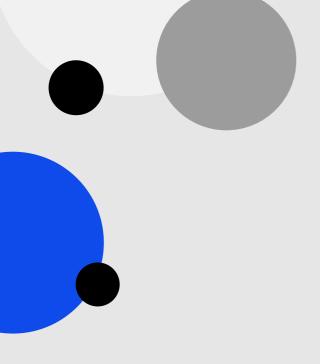


Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)





IMPACCT Annual Report

We acknowledge the Gadigal people of the Eora nation, the Boorooberongal people of the Dharug nation, the Bidiagal people and the Gamaygal people upon whose ancestral lands our university stands. We would also like to pay respect to the elders both past and present, acknowledging them as the traditional custodians of knowledge for these lands.

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CENTRE DIRECTOR'S MESSAGE

2021 cemented the need for continued efforts to improve the management and care for people living of chronic and progressive conditions, as well as for older people receiving aged care. As we tackled further challenges due to COVID-19, it brought into focus the critical importance of excellent care for our most vulnerable. It brought to the fore how important the goals of research undertaken at IMPACCT is – supporting independence, improving quality of life and symptom control, supporting carers and optimising models of care and ensure equity of access to quality care and medicines to ensure people receive care in the setting or choice using technology and innovation solutions where needed.

Despite the challenges of recent times, IMPACCT has continued to demonstrate our resilience to changing circumstances, whether it be continued working from home arrangements as a second wave of COVID-19 hit, or slow recruitment in some of our clinical trials. We could not have navigated our success without the drive and dedication of all of our academic, research and professional staff, and the support of our research partners, consumers and collaborators. Their commitment to IMPACCT is extraordinary and I thank each and every one of them. Many have contributed to national and international work to ensure the needs of the populations we advocate for were include in guidelines and guidance aiming to ensure excellent care during the COVID pandemic.

Many of our research projects have continued to shine. The Cancer Australia funded phase III clinical trial led by Professor Meera Agar completed recruitment on time of the 221 participants required for a fully powered study despite the pandemic. The MRFF Bereavement during COVID-19 project led by Adjunct Professor Liz Lobb, one of the largest national studies on bereavement undertaken in Australia during the COVID-19 pandemic, has collected preliminary data from over 1,500 bereaved and developing a plan for bereavement support will soon be underway. The Palliative Care in Prisons – A National Palliative Care Project, led by Emerita Professor Jane Phillips is continuing, having published an editorial in the International Journal for Palliative Nursing to advocate for the development of palliative care provision in prisons globally.

Teaching and Learning in the Palliative Care Program remained strong, with more than 70 enrolments, 13 subjects taught and 5 new subjects developed. Our teaching staff expanded to include 3 new subject experts, Nicole Knox (RN with experience in acute and chronic clinical nursing), Dr Mariana De Sousa (UTS Chancellors Research Fellow) and Fiona Turk, Director Pharmacist Evaluation Section, Health Products Group, Australian Government Department of Health. Our Higher Degree students, hard work and dedication was rewarded with 5 students completing their PhD, and 3 students submitting. It is always satisfying as academic supervisors to see our students reaching this significant milestone – big congratulations and success in life ahead.

In September, we welcomed both Professor Brian Le and Dr Tim Luckett who were appointed to the roles of PaCCSC Co-Chairs and they are bringing fresh ideas and a new vision for PaCCSC, while building on our track record of conducting high-quality clinical research to achieve better outcomes for the palliative patient population.

Cancer Symptom Trials (CST) received support from the clinical trials program through Cancer Australia for a further three years, an important achievement acknowledging the important place symptom control places in cancer care amongst the 15 cancer collaborative trials group supported by this program. The CST team are focused on the continuing program of work as well as a new range of deliverables focused on building equitable access to cancer symptom trials for people living with cancer, regardless of geography, diagnosis, or demographic factors.

Our Consumer Advisory Group continued their dedication to sharing their experiences as patients or caregivers to research projects and clinical trials. The continued virtual mode of delivery did not phase our team, and provided our academic team and collaborators with invaluable insight and voice to implementing research findings into practice.

