sally Inglis

- > Editorial Board, Cochrane Heart Review Group
- > Editorial Board, Journal of Nursing Scholarship
- > Editorial Board, Journal of Cardiovascular Nursing

Professor Lawrence Lam

- > Editorial Board, Advances in Medicine Journal – Public Health
- > Editorial Board, Austin Addiction Sciences
- > Editor, Cogent Medicine
- > Editorial Board, International Archives of Addiction Research and Medicine
- > Review Editor, Frontiers in Public Health

Dr Tim Lockett

- > Academic Editor, PLOS One

Prof Jane Phillips

- > Associate Editor, Chronic Illness
- > Editor, Collegian
- > Editorial Board, International Journal of Palliative Nursing
- > Editorial Board, Palliative Medicine
- > Editorial Board, Journal of Nursing Scholarship

Dr Xiaoyue Xu

- > Reviewer Editor, Frontier in Public Health

UTS Committees

- > Faculty of Health, Deans Advisory Committee (DP, LH, JLP)
- > Faculty of Health Board Member (JLP)
- > Faculty of Health, Deans Management Group (JLP)
- > Faculty of Health, Faculty Board (LH, SC)
- > Faculty of Health, Faculty Courses Committee (LH)
- > Faculty of Health, HDR Student Assessment Chair (LH, MD)
- > Faculty of Health, Research Impact Strategy Committee (JLP, LL, MA, LL)

- > Faculty of Health, Research Committee (JLP)
- > Faculty of Health, UTS International Postgraduate Research Scholarships panel (TL)
- > UTS Research Data Management Training Working Group (TL)
- > Graduate School of Health, Heads Advisory Committee (LL)
- > UTS Human Research Ethics Committee (MA, TL)
 - Clinical Trials Sub-committee (MA-Chair, LL)
- > UTS / Prince of Wales Hospital Clinical Alignment Precinct (DC)
- > UTS Social Impact Framework Committee (MA)
- > UTS Associate Professor Promotions Committee Faculty of Health Representative (LH)

UTS Teaching and Learning

- > Masters of Palliative Care subjects taught
 - Communicating and Collaborating for Optimal Person-centred Care [96801] (MD)
 - Delivering Best Palliative Care Any Place Every Time [96802] (TL)
 - Complex Symptom Management [96803] (JC, MD)
- > Masters of Palliative Care subjects developed
 - Immersive Palliative Care Futures [96804] (TL)
 - Optimising wellbeing for people living with advanced disease [96817] (MD)
- > Teaching and subject coordination (postgraduate):
 - Faculty of Health & Graduate School of Health Joint Research Methodology Workshops series (LL)
- > Teaching (undergraduate):
 - Fundamentals of epidemiology and population health [92569] (SC)
- > Guest lecturer
 - Evidence in Health [92618], Faculty of Health (MD)
 - Social Perspective of Public Health [96704] (MD)
- > Research Methodologies Consultations, Faculty of Health (LL)

IMPACCT-led Grants Awarded 2019

- Agar M, Currow D, Phillips J, Clark K., and Brown L**, Cancer Symptoms Trials (CST) Year 2; Cancer Symptoms Trials (CST) Year 2, 2019-2020, \$499,864.
- Agar M**, Chye R, Davis JM, Harlum J, Trethewie S, Harlum J, **Parker D, Currow D, Luckett T, DiGiacomo M, Hosie A, Kochovska S**, Pont L, Ries N, **Brown L, Fazekas B, Cheah S, Hickman L**, Viney R, Woods M, Seah D, Stone E, Sheehan C, Sheahan L, Brennan F, Lobb L, Lintzeris N, Sanderson C, Wiltshire J, Fernando A, Noonan K, Huynh T, Aggarwal R, Dadich A, Hammill K, Horsfall D, George A, Zhu X, Hall J, Kenny P, Street D, **Naumovski V**, Lee W, Chang S, **Phillips J**; Palliative Care Clinical Academic Group. SPHERE (Sydney Partnership for Health, Education, Research and Enterprise), 2019-2021, \$400,000.
- Currow DC**, Better Treatments For Breathlessness In Palliative And End Of Life Care – Australian Arm, National Health and Medical Research Council (NHMRC), 2019-2023, \$499,431.
- Currow, D**, Translational Cancer Research Network (TCRN) clinical PhD scholarship Wei Lee, Cancer Institute (NSW), 2019-2021, \$62,500
- Luckett T**, Phillips J, Parker D, Agar M. Review of the BaptistCare palliative approach: residential age care; BaptistCare 2019, \$10,000.
- Kochovska S, Chang S, Kinchin I**, Johnson MJJ, Ekström M, Eckert D, Adams, Reddel H; Delineating the impact of chronic breathlessness: a cross-sectional, population-based study, University of Technology Sydney Faculty of Health, 2019, \$16,600.
- Kochovska S, Phillips JL, Agar M, Davidson P, DiGiacomo, M, Luckett T, Chang S**, Morgan L, **Fazekas B**, Ferreira D, **Brassil M**, Gilmore I, **Currow D**, Discussing the impact of chronic breathlessness in clinical consultations – making the invisible, visible: perceptions and experiences of people with chronic breathlessness, their caregivers, and health professionals as they have clinical interactions, Health Futures Development Grants (University Technology Sydney), 2019, \$20,000.
- Parker D**, Travaglia J, Brooks F, Mouzakis K, McClean T, Occelli P, Digital Enhanced Living ARC Industrial Research Hub, Australian Research Council (ARC), 2019-2023, \$469,212.
- Phillips J, Agar M, Currow D, Parker D, Heneka N, Luckett T, DiGiacomo M**, Audit of National Care Standards, clinical pathways and decision support tools for patients with malignant brain cancer, Cancer Australia, 2019, \$408,659.
- Phillips J**, Translational Cancer Research Network (TCRN) clinical PhD scholarship, Cancer Institute (NSW), 2019-2022, \$84,246.

Collaborative grants led by other areas or institutions awarded in 2019

Hall J, **Agar M**, Street D, Kenny P, **Phillips J**. Community preferences for care at the end of life. NHMRC project grant. APP1159202, 2019-2022, \$516,397.

Johnson MJ, Fallon M, **Currow DC**, Norrie J, Hall P, Seymour J, Chaudhuri N, Bajwah S, Keen J, Higginson I, Buchanan D, Hart S, A parallel group, double-blind, randomised, placebo-controlled trial comparing the effectiveness and cost-consequence and cost effectiveness of low dose oral modified release morphine (MRM) versus placebo on the intensity of worst breathlessness in people with chronic breathlessness, National, Institute for Health Research (NIHR), United Kingdom, 2019-2021, £1,334,985.

Evans S, Heathcote P, Frydenberg, Mark S, Fisher J, Kirkman M, **Currow D**, Research assessment outcome measures for malignant bowel obstruction, Movember (Australia) 2019-2020, \$66,259.

Moyle W, **Parker D** (Co-Cl), Australian Aged Care Technologies Collaborative (AACTC), MHIQ Capacity Grant Scheme, 2019-2020, \$200,000.

Johnson M, **Phillips J**, Murtagh F, **Currow D**, Clinician-level quality of care reports-dealing with the complex issue of outliers, Research for England I³, 2019-2024, £403,000.

Ryan R, Ellison A, **DiGiacomo M**, Simoes dos Santos P, Van den Nieuwenhof A, Evaluation

of the Smoking Cessation Framework, Cancer Institute NSW, 2019, \$57,000.

Noble S, Boland J, Johnson M, **Currow D**, Murtagh F, Nelson, Boland E, Obita G, Seddon, Bembo, Research assessment outcome measures for malignant bowel obstruction, Marie Curie (UK), 2019-2021, £218,404.

Travaglia J, **Parker D**(Co-Cl), Debono D, Robertson H, Carmemolla P, **Visser M**, Hor S, Household Model – Quantitative Evaluation, Uniting, 2019-2020, \$100,000.

Johnson M, Murtagh, F, Walker E (Hull), **Phillips J**, **Currow D**, International Investment Initiative (i3), Research England, i3 Breathlessness and Outcomes Collaboration Grant, 2019-2024, \$162,497

Current projects - Cancer

Cannabis-Namisol

Phase IIb double-blind, placebo-controlled study of oral delta-9-tetrahydrocannabinol (Namisol®) for anorexia in people with advanced cancer.

Investigator team: Professor Meera Agar, Jennifer Martin, Professor David Currow, Nicholas Lintzeris, Nadia Solowij, Professor Jane Phillips, Melanie Lovell, Bev Noble, Richard Chye, Jessica Lee, Rajesh Aggarwal, Katherine Clark, Linda Brown, Dr Valentina Naumovski, Philip McCloud, Belinda Fazekas, Seong Leang Cheah

Consumer representation: Ms Bev Noble

Funding: NSW Health - \$1.5 million to UTS as sponsor of Namisol Study

Study design:

A prospective, randomised, double-blind, placebo-controlled, multicentre Phase IIb study of oral THC (Namisol®) versus placebo in people with advanced cancer experiencing anorexia symptoms.

Objectives:

Primary: To determine if oral THC can improve anorexia-related symptoms and concerns (as measured by the 12-item Functional Assessment of Anorexia Cachexia Therapy (FAACT) (anorexia cachexia subscale) in the advanced cancer population compared to placebo.

Secondary: To determine if oral THC:

- i. causes adverse effects
- ii. improves premeal appetite
- iii. improves taste and smell
- iv. improves quality of life
- v. provides other symptom benefits, including nausea, pain, improved sleep quality
- vi. provides treatment satisfaction
- vii. changes patterns of food intake (type and amount of food)
- viii. changes body mass index
- ix. changes patterns of hospital use or dietetics use

Intervention: Namisol®, (Echo Pharmaceuticals BV, Netherlands), an oral tablet containing pure ($\geq 98.0\%$), natural $\Delta 9$ -THC.

The supplier of the IP has signed with UNSW. MIA has been signed by all institutions. CTN is in progress, along with pharmacy handling document. Trial coordination activities are underway to ensure that the site initiation visits occur immediately Study IP becomes available and the first wave of sites will be opened to recruitment.

IP is scheduled to arrive in April 2020. PCI Pharma Services and investigator team are working through the logistics of packaging product for distribution. Trial has been registered through ANZCTR. Relevant site documentation such as CRFs are being checked in REDCap for completeness. Site initiation meeting is planned for May 2020

Cannabis – botanical leaf

Phase I/II, dose ranging study of the pharmacokinetics dose-response parameters, and feasibility of vaporised botanical cannabis flower bud in advanced cancer

Investigator team: Professor Meera Agar, Jennifer Martin, Professor David Currow, Nicholas Lintzeris, Nadia Solowij, Steve Quinn, Nikki McCaffrey, Professor Jane Phillips, Peter Martin, Melanie Lovell, Iain McGregor, David Allsop, Dr Tim Lockett, Alex Wodak, Bev Noble, Florian Strasser, Richard Chye, Jessica Lee, Rajesh Aggarwal, Katherine Clark, Linda Brown, Stephanie Reuter Lange, Peter Galettis, Valentina Naumovski, Seong Leang Cheah, Zheng Liu

Funding NSW HEALTH: \$1,332,714

Study design:

Phase I dose ranging study of vaporised botanical cannabis flower bud and phase II feasibility study in people with advanced cancer experiencing anorexia symptoms

Objectives:

- i. Phase I objectives: To understand the pharmacokinetics and dose-response parameters of vaporised botanical cannabis flower bud (VBCF) in the advanced cancer population, in order to determine dose range for a subsequent phase III study;
- ii. Phase II objectives: To evaluate feasibility and acceptability of study design and measures for the subsequent phase III study.

Intervention: Bedrobinol (Bedrocan®, Netherlands), a 'Sativa' dominant strain of cannabis, registered for medical use (Netherlands). Bedrobinol comes in the form of dried flower tips harvested from the female cannabis plants. Bedrobinol is characterised by a 13.5% THC content (and CBD content less than 1%).

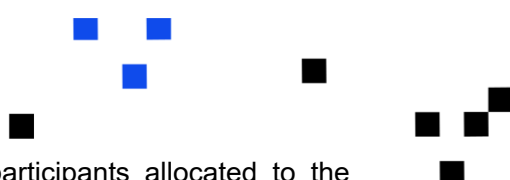
To date, recruitment has been slow with no additions since last update. This has been due to the time to recruit new (clinical) staff, refurbishment of ward, downsizing of patients and staff. A report was presented to the investigator team and DSMB regarding the recent vaping issues in the US. It has been concluded that our trial does not pose any greater risks to participants. Both the investigator team and NSW Health meet regularly to discuss the trial. Three publications are in progress. Two ILP medical students from UNSW have been recruited to work on cannabis-related projects in 2020.

Cancer Pain Assessment Study (CPAS)

Chief Investigators: Professor Jane Phillips, Professor Tim Shaw, Professor Melanie Lovell, Professor Patricia Davidson, Professor Frances Boyle, Professor Lawrence Lam, Dr Nikki McCaffery, Professor Paul Harnett

Funding: Cancer Australia \$342,483

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.



114 participants were enrolled in the study over four sites; 56 participants allocated to the Intervention group and 58 participants allocated to the waitlisted controlled group. One site has completed all study activities (intervention, T1-T3 data collection); two sites have completed the intervention and T2 data collection; and one site is awaiting T2 data collection. The recruitment target was reached in December 2019, with a total of 94 participants completing the Qstream (Intervention) and/or the pre- and post-surveys (Intervention and control). 46 Intervention participants and 48 control participants completed all study elements. As the recruitment goal was met, the study did not proceed at the fifth site.