Please take a look through the rest of our report, where I know you will join with me to see that our team continues to deliver IMPACCT vision of "best care, any place, every time".

meeranga

Professor Meera Agar, Director - IMPACCT *PhD, MBBS, FRACP, FaChPM, MPC*





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



PATIENTS, CARERS AND COMMUNITY

To actively engage with patients and carers to ensure their voices are at the centre of all we do in improving individual and community health and wellbeing.

MODELS OF CARE

To assist health services to develop sustainable, safe and cost effective models of care.



KNOWLEDGE * & CARE PROVISION

To address disparities and inequities of access to chronic and palliative care, referrals and other issues.



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.



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.



IMPACCT AT A GLANCE

RESEARCH PRODUCTIVITY & CAPACITY BUILDING



134

Peer reviewed manuscripts & publications

Book chapters

Book

17

Conference presentations Invited/Key note presentations

NEW RESEARCH GRANTS AWARDED

L3,134,262 TOTAL FUNDING

> \$3,836,949 IMPACCT-led grants \$9,297,313 Collaborative grants

40% of grants Category 1

STAFFING

- 9 Academics
- 5 Postdoctoral Research Fellows
- ▶ 20 Research Assistants
- ▶ 22 Adjunct Professors
- ▶ 28 Honorary Associates
- ▶ 1 National Business Manager
- ▶ 4 Admin, Finance & Project Officers

SERVICES TO THE UNIVERSITY & COMMUNITY

Editorial roles on peer reviewed journals



11 International



16 NSW



45 National



21 University

HOURS OF SERVICE



UTS 435 hours

Community 1100 hours

TEACHING & LEARNING

PALLIATIVE CARE POSTGRADUATE PROGRAM

13

Delivered

Students

Developed

Graduates



HIGHER DEGREE RESEARCH STUDENTS

20 Current

3 Submitted

9 Other universities

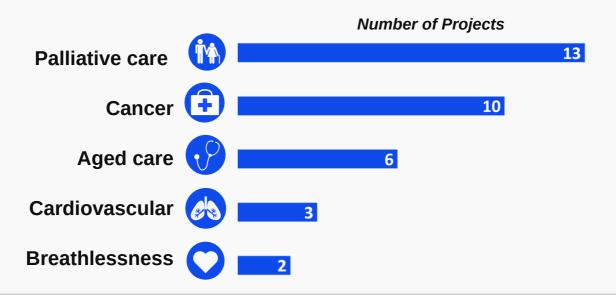
5 Completions

RESEARCH PROJECTS

ACTIVE RESEARCH PROJECTS

24 New
Description:
Description:

RESEARCH AREAS



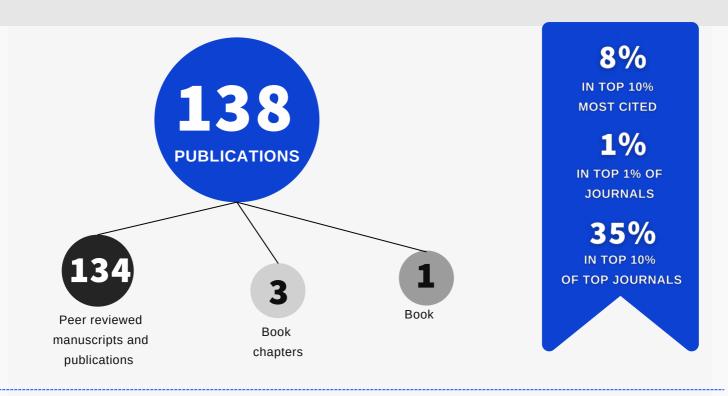
CLINICAL TRIALS

Open trials



Closed

PUBLICATIONS AND CONFERENCES



of our publications have met the <u>United Nations Sustainable Development Goals</u>.

No Poverty (2); Zero Hunger (1); Good Health and Wellbeing (48) and Quality Education (3)





IMPACCT HIGHLIGHTS

IMPACCT RESEARCHERS RECOGNISED AT PALLIATIVE CARE AUSTRALIA OPCC CONFERENCE 2021

IMPACCT was well represented at the conference across all three days of the conference.