Duloxetine versus Pregabalin for Neuropathic Cancer Pain (DEPARTURE)

An international, double-blind, dose increment, parallel-arm, randomised controlled trial of duloxetine versus pregabalin for opioid unresponsive cancer-related neuropathic pain:

Phase III trial

*Investigators: Professor Katherine Clark, Dr Jessica Lee, **Professor Jane Phillips, Professor Meera Agar, Professor David Currow**, Prof Melanie Lovell, **Ms Slavica Kochovska**, A/Prof Brian Le, Bev Noble, **Ms Linda Brown, Ms Belinda Fazekas** (Japan Investigation team) Dr. Hiromichi Mastuoka, Dr. Eriko Satomi, Dr. Hiroto Ishiki, Dr. Yoshinobu Matsuda, Dr. Hideaki Hasuo, JORTC(Kota Kihara)*

Funding: NHMRC \$973,610

Neuropathic cancer pain is experienced by approximately 33% of people experiencing cancer pain. Neuropathic pain is less responsive to opioid drugs. The effectiveness of gabapentinoids (gabapentin and pregabalin) for this population has already confirmed in two RCTs compared with placebo making this a standard of care. Duloxetine is selective serotonin noradrenalin reuptake inhibitor (SNRI) and offers the potential of analgesia in opioid unresponsive neuropathic cancer pain. However, there are no randomised controlled trials of oral duloxetine for the management of opioid unresponsive cancer neuropathic pain as a 1st line treatment. Both classes of drug have the potential to reduce neuropathic cancer pain, but there has been no head-to-head comparison for the net effect especially given differing side-effect profiles. The project includes a qualitative sub-study on the patient experience of the intervention.

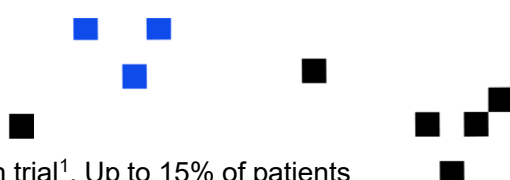
Funding awarded, HREC submission pending

IMBO (Improving management of inoperable bowel obstruction)

Improving the management of inoperable malignant bowel obstruction – a 2x2 factorial, double blind, double dummy, fixed dose, parallel arm, multi-site randomised placebo controlled feasibility study involving dexamethasone and ranitidine.

*Investigators: **Professor David Currow, Professor Meera Agar, Dr Sungwon Chang, Dr Irina Kinchin**, Dr Caitlin Sheehan, Dr Alison Davis, Professor Katherine Clark, Associate /Professor Selvan Pather, Professor Alexander Engel, **Ms Meg Brassil** (consumer)*

Funding: SPHERE palliative care CAG pilot grant, \$68,890



This study is a follow on the PaCCSC Octreotide for bowel obstruction trial¹. Up to 15% of patients with advanced cancer develop blockages in their intestines that cannot be cleared by surgery. This condition, called inoperable malignant bowel obstruction (IMBO), causes highly distressing and debilitating symptoms including nausea, stomach pain, and smelly vomiting. There is no medication approved for its medical management. The current practice in palliative care is to ensure that the patient receives enough fluids and nutrition via external means, such as through a nasogastric tube or an intravenous drip. Two commonly available and inexpensive medications, dexamethasone and ranitidine, could potentially help to manage the IMBO-related symptoms of advanced cancer patients. Research suggests that dexamethasone, a corticosteroid, could help to treat IMBO symptoms by reducing swelling, and that ranitidine, a H2 antagonist proven to reduce stomach acid, could help to reduce IMBO-related vomiting.

This phase III study will determine if taking dexamethasone and ranitidine together can help to reduce IMBO-related vomiting in advanced cancer patients. This feasibility study will recruit advanced cancer patients with IMBO to take dexamethasone 8 mg and ranitidine 200 mg for 5 days in one of four ways, either 1) together, 2) dexamethasone 8 mg only with a placebo, 3) ranitidine 200 mg only with a placebo, or 4) neither by taking a placebo only. Patients will record their symptoms and experiences on each study day.

In 2019, Pilot study funding has been obtained, and protocol development is underway and site feasibility being considered 1-2 sites in NSW, and possibly one interstate being considered.

INCA: Treatment of INSomnia in Advanced Cancer

Temazepam or Melatonin Versus Placebo for the Treatment of INSomnia in Advanced Cancer: A Three Arm, Double Blind, Phase III, Multicentre, Randomised Clinical Trial

*Investigator team: Dr Ruwani Mendis, Dr Aaron Wong, Associate Professor Prof Anne-Marie Southcott, Dr Simon Frenkel, Prof Jennifer Martin, **Prof David Currow, Prof Meera Agar, Dr Anneke Grobler, Associate Professor Brian Le, Professor Jennifer Philip***


Funding: Western Health \$35,000

Sleep disturbance is a common, distressing, under-diagnosed and undertreated problem in patients with advanced cancer, with a prevalence of 30 -78%. Multiple causative and contributing factors have been suggested and the implications of poor sleep for cancer patients include reduced quality of life, reduced energy, mood disorders, immunosuppression and even changes in the course of disease by fatigue related inability to tolerate treatments. A recent study showed a decrease in pain threshold of as much as 15% from a single night of sleep deprivation.

Melatonin, secreted by the pineal gland, is a hormone that regulates circadian rhythm and the sleep wake cycle in humans. Studies investigating the efficacy of melatonin prolonged release (PR) in people ≥55 years with primary insomnia have revealed a clinically meaningful improvement in quality of sleep as well as morning alertness compared to placebo; 32% vs. 19%. Melatonin PR is safe with an adverse effects rate comparable to placebo (37% vs. 31%)²⁹, no increased risk of cognitive impairment, psychomotor adverse events, tolerance, dependence or withdrawal effects. Melatonin has been shown to increase the total sleep time in people suffering from sleep restriction, reduce the time taken to fall asleep in people with delayed sleep phase disorder and to help reset

¹ [Double-blind, placebo-controlled, randomized trial of octreotide in malignant bowel obstruction.](#)

Currow DC, Quinn S, Agar M, Fazekas B, Hardy J, McCaffrey N, Eckermann S, Abernethy AP, Clark K. *J Pain Symptom Manage.* 2015 May;49(5):814-21. doi: 10.1016/j.jpainsymman.2014.09.013



the sleep - wake cycle in people with altered sleep schedule. It is thought to be safe up to 6 months with a recommended dose of between 1 - 3 mg in adults.

To date, there are no studies of melatonin to treat insomnia in patients with advanced cancer. In Australia, melatonin is Therapeutic Goods Administration (TGA) approved for the short treatment of insomnia (up to 3 weeks) in patient's ≥ 55 years; although it is not listed on the pharmaceutical benefits scheme (PBS). However, in the United States of America and in Europe melatonin is freely available to the public as an over the counter medication.

We have designed a phase III, double blind, randomised, placebo controlled 3 Arm study of temazepam or melatonin PR vs. placebo to evaluate the efficacy and safety of these treatment methods for insomnia in advanced cancer.

LICPain

A multi-centre double blind randomised controlled trial of continuous subcutaneous lidocaine (lignocaine) for the management of neuropathic cancer pain - a feasibility study

*Investigator team: **Jessica Lee, Meera Agar, David Currow, Melanie Lovell, Jane Phillips, Andrew McLachlan, Bev Noble, Linda Brown, Belinda Fazekas, Nikki McCaffrey, Richard Chye, Rajesh Aggarwal, Davinia Seah, Christine Sanderson, Chadi Ayoub, Caitlin Sheehan, Ghauri Aggarwal, Kat Urban, Dipti Mittal, Josh Cohen, Priyanka Bhattarai, Anthony Linton, Seong Cheah***

Funding: Palliative Care Clinical Studies Collaborative (PaCCSC)

Patients with neuropathic cancer pain are significantly more likely to receive strong opioids and adjuvant analgesia and have a reduced performance status. They report worse physical, cognitive and social function. Despite a growing body of research, there remains a proportion of pain which is poorly controlled with existing management strategies. In the European Pain in Cancer Survey, 58% of those receiving prescription medication for pain reported inadequate pain relief at least several times a week.

Lidocaine (lignocaine) offers an innovative approach to more effectively manage this challenging clinical problem and improve quality of life. It aims to provide analgesic benefit without significant psychoactive side effects unlike alternatives in this setting. There are no randomised controlled trials of continuous subcutaneous infusion of lidocaine (lignocaine) in cancer pain or in palliative care. Observational studies of continuous subcutaneous or intravenous infusion of lidocaine (lignocaine) in cancer and hospice patients have found up to 87% response but must be interpreted with caution given their design.


This mixed-methods feasibility pilot study aims to determine the feasibility of an international first definitive phase III trial which would evaluate the effect and safety of a continuous subcutaneous infusion of lidocaine (lignocaine) for neuropathic cancer pain.

The project is under recruitment.

Melatonin prevention

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: **Professor Meera Agar, Professor Jane Phillips, Dr Annmarie Hosie, Dr Tim Lockett, Dr Jane Nikles, Dr Nikki McCaffrey, Professor Wes Ely, Ms Bev Noble, Ms Meg Brassil, Associate Professor Brian Le, Associate Professor Jennifer Philip, Professor Peter Lawlor, Dr Shirley Bush, Dr Delwyn Bartlett, Professor David Currow***



Funding: Cancer Australia (\$599,820) & Palliative Care Clinical Studies Collaborative (PaCCSC)

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

In 2019, recruitment continues on track across all sites. To date there have been 157 participants randomised, with 138 recorded as reaching the requirements for primary outcome.

Melatonin treatment

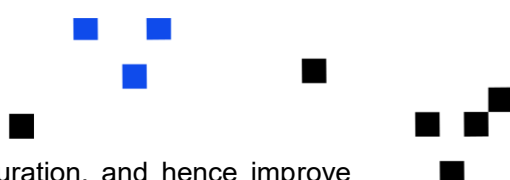
Phase II open label single arm pilot trial of oral prolonged release melatonin for the treatment of delirium in older people with cancer.

*Investigator team: **Professor Meera Agar**, Professor Gideon Caplan, Professor Vasi Naganathan, Professor Brian Draper, A/Professor Andrew Teodorczuk, **Associate Professor Annmarie Hosie**, Associate Professor Tracey Comans, Dr Phillip McCloud, Dr Christopher Steer*

Delirium is a highly prevalent, medical emergency in advanced cancer. 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.

A recent meta-analysis of antipsychotics commonly used in clinical practice for the prevention and treatment of delirium found no difference in the duration or severity of delirium in hospitalized adults. In a landmark clinical trial our team showed that treatment with antipsychotics in people with advanced cancer does not shorten the duration nor better manage specific delirium symptoms (such as agitation, hallucinations) once they occur.

Alternative therapies for delirium urgently need evaluation, and melatonin shows promise. Clinical and laboratory data identify low melatonin levels and circadian desynchrony in delirium. Prior studies have explored its role in delirium prevention and treatment. Randomised controlled trials in elderly populations and a phase II RCT by this team in people with cancer demonstrate evidence for a role for melatonin in delirium, with all studies showing a positive effect on preventing delirium or reducing its duration once it occurs, as well as encouraging safety profile. It is however not always possible or practical to institute a preventative strategy for all older people in hospital, so



evaluating the role of melatonin to reduce delirium severity and duration, and hence improve survival is needed.

In 2019, the investigator team are considering funding approach prior to finalising the nature of the pilot study

Nausea 4 Pilot

A randomised, controlled, study of oral ondansetron versus oral olanzapine versus oral haloperidol in patients with cancer and nausea not related to anticancer therapy - a pilot dose finding study (Nausea study 4 pilot).

*Investigator team: Dr Phillip Good, Professor Janet Hardy, **Professor Jennifer Philip**, Dr Jennifer Weil, Professor Greg Crawford, Dr Richard McNeil, Professor Patsy Yates*

Funding: CST \$30,000

Many people with cancer experience chronic nausea that has a significant impact on their quality of life. Nausea (and vomiting) unrelated to anti-cancer treatment remains an important and under-researched health problem. To address this, a series of high quality randomised controlled trials (RCTs) have been performed to try and improve the evidence base.

The first stage of the Nausea Management in Cancer Patients program (Nausea study 1(NS 1)) compared 'mechanistic' based guidelines to haloperidol. It found response rates and effectiveness were similar in both arms at reducing nausea (complete response rate at 72 hr were 49 vs 53%). The second phase of the study (Nausea study 2(NS 2)) was to compare the efficacy of ondansetron and methotrimeprazine, both delivered parenterally, against placebo/best supportive care. However, very few patients had nausea that remained refractory after completing NS 1 and therefore, due to the inability to recruit to NS2, we proceeded to Nausea Study 3 (NS3) to assess the efficacy of a first line treatment drug for nausea - methotrimeprazine, against one of the current standard treatments - haloperidol. This study found that methotrimeprazine (M) was not superior to haloperidol (H) for nausea in those with chronic cancer (complete response rate at 72 hr were 51% (M) vs 56% (H),paper submitted for publication).

Olanzapine and ondansetron are both used for chemotherapy-induced nausea and vomiting. They have developed widespread 'off label' use for nausea in hospital settings (in patients with cancer and nausea not related to anticancer therapy). Given their widespread use but lack of quality evidence, and the large number of patients without complete control of nausea in NS1 and 3, we have now elected to progress to Nausea Study 4 (NS4) where we will compare the efficacy of alternate first line antiemetic treatments, being ondansetron and olanzapine, to the standard treatment – haloperidol

Continuation of study is planned until mid-2020.



Older people with cancer

Phase II pilot cluster randomised controlled trial of a nurse-led triage and assessment system to optimize outcomes for older people with cancer

Investigator team: **Professor Meera Agar**, Associate Professor Gideon Caplan; Dr Christopher Steer; Professor Len Gray; Dr Elizabeth Hovey

SPHERE Cancer Clinical Academic Group Seed Funding Scheme \$199,835

In Australia, the proportion of older people 65 years is increasing, corresponding to increasing rates of cancer. In 2017, approximately 78,688 new cancer diagnoses will be in people 65. 7% of all Australians 75 had a cancer diagnosis within the previous 5 years (2012 data). Over 80% of cancer deaths will occur among those 60. Appropriate care of older people with cancer requires an interdisciplinary approach, considering comorbidities, geriatric syndromes and psychosocial-economic issues. The

National Comprehensive Cancer Network, International Society for Geriatric Oncology guidelines, and EORTC elderly taskforce all recommend routine implementation of Geriatric assessment for older people with cancer. Comprehensive geriatric assessment (CGA) identifies issues which are not typically identified (cognition, nutrition, function, social status, frailty), and predicts treatment-related toxicities, overall survival and influences treatment decisions (choice and intensity). CGA-guided treatment, in some studies, improves overall survival, quality of life and physical function; and reduces hospitalisation and aged care placement, and allows for pre-treatment patient optimisation.

There are varied approaches that have been used for embedding CGA into oncology practice.

Several models exist, including geriatricians/geriatric nurses embedded in oncology clinics, nurse-practitioners, consultative services and dual-trained geriatric oncologists. Criticisms of these models are they are resource intensive and provide a comprehensive service for a few; however they do increase expertise in geriatric principles. Importantly, guidelines recommend that model of assessments with a standardised approach need to be feasible in the local health care structure and setting. A feasible approach using standardized documentation for geriatric assessment in Australian context is needed, achieving similar outcomes of more resource intensive models.

This proposal aims to address international recommendations with the routine introduction of

Geriatric screening and triage, nurse-led comprehensive geriatric assessment using an assessment system which allows *audit and feedback* (of summary data of older clinic population to the treating oncologist).

This pilot study will determine whether implementing into routine clinical practice a three pronged approach to geriatric assessment (nurse-led screening); 2) nurse-led CGA using the interRAI system⁶; and 3) audit and feedback of summary data to treating oncologists; to support care and decision-making for older people with cancer is feasible and acceptable.

Baseline is set to commence.

Opioid risks in the cancer context

Risks from opioids prescribed to people with cancer: How should Australian policy and practice respond to international alarm?

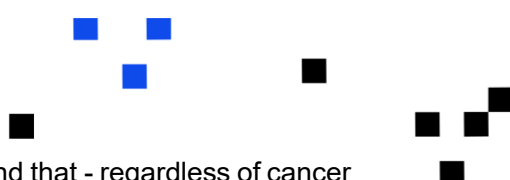
Chief investigators: **Dr Tim Luckett**, Associate Professor Toby Newton-John, **Professor Jane Phillips**, Dr Simon Holliday, Dr Karleen Giannitrapani, Associate Professor Gawaine Powell-Davies, Associate Professor Melanie Lovell, A/Prof Winston Liauw, Prof Debra Rowett, Prof Sallie-Ann Pearson, Dr Benjamin Daniels, Dr Hanna Tervonen, Ms Bronwyn Raymond, **Nicole Heneka**, Professor Karl Lorenz

Funding: UTS Faculty of Health, \$14,800

In 2019, harms from over-prescribing of opioids to people with chronic non-cancer pain continued to attract much attention in research, policy and media around the world. It has generally been assumed that prescribing opioids for people with cancer represents a different clinical paradigm to non-cancer pain, but little research has been conducted to verify this. IMPACCT conducted two studies to explore the nature and magnitude of risks associated with opioids within the cancer context. A collaborative was formed to include expertise in psychology (A/Prof Toby Newton-John, UTS Graduate School of Health), big data on medicines (Prof Sallie Pearson, Dr Benjamin Daniels, Dr Hanna Tervonen UNSW Centre for Big Data Research in Health), pharmacological management of cancer pain (A/Prof Melanie Lovell, HammondCare), medical oncology and clinical pharmacology (Associate Professor Winston Liauw, South East Sydney Local Health District Cancer Services), general practice and addiction medicine (Dr Simon Holliday, University of Newcastle School of Medicine and Public Health; Associate Professor Gawaine Powell-Davies, UNSW Centre for Primary Health Care and Equity) and pharmacy (Professor Debra Rowett, Repatriation General Hospital Adelaide). Colleagues from Stanford University (Dr Karleen Giannitrapani and Prof Karl Lorenz) who had conducted similar work in the US were also involved to promote opportunities for shared learning across contexts.

Firstly, a qualitative study was undertaken to explore general practitioner (GP) perspectives on opioid-related risks in the cancer context. Twenty-two GPs participated, and three themes emerged. Theme 1 (*Misuse is not the main problem*) contextualised misuse as a relatively minor concern compared to pain control and toxicity, and highlighted underlying systemic factors, including limitations in continuity of care and doctor expertise. Theme 2 (*'A different mindset' for cancer pain*) captured participants' relative comfort in prescribing opioids for pain in cancer versus non-cancer contexts, and acknowledgement that compassion and greater perceived community acceptance were driving factors, in addition to scientific support for mechanisms and clinical efficacy. Participant attitudes towards prescribing for people with cancer versus non-cancer pain differed most when cancer was in the palliative phase, when they were unconcerned by misuse. Participants were equivocal about the risk-benefit ratio of long-term opioid therapy in the chronic phase of cancer and were reluctant to prescribe for disease-free survivors. Theme 3 (*'The question is always, "how lazy have you been?"*) captured participants' acknowledgement that they sometimes prescribed opioids for cancer pain as a default, easier option compared with more holistic pain management.

Second, analysis was undertaken of Repatriation Pharmaceutical Benefits (RPBS) dispensing data linked with the NSW Cancer Registry for a cohort of Department of Veterans' Affairs (DVA) clients 65 years and older residing in NSW. Two analyses were undertaken to explore opioid dispensing patterns. The first of these was a descriptive analysis and found greater opioid dispensing to be associated with poor prognosis, female sex and younger age. Opioid use prior to cancer diagnosis was common, with previous users having more intense opioid use patterns after diagnosis than opioid-naïve people. The second analysis compared patterns in dispensing of oxycodone/naloxone controlled-released for DVA clients with cancer versus without cancer over the year since this



combination was first subsidised in December 2011. This analysis found that - regardless of cancer status - the new oxycodone/naloxone combination expanded the overall market for oxycodone rather than replaced use of oxycodone as a single agent. Together, results from these analyses suggest that people with cancer may be exposed to some of the same drivers of opioid over-prescribing observed in the general population.

Geriatric Oncology Trial

*Chief Investigators: **Professor Meera Agar, Professor Jane Phillips***

Funding: SPHERE Cancer Academic Group SEED 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 has commenced and is focussed on developing 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 randomised trial.

This trial remains open for recruiting.

National Brain Cancer Audit

Audit of national care standards, clinical pathways and decision support tools for patients with malignant brain cancer (RFQ1819-02)

*Investigator team: **Professor Jane Phillips, Professor Meera Agar, Professor David Currow, Professor Suzanne Chambers, Professor Richard De Abreu Lourenço, A/Professor Michelle DiGiacomo, Dr Tim Luckett, Dr Nicole Heneka, Dr Irina Kinchin, Dr Slavica Kochovska, Dr Anna Green***

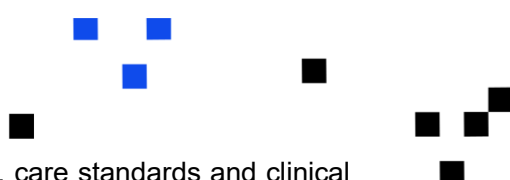
*Research assistants: **Isabelle Schaefer, Mariana Sousa, Domenica Disalvo, Ingrid Amgarth-Duff, Maja Garcia, Layla Edwards***

Funding: Cancer Australia \$447,640

Brain cancer is the sixth leading cause of cancer burden. There are more than 100 types of brain cancer and other central nervous system cancers which carry high rates of morbidity and mortality. The five-year relative survival rate for brain cancers in Australia is 22%. Despite improvements in patient care and support, survival rates for brain cancer have remained relatively unchanged for the past 30 years.

Cancer Australia sought the provision of an Audit of national care standards, clinical pathways and decision support tools for patients with primary brain cancers. The Audit aimed to identify:

available national and international evidence-based care standards, clinical pathways, and decision-support tools for patients with primary brain cancer;



the extent of use and adherence to, including variations in uptake of, care standards and clinical pathways by healthcare professionals providing treatment and care, and decision-support tools for patients with primary brain cancer in Australia;

the contribution of research and clinical trials in identifying best practice in primary brain cancer care and the enhancement of patient experiences;

gaps in care standards, clinical pathways, and decision-support tools to inform initiatives for future directions and future resource requirements, to achieve quality care for all patients with primary brain cancer;

the costs and benefits of adopting best practice national care standards, clinical pathways and decision-support tools for patients with primary brain cancer and the health system over the life of the Mission to 2027; and

approaches for the system-wide routine integration of best practice national care standards, clinical pathways and decision-support tools for patients with primary brain cancer into clinical practice.

The audit was undertaken using a three phase multi-method approach including: a rapid desktop review; stakeholder interviews and survey; and data integration using a mixed-methods analysis approach.

Current Projects – Palliative Care

A feasibility study of lorazepam for anxiety in palliative care.

A randomised, double-blind, placebo-controlled feasibility study of oral lorazepam for symptoms of anxiety in participants with advanced life-limiting disease

*Investigator team: Dr Nicola Atkin, Associate Professor Brian Le, **Professor Jennifer Philip**, Professor Mei Krishnasamy, Dr Maria Ftanou, Dr Donovan Moncur, Ms Shu-Yi Soong, **Professor Meera Agar**, **Professor David Currow***

Funding: Bethlehem Griffiths Research Foundation, \$49,495

This is a prospective, randomised, double-blind, placebo-controlled, parallel group, feasibility study of oral lorazepam for symptoms of anxiety in participants with advanced life-limiting disease. The principal aim of this study is to determine the feasibility of conducting a Phase III randomised controlled trial which is intended to compare lorazepam, an antidepressant, and placebo for symptoms of anxiety in palliative care patients.

This feasibility study will recruit approximately 21 adult palliative care inpatients and outpatients with symptoms of anxiety. All participants will receive a non-pharmacological action plan for managing episodic anxiety prior to randomisation. Following baseline assessments, participants will be randomised to the lorazepam arm or lorazepam matched placebo arm. Lorazepam 2 mg BD will be the maximum daily dose. Daily administration of the study treatment will commence on Day 1 and continue for 12 weeks.

Patient reported outcomes and medical file review will be completed on Day 3, and at the end of Weeks 1, 2, 4, and 8.

BETTER-B: BETter TreatmEnts for Refractory Breathlessness

An International, Multicentre, Randomised Controlled Pragmatic Trial of Mirtazapine to alleviate Breathlessness in Palliative and End of Life Care

UTS Investigator: **Professor David Currow**.

Funding: BETTER-B has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No. 825319.

*Funding – AUST: **NHMRC - European Union (APP1170731) \$499,430.90***

Breathlessness (also called dyspnea or dyspnoea) is a common, distressing symptom in advanced disease, particularly those affecting the heart and lungs, causing considerable disability for patients, and anxiety and social isolation for them and their family and carers. Breathlessness which continues despite optimal management of the underlying causes and current symptom relief measures, is termed 'chronic' or 'refractory'. It generally worsens as the disease progresses and is one of the most frightening aspects facing a person with advanced disease.

Breathlessness is associated with shortened life expectancy and often results in emergency visits and hospitalisation.

Non-pharmacological treatments take priority for chronic or refractory breathlessness, especially when patients are able to participate in physiotherapy, and where possible are first line treatment. However, there are few effective pharmacological treatments thus, refractory breathlessness represents a huge unmet need and new approaches are desperately required. Preliminary data suggest that serotonergic modulation is beneficial but rigorous evaluation has not been conducted. There is therefore a need to explore the potential role of antidepressants in this setting.

Mirtazapine is a widely used noradrenergic and specific serotonergic antidepressant (NaSSA). There is clinical experience to support its use in anxiety and panic disorder and clinical evidence for its use in major depressive disorders associated with anxiety.

BETTER-B will help address this unmet need by determining whether mirtazapine has a role in the management of refractory breathlessness in patients with chronic obstructive pulmonary disease (COPD) and interstitial lung disease (ILD).

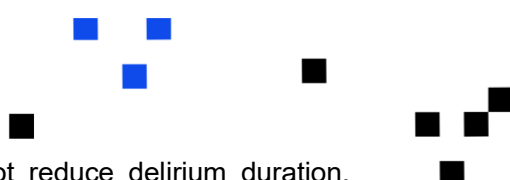
Future funding will be sought to test this new model of community palliative care.