There were contributions from our researchers, collaborators, clinical trialists and PhD candidates who presented current research and facilitated workshops to encourage discussion on key issues in palliative care.

There were also three posters including one from the ASPERT pancreatic cancer group and one from the IMPACCT Rapid Program.

Our Researchers were also among those recognised amongst a record number of nominations.



INDIVIDUAL EMERGING RESEARCHER AWARD Claudia Virdun (pictured), IMPACCT PhD candidate, was awarded the Individual Emerging Researcher Award.

Runners up two and three in this category were also IMPACCT PhD candidates, Celia Marston and Kristin Bindley.



Dr Claudia Virdun



INDIVIDUAL EXCELLENCE IN ABORIGINAL OR TORRES STRAIT ISLANDER PALLIATIVE CARE AWARD

Cheryl Porter-Pedras received this award.

Cheryl is a palliative care clinician in the South Wester Sydney Local health District. She is also a member of the IMPACCT Palliative Care in Prisons Project Aboriginal Community Engagement Advisory Committee.



FACING UNMET NEEDS IN PATIENTS WITH RESPIRATORY DISEASE

New research has highlighted the need for improved access to palliative care in patients with non-cancer respiratory disease.

Every year, malignant and non-malignant respiratory diseases account for approximately 4.6 million deaths around the world. However, despite similar symptom burdens, there are serious inequities in access to palliative care for people with non-malignant respiratory diseases.

Professor David Currow, PaCCSC Chief Investigator, was a senior investigator on a recent study that compared the functional decline and symptom distress in patients with advanced malignant and non-malignant diseases.

Read more

MAKING HEADWAY FOR DIVERSITY IN CLINICAL TRIALS

IMPACCT researchers are designing studies and trials that are inclusive for people from Culturally and Linguistically Diverse (CALD) Backgrounds. In an article posted to the ABC news website on 27 April, one clinical trial participant shared her story and concerns about diversity in clinical trials, including lack of inclusion of people from Culturally and Linguistically Diverse (CALD) backgrounds.

The article raises important issues for clinical trialists. UTS IMPACCT researchers are making progress in this space by designing studies and trials that include people from CALD backgrounds. It is important that culturally and linguistically diverse people have access to clinical research to ensure that the evidence gathered is applicable to them. We know that there are potential factors such as racial differences in opioid receptors, cultural expression of pain, interaction with healthcare professionals, perception of interventions or hospital admission that may impact this.





CORD BLOOD TRANSPLANT SUCCESS

CST Research Assistant, Dr Vanessa Yenson shares her cord blood transplant success 21 years post-treatment



In October 1999, Vanessa Yenson was the first adult in Australia to receive a bone marrow transplant from cord blood.

Following initial treatment and remission, Vanessa relapsed with leukaemia. Her further treatment choices were limited. After more chemotherapy, she needed a bone marrow transplant to live, but they could not find a suitable bone marrow donor anywhere in the world. At that stage, cord blood had only been used to help children but on consideration of Vanessa's situation, they began a search of the cord blood banks around the world, eventually finding a match in the USA.

Read more about Vanessa's story on UTS Health Blog



CHANCELLOR'S POSTDOCTORAL RESEARCH FELLOW SUCCESS FOR HEALTH



PaCCSC Postdoctoral Research Fellow, Dr Mariana de Souza e Sousa, is one of thirteen early-career researchers to have been awarded the UTS Chancellor's Postdoctoral Fellowship.

Recipients of the scheme have a four-year appointment, project funding of \$50,000 and a range of other benefits.

Mariana's project, Building multidisciplinary capacity to deliver quality cancer cachexia care, will deliver a competency-based education and training framework (CAXcare), to support health care professionals to make timely diagnoses and provide best-practice cancer cachexia care in Australia.

Congratulations to Mariana and to the all the award recipients.