Clinical Practice in the treatment of delirium

*Investigators: **Dr Annmarie Hosie, Professor Meera Agar, Ms Linda Brown, Associate Professor Gideon Caplan, Professor Brian Draper, Associate Professor Stephen Hedger, Professor Debra Rowett, Ms Penny Tuffin, Dr Seong Leang Cheah, Professor Jane Phillips, Professor David Currow***

This study will use a mixed-methods design and behaviour change theory to survey and interview Australian doctors, nurses and pharmacists about their treatment of delirium, with a focus on the use of antipsychotics.

Delirium is an acute, debilitating and distressing neurocognitive condition that occurs as a result of illness, injury and hospitalisation, with older people most at risk. Recommended clinical strategies for delirium are to assess the patient; identify and treat underlying risk factors and causes; ensure that they are safe and have sufficient sleep, sensory aids, hydration, and physical and cognitive activity; and advise and reassure the patient and their family. These strategies prevent delirium in around one in three older patients, with less evidence available that they effectively treat delirium.



Recent high-level studies have reported that antipsychotics do not reduce delirium duration, severity, associated distress or other poorer outcomes. Clinical practice change to reduce the use of antipsychotics for delirious patients is therefore warranted but challenging because delirium can be very distressing for patients, their family and clinicians, and there is uncertainty about the effectiveness of alternative strategies.

The project will ascertain clinicians' current practice; the degree and nature of their practice change following publication of evidence that antipsychotics are ineffective for delirium; and what has influenced their current practice and practice change. The outcome of the project will be evidence- and theory-based recommendations for clinical research in the treatment of delirium.

In 2019, data collection was completed and analysis of these findings are underway.

Defining a new model of care that supports people with palliative care needs to spend more time in their preferred place of care: a co-design project.

*Investigators: **Professor Jane Phillips, Professor Meera Agar, Professor Caplan, Sheehan, C., Harlum, J., Trethewie, S., Dr Tim Lockett, Dr Irina Kinchin and Dr K Urban and N Heneka***

Funding: SPHERE (Palliative Care Clinical Academic Group), \$69,469

Timely access to appropriate information, care and support is critical to enabling people with palliative care needs to spend more days in their preferred place care, which is typically their own home. Achieving this vision requires the development of new and more responsive models of care that can provide access to timely care and support 24 hours a day. This coverage is required so that people with palliative care needs can access the physical, psycho-social and spiritual care they need to become comfortable at home at any time of the day and night. Understanding the best way of providing responsive community-based palliative care, and determining how available digital health technology may assist with this process, is an important first step in planning a new model of community palliative care.

This co-design project is designed to define the key elements required to deliver optimal 24-hour, seven day per week care to people with palliative care needs who wish to spend as many days as possible at home. It will achieve this by 1) identifying and combining the available global knowledge; 2) seeking the input of consumers, health professionals and identified digital health providers; and 3) collaboratively co-designing a new model of care.

The projects findings will form the basis for collaboratively developing a new model of care with key stakeholders that integrates best available evidence and digital health technological solutions to enable people with palliative care needs to spend more days at home.


Ketamine for Depression Pilot Study

Subcutaneous ketamine infusion for major depressive disorder in palliative care patients with advanced life limiting illness: a phase II pilot feasibility study

*Chief Investigators: Dr Wei Lee, Dr Caitlin Sheehan, Dr Fiona Stafford-Bell, Professor Richard Chye, Professor Colleen Loo, Professor Brian Draper, **Professor Meera Agar, Professor David Currow***

Funding: Palliative Care Clinical Studies Collaborative

This study is in start-up phase with sites to open for recruitment early 2019. Dr Wei Lee was awarded a TCRN (Translational Cancer Research Network) Clinical PhD top-up scholarship for this work.



Depression is common in patients who have advanced life-limiting illness that significantly impacts quality of life. Most antidepressants have limited therapeutic benefits in patients with extremely short prognoses, due to the slow onset of action. In the psychiatry literature, subanaesthetic doses of ketamine are emerging as a novel rapid onset antidepressant for patients with treatment resistant major depression with high response rate, though having short-lived effect.

This study aims to explore the use of ketamine in palliative care for people with major depressive disorder, in particular to see if this agent can address significant need for antidepressants to have rapid effects. The specific primary aim is to determine the feasibility, safety, tolerability, acceptability and activity of individually tailored subcutaneous ketamine as a treatment for major depressive disorder in hospitalised patients with advanced life-limiting illnesses, and to generate pilot data on ketamine's antidepressant effectiveness to inform a larger phase III trial.

Study is currently open to recruitment at 4 sites with 2 randomisations.

Lifespace Assessment Validation

Validation of Modified Life-Space Assessment for palliative care populations

Chief Investigators: Professor Jane Phillips, Professor Lawrence Lam, Dr Tim Luckett, Professor Meera Agar, Professor David Currow

The original Life Space Assessment (LSA) questionnaire focused on measuring the spatial extent of the person's typical life space over a three- day time frame. This questionnaire was validated in a sample of older community-based Americans undergoing cataract surgery (N=242) who were followed up for 3 years, with test- re-test reliability evaluated at 12 and 24 months. The original Life Space Assessment has subsequently been expanded to include two additional domains: i) frequency and ii) independence. The expanded Life Space Assessment now measures the extent, frequency of movement and the assistance required to enable a person to interact within their physical environment over the 4 weeks preceding assessment with follow-up at 4 weeks. The strengths of this expanded LSA assessment is that it maps where the person goes, the frequency with which they go there, and their need for equipment or help from another person. The limitation of using this validated expanded LSA questionnaire with palliative care patients would need to recall their activity levels two weeks post baseline assessment and then again at six months, which is not feasible given the limited life expectancy of this population. This study proposes to validate a modified expanded Life-Space Assessment for use in community dwelling palliative care populations using a shorter follow-up time period (one, two, three, or four-week follow-up).

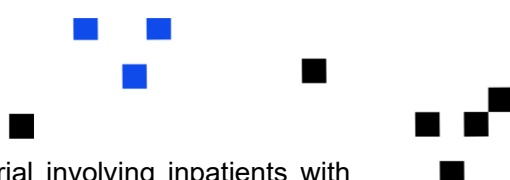
Currently study open to recruitment at 5 sites with 83 randomisations.

PRESERVE II

A multicomponent non-pharmacological intervention to prevent delirium for patients with advanced cancer: a phase III cluster randomised controlled trial

Investigator team: Professor Meera Agar and Associate Professor Annmarie Hosie

Delirium is a significant medical complication for hospitalised patients. Up to one-third of delirium episodes are preventable in older inpatients through non-pharmacological strategies that support essential human needs, such as physical and cognitive activity, sleep, hydration, vision and hearing. We hypothesised that a multicomponent intervention similarly may decrease delirium incidence, and/or its duration and severity, in in-patients with advanced cancer. Prior to a phase III trial, we aimed to determine if a multicomponent non-pharmacological delirium prevention intervention is feasible and acceptable for this specific inpatient group.



The study is a phase II cluster randomised wait-listed controlled trial involving inpatients with advanced cancer at four Australian palliative care inpatient units. Intervention sites will introduce delirium screening, diagnostic assessment and a multicomponent delirium prevention intervention with six domains of care: preserving natural sleep; maintaining optimal vision and hearing; optimising hydration; promoting communication, orientation and cognition; optimising mobility; and promoting family partnership. Interdisciplinary teams will tailor intervention delivery to each site and to patient need.

Control sites will first introduce only delirium screening and diagnosis, later implementing the intervention, modified according to initial results. The primary outcome is adherence to the intervention during the first seven days of admission, measured for 40 consecutively admitted eligible patients. Secondary outcomes relate to fidelity and feasibility, acceptability and sustainability of the study intervention, processes and measures in this patient population, using quantitative and qualitative measures. Delirium incidence and severity will be measured to inform power calculations for a future phase III trial.

PRESERVE Aotearoa pilot study

A feasibility study of a non-pharmacological delirium prevention intervention for hospitalised Māori and non-Māori with advanced cancer

Investigator team: Dr Aileen Collier, Professor Meera Agar, Professor Annmarie Hosie

Funding: The Cancer Research Trust NZ Board \$79,123

Delirium is a serious and highly distressing neurocognitive condition that occurs for one in every two people with advanced cancer in hospital. Even when delirium is recognised and the causes treated, it is reversible in only half of inpatients with advanced cancer. Nor are there any approved or proven pharmacological interventions that directly prevent or treat delirium.

Prevention of delirium is more effective than trying to reverse it once it has occurred. The strongest evidence for prevention is through non-pharmacological strategies that support essential human needs, such as physical and cognitive activity, sleep, hydration, vision and hearing. When implemented together as a 'multi-component intervention', these strategies reduced delirium incidence in older hospitalised patients in a number of studies. The magnitude of this benefit in a recent meta-analysis is in the order of 1 in 3 episodes of delirium prevented.

The aim of this study is to determine if a tailored multi-component non-pharmacological delirium prevention intervention is feasible and acceptable for people with advanced cancer in hospital. The study will be a single arm feasibility study and include semi-structured interviews with patients, family caregivers, staff and volunteers will also be used to obtain their perspectives about the feasibility and acceptability of study processes and measures. The main objectives are 1. Determine if a non-pharmacological delirium prevention intervention is feasible, acceptable and deliverable with high adherence and fidelity to Māori and non-Māori patients, families/whānau, staff and volunteers in the New Zealand hospice setting; 2. Determine the feasibility of a collaborative Australian and New Zealand Phase III trial of a non-pharmacological delirium prevention intervention for palliative care unit/hospice inpatients with advanced cancer.

Research England: Building Critical Mass for Palliative Care Research through Collaborative Support, Exchange, and Challenge: application to the International Investment Initiative (i3)

Investigator team: Professor Miriam Johnson, Professor Fliss Murtagh, Professor Liz Walker, Professor Jane Phillips, Professor David Currow

Funding: Research England, International Investment Initiative, \$162,497

IMPACCT is a partner in the Research England i3 grant awarded to the Wolfson Palliative Care Research Centre ('Wolfson') at the University of Hull. This grant allows these two significant palliative care groups to build on their strategic partnership and expand the scale and impact of collaborative research activities. Although both research groups are relatively new our closely aligned research priorities and our committed to producing excellent and practice-changing outputs has generated 69 joint research publications and grant income of £10.5 million.

Palliative care research is still in its infancy, despite the serious population changes that are already increasing the need for high-quality palliative care. Sizeable research groups are rare, yet a critical mass is required to provide the momentum needed to deliver the innovations in health and social care that are urgently needed for an ageing worldwide population. Strengthening, deepening and broadening our established collaboration is the obvious next step to ensure that such critical mass is generated, further expanded and delivers impactful research. Joint supervision across institutions and countries broadens input and helps develop rounded early career researchers. Such an exchange program and exposure to each other's institutional networks will provide a stimulating environment, cross-fertilise ideas and support the growth of early career researchers. There are few research active professors of palliative care worldwide. Closer working between Wolfson and IMPACCT will stimulate peer challenge between senior colleagues, stimulate the quality and raise the success and impact of grant applications, publications and dissemination. Our two countries face very similar challenges with regard to an ageing population and joint research will automatically have a greater international impact.

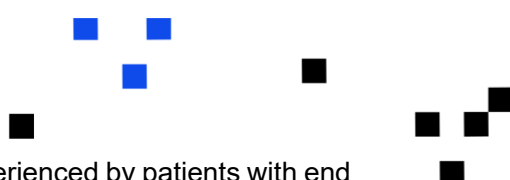
This grant reflects the two group's substantial commitment to palliative care and provides both new funds and in-kind provision. UTS has provided funding for two full time PhD studentships to match those funded by the University of Hull, to start in 2019 and 2020. UTS's "in kind" contribution will allow time from IMPACCT academics to participate in the proposed exchange program and joint supervision/teaching commitments. This time will be provided both during visits to the University of Hull, and as remote collaborative working. IMPACCT Staff at all levels will be involved in face-to-face visits, from Professorial (Phillips, Agar, Parker [Currow already has a substantive appointment at the University of Hull]), senior lecturer (Luckett), postdoctoral researcher (Kochovska) through to the PhD students. This five-year exchange program commenced in August 2019.

The UP Study

A Phase II, prospective, open-label, dual-centre, single-arm feasibility study of Pregabalin for the management of uraemic pruritus in patients with End Stage Kidney Disease (ESKD) who are conservatively managed.

Chief Investigators: Professor Meera Agar, Dr Frank Brennan, Professor Mark Brown, Dr Jessica Lee, Dr Rajesh Aggarwal, Dr Thang Du Huynh, Ms Celine Foote, Ms Elizabeth Josland, Dr Caitlin Sheehan

Funding: Palliative Care Clinical Studies Collaborative



Uraemic Pruritus (UP) is a common and often disabling symptom experienced by patients with end stage kidney disease (ESKD). It is associated with an impaired quality of life, disrupted sleep, depression and reduced mortality. In a large systematic study of symptom prevalence in patients with ESKD on dialysis, the mean weighted prevalence of uraemic pruritus was 55 % and in studies of symptom prevalence in patients with ESKD being managed conservatively the prevalence ranged from 69 % to 74 %.

While many theories abound, the aetiology of uraemic pruritus remains uncertain. Equally, until recent years, the management of uraemic pruritus has been largely empirical. Amongst those medications that have shown encouraging results in the treatment of uraemic pruritus are alpha 2 delta subunit ligands (gabapentinoids). The very little evidence for the use of Pregabalin in UP. There has been 5 poorly designed RCTs of Gabapentin on UP which showed it to be of benefit. A recent qualitative systematic review of the literature on the management of UP with Gabapentin called for more high quality research.

This multi-centred pilot study is a prospective, randomised, placebo-controlled trial to determine the efficacy and side effect profile of Pregabalin in the management of uraemic pruritus in patients with End Stage Kidney Disease (ESKD) who are conservatively managed. Its objective is to test the feasibility, safety and preliminary signal of efficacy to inform a definitive phase III study.

Pregabalin is emerging as a substitute for Gabapentin and second-line treatment after emollients for UP treatment. Pregabalin is believed to be more potent in reducing the intensity of UP with fewer side effects compared to Gabapentin. Therefore, it is increasingly being used off-label in clinical practice to treat UP in patients with ESKD.

The Phase II, prospective, open-label, dual-centre, single-arm feasibility study will evaluate the feasibility and acceptability of the use of Pregabalin in the treatment of uraemic pruritus in patients with end stage renal failure (eGFR <30) who are conservatively (not for Dialysis) treated. The results of this study will facilitate the development of a full-scale Phase III study.

VR and Pain

Virtual reality for the treatment of people with cancer-related pain

Investigators: Dr's Philip Austin, Melanie Lovell, Philip Siddall

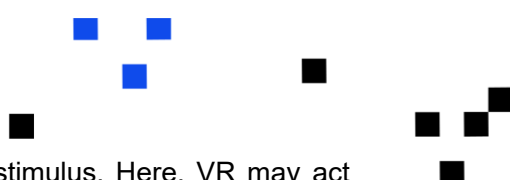
Consumer: Cassandra Bennet

Funding: Sydney Vital \$50,000

Despite the availability of cancer pain guidelines, the management of pain in people with cancer remains inadequate. As such, there is a need to develop innovative alternative therapeutic options, particularly those with no adverse effects. One potential option that is gathering interest is the use of virtual reality (VR) devices. Developments in VR technology offer an alternative approach that has been used with good effect in the treatment of several medical and psychological conditions. This technology shows promise in reducing pain and psychological symptoms in both the short and long-term.

VR is a simulated creation of a 3D environment using computer technology. While early VR systems used computer screen technology, current VR systems include immersive head-mounted devices with 3D-enabled glasses with other sensory input devices such as headphones for noise-cancelling, sound and music, head and/or body-tracking sensors and other input hardware such as joysticks and data gloves. Together, this system forms a realistic multisensory experience

The mechanisms underlying the effect of VR on pain have been divided generally into two types or processes: distraction and neuroplasticity. These processes that are thought to contribute to the analgesic effect of VR have quite different mechanisms of action. Distraction refers to the short-



term diversion of attention away from pain towards an alternative stimulus. Here, VR may act directly and indirectly by ‘hijacking’ attention, emotion and memory away from pain using auditory and touch senses. Neuroplasticity refers to long-term structural changes in neuronal populations. This may occur harmfully due to a stroke, or positively following long-term practice of a skill such as playing a musical instrument. In the case of VR, repeated immersion into interactive real-time simulations of scenes or activities appears to be associated with positive neuroplastic alterations in sensory and motor brain regions. Although cancer-related pain has strong contributions from a number of peripheral, spinal and supraspinal nervous system mechanisms, pharmacological treatments using antidepressants and antiepileptics carry a significant adverse effect burden affecting quality of life as well as the potential for interactions with anti-cancer drugs. VR may present an effective and relatively harmless alternative option for the management of pain in people

Current Projects - Aged Care

BaptistCare review

Review of BaptistCare policies and procedures for a palliative approach in residential aged care

*Chief Investigators: **Dr Tim Lockett, Professor Deborah Parker, Professor Meera Agar, Ms Carolyn Moir, Professor Jane Phillips***

Funding: BaptistCare Australia, \$10,000

A review was undertaken of BaptistCare policies and procedures for a palliative approach in residential aged care by means of the following steps:

1. BaptistCare’s current palliative approach was mapped against requirements of new Aged Care Quality Standards selected to be relevant to palliative care (Standards 1, 2, 3, 7 and 8).
2. BaptistCare’s current palliative approach was mapped against best practice as recommended by Australia’s major Commonwealth-sponsored resource suites for palliative care in aged care, ELDAC and palliAGED.
3. A rapid ‘overview’ was conducted of the latest research evidence from systematic reviews published in the peer-reviewed literature.
4. Findings from the above methods were integrated by means of a half-day workshop who generated ideas for quality improvement to be explored at Step 5.
5. Four focus groups were conducted with clinical staff at two BaptistCare facilities (one metropolitan and one regional). Focus groups were conducted at each facility separately with nurses and care workers to reduce unwanted group effects and encourage frank reporting. Focus group questions were concerned with staff perceptions of BaptistCare policies and procedures considered to be working well or in need of improvement.

The review culminated in 29 recommendations for improving policy and procedures that were presented to BaptistCare in a detailed report and at the November meeting of their Residential Managers Forum.

Carers, we see you: Exploring the experiences of student carers

Investigators: Svejkar, D, Gleeson, P. and Viswanathan, P., Teague T., **DiGiacomo M.**

Funding: Centre for Carers Research, Institute of Public Policy and Governance, University of Technology Sydney

This project represents a collaboration between the UTS Centre for Carers Research, Centre for Social Justice and Inclusion (Equity and Diversity Unit), Carers NSW Australia and the UTS Design Innovation Research Centre (DIRC). Research by Carers NSW reveals that carers, particularly young carers, commonly report lacking support from institutions regarding flexibility to assist them to balance their studies with their caring responsibilities. Informed by participatory action research, the aims of the project are to better understand the experiences and challenges faced by university student carers to inform develop a framework of inclusive policies and practices that accommodate carer participation in higher education. The project involves a review of current policies and practices of tertiary education institutions, interviews with university representatives and support staff, and focus groups with academic liaison officers and university students who are carers.

Caring@home

Caring safely for Australians at home

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

Online modules to train registered nurses caring for people at home are now available as is a resource pack for training carers: www.caringathomeproject.com.au

This project is continuing.

Delirium practice change survey


Delirium treatment practice, practice change and influencing factors: an online survey of interdisciplinary clinicians working in palliative care and other specialties

*Investigator team: **Anmarie Hosie, Meera Agar, Linda Brown, Gideon A Caplan, Brian Draper, Stephen Hedger, Debra Rowett, Penelope Tuffin, Seong Cheah, Jane Phillips, Manraaj Sidhu, David Curow***

Recent high-level studies and the Delirium Clinical Care Standard signal the need to reverse the routine use of antipsychotics and other unregistered medications for delirium.

Objectives

1. To investigate clinicians' (doctor, nurse practitioner, registered nurse, pharmacist) self-reported practice and practice change since 2016 in delirium treatment in palliative care and other specialties, focused on antipsychotic use;



2. Identify factors influencing delirium treatment practice according to the Theoretical Domains Framework (TDF).

Methods

Online survey with 22 items: nine demographics; a question about frequency of encountering new patients with delirium; ten on current practice; and ten on practice change and influencers. Current practice items included goals of antipsychotic use for delirium. Practice influencer items included prompts about key negative studies of antipsychotics for delirium. Open-ended items enabled unprompted responses about other influencers and practice change characteristics. Recruitment via 15 professional organisations was in April-July 2019. Practice influencers were categorised using the TDF. Descriptive statistics were used to summarise results.

Approach to Market: Audit of national care standards, clinical pathways and decision support tools for patients with malignant brain cancer (RFQ1819-02)

Digital Enhanced Living ARC Industrial Research Hub

Investigator team: **Professor Deborah Parker**, Professor Jo Travaglia, Professor Fiona Brooks, Dr Tom McClean, Patricia Occelli

Funding: Australian Research Council (ARC)

Deakin University along with several key partner companies and organisations aim to address this societal gap with approved funding from the Australian Research Council for the ARC Industrial Transformation Research Hub that focuses on the concept of digitally enhanced living. The research and development activities conducted by the hub aim to develop intelligent sensed spaces within residential homes and aged care facilities. Such spaces will provide a range of proactive physical, cognitive and social support to residents, thus increasing the quality of care provided to Australia's ageing population. The University of Technology Sydney joined the Hub in 2019 with industry partners Uniting and Interrelate. Projects undertaken in the Hub will support digital technology from children and adolescents to older Australians.

End of Life Directions in Aged Care

Specialist palliative care and advance care planning advisory services

*Chief Investigators: Professor Patsy Yates, Professor Jennifer Tieman, **Professor 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 improve 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.

Exploring patient and clinician perspectives on the use of wearable cardiac monitoring technology

Chief Investigators: **Dr Caleb Ferguson**, Associate Professor **Louise Hickman**, Associate Professor **Paul Breen**, Associate Professor **Sally Inglis**, Professor **Kate Stevens**, Professor **Phillip Newton**, Professor **Peter MacDonald**

Funding: **Maridulu Budyari Gumal - The Sydney Partnership for Health, Education, Research and Enterprise (SPHERE)**, **Age and Ageing Group**

There are many novel wearable devices available to monitor heart function in older people. Yet, there has been limited research to explore: the clinical indications for use; how these could be used in healthcare and; the usability of devices from the patient perspective. Our research will explore clinician and patient perspectives on the use of wearable cardiac monitoring technology for older adults. A co-design approach has been used to gain perspectives into the use, application and feasibility of applying these devices in routine care. A series of focus groups and interviews with clinicians, patients and caregivers has been completed. A usability study will be conducted to evaluate the user experience of these devices and identify areas for potential improvement. How these devices could be implemented within everyday healthcare will be explored. Recommendations will be developed for the integration of wearable devices to monitor heart function in older people

Older people and diet in the 45 and Up study

Chief Investigators: **Dr Luna Xu**, Associate Professor **Louise Hickman**, Associate Professor **Sally Inglis**, Professor **Deborah Parker**

Funding: University of Technology Sydney Faculty of Health seed funding.

Summary: While, there is emerging evidence that dietary pattern is linked to the health outcomes of older adults, there remain significant gaps in knowledge for an Australian population. This study of using NSW 45 and up dataset has two aims: 1) to evaluate status of dietary consumption and dietary transition; 2) explore cross-sectional and longitudinal links between diet and health outcomes for older Australians. Results will inform health policy and health service delivery by increasing the evidence base for dietary guidelines in improving health outcomes and the design of an effective dietary intervention for older Australians at risk of chronic diseases.

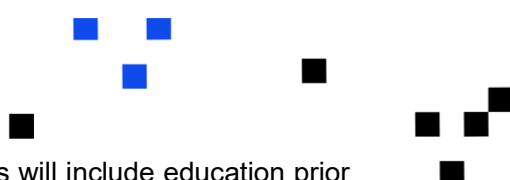
Optimising the toileting capability of people with advanced cancer as function declines

This prospective cohort study (proof of concept) aims to evaluate the feasibility and acceptability of interventions and outcome measures for use in a future RCT

Investigator team: **Dr Deidre Morgan**, **Ms Celia Marston**

Collaborating partners: **PaCCSC**, **Peter MacCallum Cancer Institute**, **Flinders Medical Centre**

Participants with advanced cancer will be recruited from 2 acute hospitals in South Australia and Victoria. They will receive a hands-on OT intervention to optimise independence with toileting while an inpatient and also receive. Interventions will be standardised across both sites to ensure consistency of approach. Baseline measures will be taken pre OT assessment, Time point 2 (during admission & within 24 hours of last intervention, TP 3 (post discharge and within 24 hours of last OT intervention, phone follow up), and TP 4 (1 week post intervention (phone follow up). Carers play a significant role in supporting patients at home who have difficulty managing toileting. For this



reason carers will be included in the intervention where relevant. This will include education prior to discharge and a needs assessment post discharge. This study builds on existing a successful CI research collaboration (competitive grant from Occupational Therapy Australia) that examines dignity with intimate hygiene at the end-of-life.

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: Professor Peter Hudson, **Professor Deborah Parker**, Professor 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.

This project is continuing.

Taking first steps - identifying local issues and workable solutions to improve healthcare for older people

*Chief Investigators: Dr Carla Saunders, Associate Professor Peter Gonski, **Professor Deborah Parker**, Dr Deborah Debono, **Associate Professor Louise Hickman**, Dr Joanne Lewis, Professor Joanne Travaglia*

Funding: Maridulu Budyari Gumal - The Sydney Partnership for Health, Education, Research and Enterprise (SPHERE)

Healthcare provision and administration, and the settings in which healthcare takes place influence when, what and how healthcare is delivered. Gaining a sound understanding of these influences at the local level is very important as efforts to change healthcare delivery will need to incorporate this knowledge.

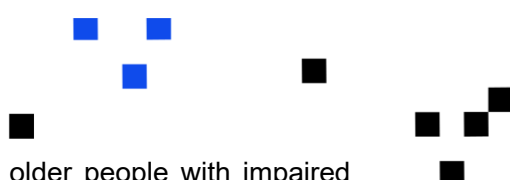
Understanding these influences can be gained from multiple perspectives, one of which is the patient perspective and since most benefit is reported to be gained from placing patients at the centre of healthcare delivery, it is logical to suggest that their perspective is needed above all. This research will investigate the older patient experience of healthcare and offer health professionals and researchers an opportunity to identify enhanced or new models of care to improve the healthcare experience of older adults.