Read more: https://www.uts.edu.au/about/faculty-health/news/chancellors-postdoctoral-research-fellow-success-health

OPTIMISING ACCESS TO RESEARCH PARTICIPATION FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

Linda Brown, PaCCSC/CST National Manager, has been invited to join the investigator team of a project titled Optimising equitable access to cancer research participation for Aboriginal and Torres Strait Islander people: Development of culturally-responsive resources to guide informed decision-making.

The project, funded by Cancer Australia through the Supporting people with cancer grant initiative, is being led by Chief Investigator Dr Bena Brown from the Menzies School of Health Research and The University of Queensland.

The aim of the project is to support Australia's First Nations participation in cancer research/clinical trials, thus optimising equity in access and representation in cancer research.

The team will co-design culturally-responsive resources to support Aboriginal and Torres Strait Islander people to make informed decisions about cancer research participation. Through the application of Indigenist and co-design principles, the initiative seeks to develop culturally-responsive resource through completion of:

- 1. A Consumer Advisory Group
- 2. Understanding perspectives
- 3. Information package, question prompt list and decision aid
- 4. Evaluation

ACADEMICS



Professor Meera Agar, PhD, MBBS, FRACP, FaChPM, MPC Director of IMPACCT

Meera is an experienced clinical researcher, with specific interests in the supportive care needs relating to the impacts of advanced illness on the brain and innovative models to integrate symptom management and support for people living with cancer. Meera leads a clinical research portfolio which includes clinical trials and health service evaluation, geriatric oncology, cachexia, medicinal cannabis, delirium prevention, malignant bowel obstruction and brain cancer supportive care.



Professor David Currow PhD, MPH, BMed, FAHMS

David is an internationally recognised expert in improving the delivery of palliative care. David's research expertise 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. David left UTS in November 2021 and remains as an Adjunct Professor at IMPACCT.



Professor Louise Hickman PhD, MPH, BN, RN

Louise's research program builds upon the crucial urgency to address unmet chronic health care needs in our ageing population, and moving care from a traditional acute episodic care model of treating one patient, one disease, to a person-centred, culturally safe care continuum model across care settings.



Professor Debra Anderson RN, BA, GDNS(Ed), MN, PhD

Debra is Director and Founder of the Women's Wellness Research Program, a Program for midlife women who want to focus on wellness in midlife with particular attention to managing menopause and other midlife concerns and developing healthy eating and exercise habits. Her research focuses on understanding the basis and effects of risk behaviours in women and the interventions to change them; focusing on wellness and healthy behaviours. Her research aims to promote healthy behaviour change in women with and without chronic disease, including midlife women, women with Diabetes type 2 and women cancer survivors, including physical activity, dietary intake, stress management, and smoking cessation; and to develop and test interventions that promote these behaviours. Professor Anderson is Dean of Faculty of Health, UTS.

ACADEMICS



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

Sally's research interests are chronic cardiovascular diseases, including peripheral arterial disease and heart failure. She is a NSW Cardiovascular Research Network Life Science Fellow, supported by the Heart Foundation. Sally has established a program of research into the management of peripheral arterial disease in Australia and the use of health technology to support people with heart failure. Sally has completed a large Cochrane review of telemonitoring in heart failure and is also leading Cochrane reviews examining self-management interventions for people with peripheral arterial disease and the use of m-health technology for health education in heart failure.



Professor Deborah Parker PhD, MSocSc, GradCert Leadership, BA

Deborah' research seeks to improve the quality of life and care for senior Australians. This includes programs of research in palliative care, digital technology and sustainable business models. She is Co-Director of the University of Technology Ageing Research Collaborative and leads the Quality of Care research theme.



Associate Professor Michelle DiGiacomo PhD, MHSc (Hons), BA

Michelle's program of research appreciates the contexts within which individuals, families, and communities negotiate, cope, and adjust to living with chronic conditions. She endeavours to underscore the importance and utility of tailoring health service initiatives to meet the diverse needs and preferences of individuals and groups. Michelle teaches subjects as part of the IMPACCT Palliative Care course.