The OPARI study

Research participation by older people with impaired decision-making capacity: a scoping review of consumers' perspectives and experiences

*Chief Investigators: **Dr Annmarie Hosie**, **Dr Slavica Kochovska**, **Professor Deborah Parker**, Associate Professor Nola Ries, Associate Professor Gideon Caplan, Dr Caitlin Sheehan, Mrs Imelda Gilmore, **Professor Meera Agar***

Funding: Maridulu Budyari Gumal - The Sydney Partnership for Health, Education, Research and Enterprise (SPHERE)



This project aimed to identify the perspectives and experiences of older people with impaired decision-making capacity and their caregivers about clinical research participation, via a scoping review and a workshop with key stakeholders (consumers, researchers, and clinicians).

The scoping review identified the perspectives and experiences of older people with impaired decision-making capacity and their caregivers ('consumers') in participating in clinical research. Older people are frequently omitted from participating in the research that is often being conducted to inform their needs. Findings are being used to inform recruitment, consent, and participation strategies to enable older peoples' engagement in future research relevant to their needs, thus improving quality of life. Findings have specific relevance to research to explore management of cognitive disorders, as well as those intending to improve quality of life, and are critical to better align research methods with consumer perspectives.

The workshop provided a critical platform to present the findings of the scoping review. This has been identified as an important area in ageing health research as often older people are excluded from research. Discussions with experts, including consumer representatives, researchers and clinicians within the area of palliative and aged care provided opportunities to investigate the findings of the review in the broader research context with implications for research ethics and governance, legislation, and clinical policy and practice.

Quantitative Evaluation of the Uniting Household Model

Investigator Team: **Professor Deborah Parker, Dr Luna Xu**, Professor Jo Travaglia, Dr Deb Debono

Funding: Uniting

Uniting NSW/ACT has been implementing a Household Model of care across 75 residential aged care facilities since 20015. This study will evaluate the impact of the Household model on financial, human resource and clinical outcomes.

Qualitative Evaluation of the Uniting Household Model

Investigator Team: Professor Jo Travaglia, Dr Deb Debono, **Professor Deborah Parker**, Dr Hamish Robinson, Dr Phillipa Carnemolla P, Dr Suyin Hor, **Dr Mandy Visser**

Funding: Uniting


Uniting NSW/ACT has been implementing a Household Model of care across 75 residential aged care facilities since 20015. This study evaluates the impact of the Household model from the perspective of staff, residents and families.

Current Projects - Chronic Breathlessness

Delineating the impact of chronic breathlessness: a cross-sectional, population based study

Chief Investigators: **Dr Slavica Kochovska**, Professor David Currow, Dr Sungwon Chang, Dr Irina Kinchin, Professor Miriam Johnson, Associate Professor Magnus Ekström, Professor Danny Eckhart, Professor Robert Adams, Professor Helen Reddel, Dr Diana Ferreira

Funding: University of Technology Faculty of Health Seed Funding Grant



Chronic breathlessness is a distressing symptom that affects people's quality of life, compromising their functionality, and leading to increased anxiety and depression. This international collaborative research will enable a better understanding of the predictors and impact of chronic breathlessness to facilitate more effective assessment of its symptom burden in clinical consultations, leading to better symptom management and care provision aligned with people's unmet needs.

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

Funding: NSW Health Translational Research Grant

This project addresses 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. In 2019, sampling was completed for interviews at the first time-point (N=41). Follow-up interviews will be ongoing into 2020.

The BEAMS Study


A pragmatic, phase III, multi-site, double-blind, placebo controlled, parallel arm, dose increment randomised trial of regular, low dose extended release morphine for chronic refractory breathlessness

*Chief Investigator: **Professor David Currow***

Project officer: IMPACCT Trials Coordination Unit

Funding: NHMRC (awarded to Flinders University)

Three hundred thousand (300,000) Australians are breathless at rest or on minimal exertion, often for years, despite optimal treatment of the underlying cause(s). This includes more than 70,000 people who are too breathless to leave their homes often for long periods of time. Underlying causes for such severe and ongoing breathlessness include chronic obstructive pulmonary disease (COPD), interstitial lung disease, heart failure, neurodegenerative diseases such as motor neurone disease and cachexia from any cause. The prevalence of chronic refractory breathlessness will continue to increase as the population ages because the chronic progressive diseases where breathlessness is common are increasing in prevalence. Nearly one half of all people experience distressing breathlessness during the last year of life. Internationally, no medication is registered for the symptomatic reduction of chronic breathlessness despite recommendations from the



American Thoracic Society, the American College of Physicians, the Canadian Thoracic Society and the American College of Chest Physicians that regular, low-dose morphine is the evidence-based pharmaceutical option.

This study aims to enhance the evidence base for the pharmacological treatment of chronic breathlessness using potential therapies compared to placebo.

This study has now closed to recruitment having met its full sample size and analysis of results is now underway.

The Impact of Chronic Breathlessness in Clinical Consultations – making the invisible, visible

Discussing the impact of chronic breathlessness in clinical consultations – making the invisible, visible: perceptions and experiences of people with chronic breathlessness, their caregivers, and health professionals as they have clinical interactions

Chief Investigators: Dr Slavica Kochovska, Professor Jane Phillips, Professor Meera Agar, Professor Patricia Davidson, Associate Professor Michelle DiGiacomo, Dr Tim Lockett, Dr Sungwon Chang, Associate Professor Lucy Morgan, Ms Belinda Fazekas, Dr Diana Ferreira, Ms Meg Brassil, Mrs Imelda Gilmore, Professor David Currow

Funding: Health Futures Development Grant, University of Technology Sydney

Chronic breathlessness is one of the most prevalent and feared symptoms in people with life-limiting illnesses. Chronic breathlessness is highly debilitating and has a profound impact on people's lives and those of their families, affecting their function (both physical and psycho-social), compromising their ability to perform everyday tasks, and resulting in poor quality of life, and greater anxiety and depression. Despite these effects, chronic breathlessness is often under-reported by patients and under-detected by their clinicians, making this symptom particularly 'invisible' and, subsequently, under-treated. Reductions in activities of daily living (i.e. 'doing less') can reduce the intensity of breathlessness while magnifying its impact. Because of its insidious nature, early detection of chronic breathlessness is important, before deconditioning sets in and people self-impose ever more limiting function. Finding an effective means to engage clinicians to identify and respond to this symptom during clinical consultations is crucial.

This qualitative study is exploring the experiences of people with chronic breathlessness, their caregivers, and clinicians (respiratory and palliative care physicians and nurses) in discussing chronic breathlessness. Using focus groups and semi-structured interviews, and participants from English- and Arabic-speaking background, the study is exploring whether chronic breathlessness is discussed in clinical consultations and whether current communication practices are effective in identifying the presence and burden associated with this symptom.

Current Projects – Cardiovascular Disease

Remote monitoring and mHealth interventions for people with heart failure

Chief Investigator: Associate Professor Sally Inglis

Funding: Cardiovascular Research Network Life Science Research Fellow, supported by the Heart Foundation and the NSW Office for Medical Research and UTS Re-establishment Grant.

This research examines the use of eHealth and mHealth technologies to support and educate people with chronic conditions, especially heart failure and atrial fibrillation to better self-manage their condition. This research includes Cochrane Reviews.

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: Associate Professor Sally Inglis, Associate Professor 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.

- Allida S, DiGiacomo M, Inglis SC. *Cochrane 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. (*Under review at Chronic Illness*).

RAPID PROGRAM

RAPID is an international, multi-site, consecutive cohort, post-marketing study of the real world net clinical effects of medications and non-pharmacological interventions used in palliative and supportive care. The program of individual research series provides data on widespread and longer term use of medications and non-pharmacological interventions such as blood transfusions. These series are cost-effective, timely and genuinely add to the knowledge for clinical care, by defining the net benefit (clinical response together with toxicity) on data from the target audience. Additionally, RAPID paediatric program is a prospective observational study of paediatric palliative and supportive care interventions – understanding the burden of the adverse effects.

Symptom Node	Series	Population	Status	Chair
Appetite and Cachexia	Mirtazapine	Palliative Care	Open	Dr Tina Naumovski
	Anamorellin	Palliative Care	Open	
Breathlessness	Benzodiazepines	Palliative Care	Open	Dr Peter Allcroft
	Opioids for breathlessness	Palliative Care	Open	
Gut Dysfunction	Macrogol for constipation	Palliative Care	Open	Prof Katherine Clark
Nausea	Cyclizine	Palliative Care	Open	Dr Phillip Good
Neurological Mood & Cognitive Disorders	Midazolam	Palliative Care	Open	Prof Meera Agar
Nursing Interventions	Noisy respiratory secretions	Palliative Care	Open	Prof Jane Phillips
	Nursing care of disoriented patients	Palliative Care	Start Up	Associate Prof Annmarie Hosie
Pain	Amitriptyline	Palliative Care	Open	Dr Jessica Lee
	NSAIDS	Palliative Care	Open	
	Oxycodone/Naloxone	Palliative Care	Closed/Results published	
	Gabapentinoids	Paediatric palliative and supportive care	Open	
Fatigue	Dexamethasone	Palliative Care	Open	Kat Urban/ Gemma Ingham
Intervention Series	Ascitic Taps	Palliative Care	Open	Davinia Seah
	Hypodermoclysis	Palliative Care	Closed	Wendy Read
	Lymphoedema Tri Series: • Compression & related physical therapies • Diuretics • Sub cutaneous needle drainage	Palliative and supportive care	Start Up	Dr Beth Russell
Extraordinary Series	Medical Cannabis	Palliative and supportive care	Open	Prof Jenny Phillips
	Gabapentin/Pregabalin for itch and restless legs	Renal supportive care	Open	Dr Nina Vogel
	Tranexamic Acid	Haematology/ Palliative Care	Open	Kathryn Forwood



Presentations

Oceanic Palliative Care Conference Perth

1. RAPID Program - Nursing Interventions in Palliative care - Poster
David C. Currow, Debra Rowett, Matthew Doogue, Jane Phillips, Linda Brown, Jane Hunt

2. RAPID Program - Deprescribing Targinin Palliative Care – Oral
Katherine Clark, Jane Hunt, David Currow, Matthew Doogue, Debra Rowett

3. RAPID Paediatric Program - Poster
David C. Currow, Debra Rowett, Matthew Doogue, Ross Drake, Jane Hunt

Department of Psychosocial Oncology and Palliative Care Dana-Farber Cancer Institute
RAPID Paediatric Program – Oral
Ross Drake, Jane Hunt



Publications

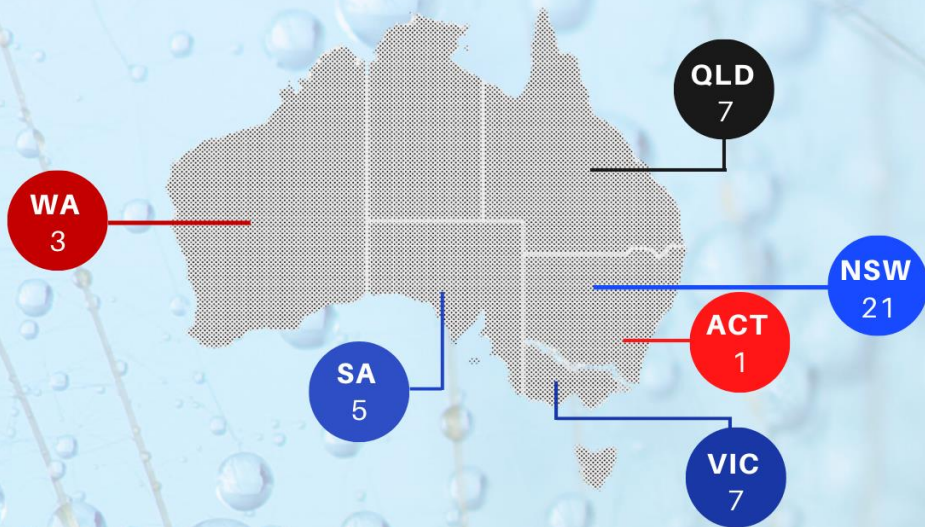
Pharmacovigilance in Hospice/Palliative Care: De-Prescribing Combination Controlled Release Oxycodone-Naloxone. *Journal Palliative Medicine Katherine Clark, Jane Hunt, Linda Brown, Debra Rowett, Gareth Watts, Melanie Lovell, David C. Currow*

RAPID SITES



Australia

44 sites



International

13 countries | 79 sites



Higher Degree Research Students

Current PhD students

Peter Allcroft

Early referral to palliative care for patients with heart failure
Supervisor: Meera Agar

Ingrid Amgarth-Duff

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

Bronwyn Arthur

The Walking Dying: The relevance of aggression as a sign or symptom of approaching death in people demonstrating severe Behavioural and Psychological Symptoms of Dementia (BPSD)
Supervisors: Deborah Parker, Louise Hickman

Adam Beaman

Health systems strengthening in global service-learning: A mixed-methods investigation
Supervisors: Patricia Davidson, Phillip Newton, David Sibbritt

Kristen Bindley

Experiences of social welfare policy post-caring at end of life in Western Sydney
Supervisors: Michelle DiGiacomo, Joanne Lewis, Jo Travaglia

Nicola Brown

Family based interventions for a smoke free home: A mixed methods approach to intervention development & pilot implementation

Supervisors: Michelle DiGiacomo, Tim Luckett, Patricia Davidson

Andrew Donkor

Access to Radiotherapy for Cancer Treatment (ARC) Project: Guidance for Low and Middle Income Countries Establishing Safe and Sustainable Radiotherapy Services
Supervisors: Jane Phillips, Tim Luckett, Sanchia Aranda

Layla Edwards

Building the evidence for a tailored post-release program for substance using females recently released from prison in NSW: a mixed methods study
Supervisor: Sungwon Chang

Kevin Koo

Implantable devices monitoring in atrial fibrillation and heart failure: evidence and user perspectives
Supervisors: Sally Inglis, Caleb Ferguson

Annie Hepworth

Can post-operative delirium management be improved for older patient patients undergoing cardiothoracic surgery and gastrointestinal surgery through early detection of risk by cognitive screening pre-admission
Supervisors: Deborah Parker, Louise Hickman

Jessica Lee

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

Wei Lee

Challenging issues in managing depressed mood in advanced life limiting illness
Supervisors: David Currow, Meera Agar, Brian Draper

Julee McDonagh

The FRAIlty MEasurement in Heart Failure Study (FRAME-HF)
Supervisors: Phillip Newton, Caleb Ferguson

Elyn Montgomery

Frailty in lung transplantation
Supervisor: Philip Newton, Sungwon Chang, Peter MacDonald, Monique Malouf

Lucinda Morris

Optimising clinical decision making for elderly cancer patients undergoing radiation therapy
Supervisors: Meera Agar, Sandra Turner, Jane Phillips

Pauline Murray-Parahi

Preparing nurses for roles in primary health care
Supervisors: Patricia Davidson, Debra Jackson, Michelle DiGiacomo, Jane Phillips

Glenn Paull

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

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

Maddie Radnan

Time Travelling with Technology (TTT): The effect of technology enhanced reminiscence therapy on engagement and care worker relationships of people with dementia in aged care facilities
Supervisors: Kate Stevens, Caroline Jones, Deborah Parker

Christine Sanderson

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

Mia Taylen-Smith

Improving palliative care for older Australians in Residential Aged Care: An evidenced based model of support
Supervisors: Deborah Parker, Liz Raymond

Claudia Virdun

Title: Developing and pilot-testing person-centred quality improvement measures to improve end-of-life care in Australia's acute care system
Supervisors: Jane Phillips, Tim Lockett, Patricia Davidson, Karl Lorenz

Aileen Wyllie

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

Submitted

Priyanka Bhattarai (UNDA)

Using digital health technology to optimise older people's pain self-management capabilities: a mixed methods project
Supervisors: Jane Phillips, Toby Newton-John

Domenica DiSalvo

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

Nicole Heneka (UNDA)

Knowledge translation intervention to reduce opioid medication errors in adult oncology and palliative care
Supervisors: Jane Phillips, Tim Shaw, Debra Rowett, Sam Lapkin

Angela Rao

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

Sara Shishegar

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

New in 2019

Ramkumar Govindaraj

Evaluating the impact of using patient-reported outcomes in oncology clinical practice
Supervisors: David Currow, Meera Agar

Celia Marston

Optimising transitions from inpatient care to home for people with palliative care needs
Supervisors: Meera Agar, Tim Lockett

Angela Phillips

Indigenous Issues in Nursing Content in Academic Curricula: A Mixed Methodology Study and Implications for Clinical Practice
Supervisors: Larissa Behrendt, Mary Stein-Parbury, Patricia Davidson

Stephanie White

Developing an intervention to build the capacity of doctors and nurses specialising in palliative care to initiate genetics/genomics discussions with patients and their families.
Supervisors: Jane Phillips, Christine Jacobs

Other universities

Philippa Cahill (UNDA)

Family meetings in palliative care
Supervisors: Jane Phillips, Liz Lobb, Chris Sanderson

Helen Dick (UQ)

Grief and loss for staff working in residential aged care facilities
Supervisors: Neil Pembroke, Deborah Parker

Diana Ferreria (Flinders)

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)

Sleep disturbance in patients with brain tumours and their family caregivers: Building evidence for an effective intervention

Supervisors: Meera Agar, Haryana Dhillon, Lawrence Lam

Nikki Mellor (WSU)

Personal and professional grief of nurses working in acute care

Supervisors: Deb Hatcher, Athena Sheehan, Deborah Parker

Fahad Shaikh (WSU)

PCOAF Study:
Pharmacological
Considerations for Obese

individuals with Atrial Fibrillation

Supervisors: Caleb Ferguson, Sally Inglis, Yenna Salamonsen, Rochelle Wynne

Emily Stone (USYD)

Multi-disciplinary care planning for people newly diagnosed with lung cancer

Supervisors: Tim Shaw, Jane Phillips, Nicole Rankin, David Currow

Mark Wilbourne (WSU)

Intention to pursue a career in mental health nursing among undergraduate students (INTENT) project

Supervisors: Yenna Salamonsen, Lucie Ramjan, Sungwon Chang

Ninik Yunitri (UMJ)

Mental Health intervention among high school students in Indonesia

Supervisors: Lawrence Lam, Mary K Lam

Masters by research**Rebecca Burgess (UniSA)**

Exploring breathlessness beliefs, expectations and language preferences of people living with chronic breathlessness

Supervisors: Marie Williams, Kylie Johnson, Slavica Kochovska.

Publications

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Book Chapters

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Conference Presentations

Agar M, Applying the evidence for better delirium care at the end of life, British Geriatrics Society Spring Meeting, Cardiff UK.

Currow DC, The value of research in improving the palliative care that we offer, Patient Reported Outcomes and Early Integration of Palliative Care Knowledge Transfer Meeting – Canadian Partnership Against Cancer (CPAC), Montreal Canada.

Currow DC, Population-based models of planning for palliative care in older people, Jockey Club End-of-life Community Care Project (JCECCP) Hong Kong Special Administrative Region (SAR), Hong Kong.

Currow DC, Prioritisation experiences in cancer control in Australia, Cancer at the Crossroads Conference, Wellington New Zealand.

Currow DC, Measuring what matters in palliative care, Where to from here? Quality in palliative care, Improving healthcare at a national level, How can national care processes improve care?, Singapore Hospice Council National Palliative Care Quality Improvement Conference, Singapore.

Currow DC, The value of interdisciplinary assessment in improving palliative care outcomes, Palliative Care Outcomes Collaboration (PCOC) Outcomes and Benchmarking Conference, Wollongong NSW.

Currow DC, Chronically breathless patients – what more can we offer them?, 13th Asia Pacific Hospice Palliative Care Network Conference, Jawa Timur, Indonesia.

Currow DC, Essential skills for a changing world, Assessing breathlessness, Surabaya, Indonesia.

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Currow DC, Evidence-based medicine in palliative care – applying research findings to clinical practice, Hospice and Palliative Medicine 20th Anniversary Conference, Madrid Spain.

Currow DC, Using the cancer registry for public health and clinical improvements in New South Wales: Elimination of Cervical Cancer in Australia: - Monitoring the quality of cancer care in New South Wales (NSW), Health Promotion Administration, Taiwan, Taipei Taiwan.

Currow DC, Medical management of breathlessness in heart failure, European Association of Palliative Care (EAPC) biennial conference, Berlin Germany.

Currow DC, Prioritisation experiences in cancer control in Australia, Cancer at the Crossroads Conference, Wellington New Zealand.

DiGiacomo M, Equipping tomorrow's professional leaders in palliative care to recognise and work with assets beyond the healthcare system, Public Health and Palliative Care International, Leura NSW.

DiGiacomo M, Recognising and working with assets beyond the healthcare system: preparing future leaders in palliative care, Ocean Palliative Care Conference, Perth WA.

Kochovska S, Do we harm participants of clinical trials?, Oceanic Palliative Care Conference, Perth WA.

Kochovska S, The PRESERVE pilot study. A phase II cluster randomised controlled trial of a multi-component non-pharmacological intervention to prevent delirium for hospitalised people with advanced cancer, 16th World Congress of the European Association for Palliative Care, Berlin Germany.

Kochovska S, Patients and carer dyads' perspectives of living with chronic breathlessness: A qualitative study, Oceanic Palliative Care Conference, Perth WA.

Kochovska S, Phase III clinical trials, ATN Collaboration & Commercialisation MedTech/Oncology conference, Sydney NSW.

Luckett T, Opioid-related problems in the cancer pain context: a qualitative study of the experiences, beliefs and attitudes of Australian general

practitioners, Oceanic Palliative Care Conference, Perth WA.

Parker D, End of Life Directions in Aged Care in Australia, 16th World Congress of the EAPC, Berlin Germany.

Phillips J, How important is it to close the gap in outcomes between hospital and home, and how might we close it?, PCOC Outcomes and Benchmarking Conference, Sydney.

Phillips J, Older cancer patients: the evolution of palliative care and geriatric oncology, Clinical

Oncology Society of Australia, Adelaide SA.

Phillips J, Palliative Care for men living with advanced prostate cancer, Implementation Forum, Changing the Face of Prostate Cancer Survivorship in Australia, Brisbane QLD.

Collaborations

New South Wales

- > Art Gallery of New South Wales, co-design of workshops to explore solutions to communication difficulties related to dementia (MV)
- > Australian Cancer Research Foundation Oncology Alliance for the Science of Integrated Survivorship (ACRF OASIS) Centre (MA)
- > Blacktown & Mt Druitt Hospitals Sydney (MD, LH)
- > Calvary Health Care Sydney (MA, MD, AH)
- > Cancer Institute NSW (DC)
- > Cancer Institute NSW – Translational Cancer Research Network (JLP)
- > Camden Palliative Care Unit (MA, AH, JLP)
- > Caresearch, Flinders University (DC, DP)
- > Central Adelaide Palliative Care Service (MA, AH, JLP)
- > Flinders University (DC, LH, DP)
- > Greater West Aboriginal Health Service (MD)
- > Griffith University (MA, AH, DP)
- > HammondCare (MA, AH, DP, JLP)
- > Melbourne University (DP)
- > NSW Cardiovascular Research Network (LH, SI)
- > NSW Ministry of Health (MA)
- > Palliative Care Outcomes Collaboration (DC)
- > Palliative Care Council of South Australia (DC)
- > Queensland University of Technology (LB, DC, LH, DP)
- > Research in Implementation Science and eHealth (RISe), Sydney University (JLP)
- > South Eastern Sydney Translational Cancer Research Network, University of New South Wales (MA)
- > Southern Adelaide Palliative Care Service (MA, DC, JLP)
- > SPHERE - Sydney Partnership for Health, Education, Research and Enterprise
 - o Aboriginal Health & Wellbeing Clinical Academic Group (MD)
 - o Age and Ageing Clinical Academic Group (MA, LH, DP, JLP, MV)
 - o Early Life Determinants of Health Clinical Academic Group (MD)
 - o Cancer Clinical Academic Group (MA, JLP)
 - o Cardiovascular Clinical Academic Group (SI)
 - o Mindgardens Clinical Academic Group (MA)
 - o Palliative Care Clinical Academic Group (MA, SC, DC, MD, LH, AH, SK, TL, DP, JLP)
- > St Vincent's Hospital and/or Sacred Heart Health Service Sydney (MA, LH, AH, SI, JLP)
- > South Western Sydney Local Health District Palliative Care Service (MA)
- > South Eastern Sydney Local Health District (LH, DP)
- > Translational Cancer Research Network, University of New South Wales (JLP)

- > Uniting (DP, MV, XX)
- > University of Newcastle, Priority Research Centre for Generational Health and Ageing (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 Queensland, Centre for Health Services Research (MA, JLP)
- > University of Sydney
 - Brain and Mind Centre (MV)
 - School of Medicine (DC, LL)
- > Victorian Comprehensive Cancer Centre (MA, LB)
- > War Widows' Guild of Australia (NSW) (MD)
- > Western Sydney University
 - MARCS Institute for Brain, Behaviour and Development (DP, LH, MV)
 - School of Nursing and Midwifery (DP, LH)
- > Westmead Hospital Sydney (DC, TL, JLP)

National

- > Aged Care Services Australia (DP)
- > Alzheimer's Australia (DP)
- > Australian Association of Gerontology (DP, LH, MV,XX)
- > Australasian Delirium Association (MA, LH, AH)
- > Australian and New Zealand Society of Palliative Medicine (MA, DC)
- > Australian Commission on Safety and Quality in Health Care (MA, LH, AH, JLP)
- > Australian Healthcare and Hospital Association (DP)
- > Blood Cancer Taskforce (LB)
- > Cancer Australia (MA, LB)
- > Cancer Council Australia (including NSW) (TL, JLP)
- > Cardiac Society of Australia & New Zealand (LH, SI)
- > Carers Australia (DP)
- > Caresearch, Flinders University (DP)
- > Catholic Health Australia (DP)
- > Leading Aged Services Australia (DP)
- > NHMRC Centre for Research Excellence, Peripheral Arterial Disease (SI)
- > NHMRC Cognitive Decline Partnership Centre (MA)
- > Palliative Care Australia (MA, DP)
- > Palliative Care Clinical Studies Collaborative (MA, MD, AH, LL, TL, DP, JLP)
- > Palliative Care Nurses Australia (LH, AH, DP, JLP)
- > Patient reported outcomes working group member (LB)

ITCC Clinical Trials Sites

- > Barwon Health, Geelong
- > Braeside Hospital, Sydney
- > Calvary Bruce, Clare Holland House, Canberra
- > Calvary Health Care Kogarah, Sydney
- > 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 Canberra Hospital, Canberra
- > Westmead Hospital, Sydney

International

- > Asia Pacific Hospice and Palliative Care Network (DC)
- > American Delirium Society, USA (AH)
- > Asia Pacific Hospice and Palliative Care Network (DC)
- > Bruyère and Ottawa Hospital Research Institutes (MA, AH, JLP)
- > Bengbu Medical College, Anhui, China (XX)
- > Chinese University of Hong Kong, Hong Kong (LL)
- > Cochrane Collaboration (SCI)
- > Eindhoven University of Technology, The Netherlands (MV)
- > Evangelische Hochschule Dresden (EHS), Germany (MA, AH, TL, JLP)
- > Guangxi Medical University, Nanning, China (LL)
- > Hong Kong Polytechnic University, Hong Kong (TL, JLP)
- > 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 (PD, MD)
- > International Learning Collaborative connected to care (LH)
- > International Network for Doctoral Education in Nursing (PD)
- > Johns Hopkins University, Baltimore, (PD, MD, LH, JLP)
- > Lancaster University, UK (DP)
- > Leiden University Medical Centre, Netherlands (DP, MV)
- > Mental Health Association of Hong Kong (LL)
- > Mahidol University, Salaya, Thailand (PD)
- > McGill University, Montreal, Canada (DP)
- > McMaster University, Hamilton, Canada (DP, XX)
- > Multinational Association of Supportive Care in Cancer (DC)
- > Queens University Belfast, Ireland (DP)
- > Stanford Primary Care and Population Health, USA (TL, JLP)
- > Sun Yat-sen University, Guangzhou, China (LL, JLP)
- > The Education University of Hong Kong, China (LL)
- > Tilburg University, The Netherlands (MV)
- > Tung Wah College, Hong Kong (AH)
- > University of Auckland, New Zealand (MA, AH, JLP)
- > University of Technology Auckland, New Zealand (LH, JLP)
- > University of Basel, Basel, Switzerland (JLP)
- > University of California, San Francisco, USA (JLP)

- > University of Cambridge, UK (DC, JLP)
- > University of Hertfordshire, UK (MA, TL, JLP)
- > University of Ottawa, Canada (MA, AH)
- > University of Manitoba, Canada (DP)
- > University of York, UK (AH, MA)
- > Vanderbilt University, Nashville, USA (MA, AH)
- > Vrije Universiteit Brussel, Brussels, Belgium (DP)
- > Wolfson Palliative Care Research Centre, University of Hull, UK (MA, DC, AH, TL, JLP)

Adjunct Professors

International

- > Professor Sabina De Geest, Professor of Nursing, Institute of Nursing Science, Department Public Health, Faculty of Medicine, University of Basel, Switzerland
- > Professor Thomas Fischer, Prof of Nursing, Evangelische Hochschule Dresden (University of Applied Sciences for Social Work, Education and Care), Dresden, Germany
- > Professor Claire Goodman, Professor Health Care Research, Centre for Research in Primary and Community Care, University of Hertfordshire; Deputy Director of the NIHR CLAHRC (Collaboration for Leadership in Applied Health Research and Care), East of England, UK
- > Professor Sonja McIlpatrick, Prof in Nursing and Palliative Care, Head of School of Nursing, Ulster University, Newtownabbey, UK
- > Professor Miriam Johnson, Professor of Palliative Medicine, Director of the Wolfson Palliative Care Research Centre, Hull York Medical School, Hull, UK

National

- > Professor Sanchia Aranda, CEO, Cancer Council Australia, Sydney, NSW
- > Associate Professor Richard Chye, Director, Sacred Heart Health Service, St Vincent's Hospital Sydney, NSW
- > Associate Professor Katherine Clark, Clinical Director of Palliative Care, Northern Sydney Local Health District, NSW
- > Professor Jonathan Golledge, Director, Queensland Research Centre for Peripheral Vascular Disease, James Cook University, Cairns, QLD
- > Professor Christopher Hayward, Consultant Cardiologist, St Vincent's Clinic and St Vincent's Private Hospital Sydney, NSW
- > Professor Elizabeth Lobb, Professor of Palliative Care (Allied Health), Chair of the Palliative and End of Life Care Research Institute, Calvary Health Care Kogarah; NSW
- > Dr Melanie Lovell, Palliative Medicine Physician, Greenwich Hospital, HammondCare, Sydney, NSW
- > Professor Peter Macdonald, Medical Director, Heart Transplantation, Senior Staff Cardiologist, St Vincent's Hospital Sydney, and Victor Chang Cardiac Research Institute, Sydney, NSW
- > Professor Phillip Newton, Professor of Nursing, Director, Nursing Research Centre, Western Sydney University and Western Sydney Local Health District, NSW
- > Professor Abdullah Omari, Head of Vascular Medicine and Staff Specialist, St Vincent's Hospital Sydney, NSW
- > Professor Tim Shaw, Professor 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
- > Dr Peter Eastman, Palliative Care Consultant, Barwon Health, Melbourne Health, VIC
- > Dr Magnus Ekstrom, Consultant, Department of Medicine, Blekinge Hospital, Sweden
- > Dr Caleb Ferguson, Senior Research Fellow, Nursing Research Centre, Western Sydney University and Western Sydney Local Health District, NSW
- > 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 Caitlin Sheehan, Staff Specialist, Palliative Care, Calvary Health Care, NSW
- > Dr Tracy Smith, Staff Specialist, Respiratory Medicine, Westmead Hospital, Sydney, NSW
- > 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 2019, 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.

Professor Phillip Moons



Professor Philip Moons from the Department of Public Health and Primary Care of the KU Leuven – University of Leuven, Belgium. Professor Moons is an international expert in nurse-led management of adult congenital heart disease. He is involved predominately in outcome and quality of life research in congenital heart disease and he has developed and implemented the role of advanced practice nurse in Adult Congenital Heart Disease Program, University Hospitals of Leuven

Professor Thomas Fischer



Professor Thomas Fischer, Head School of Nursing Evangelische Hochschule, Dresden Germany and UTS adjunct spend several weeks with the IMPACCT Team progressing a program of research on identifying and managing pain in people experiencing delirium. While at UTS, the team had an opportunity to celebrate their first output from this collaboration in Journal of Pain and Symptom Management

Professor Fliss Murtagh



Professor Fliss Murtagh is a Professor of Palliative Care at Hull as well as Visiting Professor of Palliative Care at the Cicely Saunders Institute, King's College London and consultant in Palliative Medicine at Hull University Teaching Hospitals NHS Trust UK. She is published extensively on palliative and end-of-life care needs, especially for older people and those with advanced kidney disease.

Professor Claudia Bausewein



Professor Claudia Bausewein is the Chair for Palliative Medicine at Ludwig-Maximilians University and Director of the Department of Palliative Medicine at Munich University Hospital. She is currently also Secretary of the German Association for Palliative Medicine and is a former Member of the Board of Directors of the European Association for Palliative Medicine. Her research is focused on breathlessness in advanced disease as well as complexity, outcomes measurement, palliative sedations and palliative care in non-cancer patients

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 Centre Committee, Flinders Medical Centre (DC)
- > 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, LH, SI)
- > Improving Palliative Care through Clinical Trials NSW (ImPaCCT:NSW), Management Advisory Committee (MA, TL, JLP)
- > NSW Australian Association of Gerontology, Executive member (XX)
- > Palliative Care NSW, President (DP)
- > SPHERE (Sydney Partnership for Health, Education, Research and Enterprise)
 - o Aboriginal Health & Wellbeing Clinical Academic Group (MD)
 - o Age and Ageing Clinical Academic Group - Quality of Life, Co-chair (MA), Education and Workforce, Co-Chair (DP)
 - o Cancer Clinical Academic Group - Living with and After Cancer, Chair (MA)
 - o Clinical Trials: Clinician, Public and Patient Involvement Steering Committee (LB)
 - o Clinical Trials: Conduct & Enhanced Recruitment Performance Steering Committee (LB)
 - o Mindgardens Clinical Academic Group, Steering Committee (MA)
 - o Palliative Care Clinical Academic Group, Management Committee (MA, LB, AH, DP, JLP)
- > South Western Sydney Local Health District (SWSSLHD)
 - o Human Research Ethics Committee (MA)
- > Sydney Catalyst, T2 Advisory Group (JLP)
- > Translational Cancer Research Network
 - o TCRN Executive (JLP)
 - o Workforce 2025 Flagship, Co-chair (JLP)

National Committees

- > ANZUP Cancer trials group, Quality of Life Subcommittee (TL)
- > Australian Clinical Trials Alliance (ACTA)
 - o Advisory Council (LB, DC)
 - o Reference Group A – Efficient and Effectives Clinical Trial Networks (LB)
 - o Special Interest Group for Clinical Trial Network Managers (LB)
 - o Workforce Special Interest Group (DP)
- > Australian Association of Gerontology
 - o Culturally and Linguistically Diverse Special Interest Group (XX)
 - o Student and Early Career Professional Development and Events Group (XX)
- > Australasian Delirium Association, Management Committee (MA, AH)
- > Australasian Palliative Link International, Executive Committee (MA)
- > Australian Adult Cancer Pain Management Guidelines
 - o Organising Committee (MA, TL)
 - o Working Party (MA, TL, JLP)
- > Australian College of Nursing, Policy Chapter Chair – Healthy Ageing (DP)
- > Australian Diabetic Educators Association, Diabetes Research Foundation Council (DC)

- > Australian Hartford Consortium of Gerontological Nursing Excellence -Foundation Member (DP, JLP)
- > Australian New Zealand Society of Palliative Medicine
 - President (MA)
 - 2019 ASM Conference Committee (Scientific and Organising), Chair (MA)
- > Cancer Australia
 - Cancer Cooperative Trials Group – Executive Officers Network (LB)
 - National Lung Cancer Steering Committee (JLP)
- > Cancer Symptom Trials
 - Management Advisory Committee, (MA-chair, DC, JLP)
 - Scientific Committee (MA)
- > Cardiac Society of Australia & New Zealand
 - Board (SI)
 - Cardiovascular Nurses Council, Chair (SI)
 - Professional and Ethical Standards Committee (SI)
 - Scientific Committee (SI)
 - Scientific Programming Committee (SI)
- > Caresearch
 - palliAGED National Advisory Group, Chair (DP)
 - National Advisory Group (DP)
- > 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)
 - Geriatric Oncology Special Interest Group, Chair (MA)
 - Tele-Trials Cancer Cooperative Trials Groups Advisory Group (LB, JLP)
- > Cooperative Trials Group in Neuro-oncology
 - Management Advisory Committee (MA)
 - Scientific Committee (MA)
- > European Association for Palliative Care, ASM 2019 Abstract Review Committee (MA)
- > Lung Cancer Foundation, Kylie Johnston Lung Cancer Network Committee (JLP)
- > National Cancer Expert Reference Group (DC)
- > NPS MedicineWise, Clinical Advisory Committee (MA)
- > Palliative Care Australia
 - National Policy Advisory Committee (MA, DP, JLP)
 - National Standards Review Group (MA)
- > Palliative Care Clinical Studies Collaborative
 - Management Advisory Board, Member (JLP)
 - Member (MA, MD, AH, LL, DP, JLP)
 - Mood and Cognitive Disorder Symptom Node Sub-Committee (MA-Chair, AH)
 - Qualitative Sub-committee (MD, JLP)
 - Scientific Committee, Member (JLP)
 - Trials Management Group, (AH, Chair - JLP)
- > Palliative Care Nurses Australia
 - President (JLP)
 - Committee member (LH, 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 (MA)
 - Chapter of Palliative Medicine Committee (MA)
 - Medicinal Cannabis Reference Group (MA)
- > Tele-Trial Project Cancer Cooperative Trials Groups Advisory Committee (JLP)
- > Therapeutics Good Administration Opioid Regulation Advisory Group (MA, DC)
- Victorian Cancer Agency Research Funding Sub-committee (DC)

International Committees

- > Canadian Partnership Against Cancer, Quality Initiatives and System Performance Advisory Group (DC)
- > European Palliative Care Research Network, Scientific Advisory Board (DC)
- > International Association Hospice Palliative Care, Board member (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 Palliative Care Family Carer Research Collaborative, Advocate (DP)
- > International Research Conference, Scientific and Technical Committee on Medical and Health Sciences (XX)
- > International Society Nursing Cancer Care
 - Communications Committee (JLP)
 - Policy and Advocacy Committee (JLP)
- > 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) (JLP)
- > Scientific Committee Wolfson Palliative Care Research Centre, University of Hull, UK (DC, 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.



Professor Jane Phillips, RN PhD, FACN

Professor Palliative Nursing, Director IMPACCT

IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation

Faculty of Health

T. +61 (02) 9514 4862 M. +61 (0) 4111 00617

E: jane.phillips@uts.edu.au

Level 3, 235 Jones St. Ultimo NSW 2007
PO Box 123. Broadway NSW 2007 Australia

uts.edu.au/impacct



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

Visiting Professor, Oxford Brookes University, Faculty of Health and Life Sciences, Oxford, United Kingdom

President, Palliative Care Nurses Australia 30 March 2019

IMPACCT Annual Report: 2019

Co-ordination: Vanessa Moore

Infographics: Yinyin Phyo