Dr Tim Luckett PhD, BSc (Hons)

Tim's research focuses on the development and evaluation of complex interventions to improve quality of care and outcomes for people with life-limiting illness and their families. Using both quantitative and qualitative research methods, Tim's work explores the intersections between health, social and implementation sciences to inform person-centred care. Tim coordinates 4 subjects in the IMPACCT postgraduate Palliative care course.



Dr Sungwon Chang PhD, MS, BScBM

Sungwon is a Biostatistician and a Senior Lecturer. She has solid theoretical training in statistics and extensive experience in the application of epidemiology and biostatistics in public health and health services research. Having developed a strong collaboration with Palliative Care Clinical Studies Collaboratives, her research focuses mainly on palliative and chronic care research.

RESEARCH FELLOWS



Dr Anna Green, PhD, MDev, BSocSci

Anna's 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. In collaboration with the Prostate Cancer Foundation of Australia, Anna was involved in the formation of an Expert Panel and Delphi study to develop a survivorship framework for men with prostate cancer and their families in Australia and New Zealand.



Dr Serra Ivynian, PhD, BMedSci(Hons)

Serra is a Research Fellow and Project Manager for the MRFF National COVID-19 Bereavement project support by MRFF investigating mental health effects and support needs of Australians bereaved during and following COVID-19. Her PhD thesis investigated care-seeking behaviour in patients with heart failure, with inferences for patient-provider communication for people with chronic illness



Dr Slavica Kochovska, PhD

Dr Slavica Kochovska was the inaugural Postdoctoral Research Fellow with the Palliative Care Clinical Studies Collaborative (PaCCSC). Slavica's research aims to improve the experience of advanced symptoms for people with serious, advanced illnesses. Her goal is to improve communication between patients, caregivers, and clinicians developing innovative interventions that facilitate patient-clinician communication.



Dr Rayan Saleh Moussa, BMedSci (Hon 1), PhD

Dr Rayan Saleh Moussa is the CST Postdoctoral Research Fellow. Rayan was awarded her doctorate in cancer therapeutics in 2017 by the University of Sydney. Her postdoctoral research is focused on improving the preclinical to clinical pipeline through multidisciplinary translational research in cancer symptom therapeutics and interventions.



Dr Mariana Sousa, PhD

Dr Mariana Sousa is the PaCCSC Postdoctoral Research Fellow as well as the UTS Chancellor's Research Fellow. She is a clinician researcher with interests in cancer-associated symptoms, including treatment-related harms and the impact of health on quality of life. Her postdoctoral fellowship focuses on better understanding cancer cachexia and identifying advances to support patients' nutritional and functional state across the cancer care continuum.

ADMIN & RESEARCH SUPPORT

ADMINISTRATIVE SUPPORT

Vanessa Moore

Centre Manager and Executive Assistant

Catherine Lambert

Finance and Administrative Officer

Therese Schroeder

Master Palliative Care and Masterclass program support

RESEARCH SUPPORT

Ingrid Amgarth-Duff, PhD, BSc (Hons)

Research Assistant

Andrew Donkor, PhD

Research Assistant

Domenica DiSalvo, PhD, BMedSci (Hons)

Research Assistant

Layla Edwards, BAppPH

Research Assistant

Sally Fielding, RN, MPH

Research Assistant, Project Officer, National Prisons Project

Maja Garcia, BIntSt, BMedSci (Hons)

Research Assistant

Kimberley Jones, MBMSc, BPsycSci,

Research Assistant, MRFF National COVID Bereavement project

Michelle Kaczurowski, BSc

Data Assistant

Kim Offner, MPH, BNursing

Project Manager, National Prisons project

Sara Roberts, BBehSci(Hons)

Research Assistant, MRFF National COVID Bereavement project

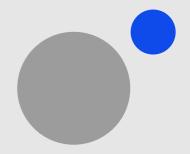
Isabelle Schaefer, PhD

Research Assistant and Project Officer, National Prisons Project

Simone Simonetti, PhD, BPsyc (Hons)

Research Assistant working with Professor Deborah Parker

ADJUNCT PROFESSORS



NATIONAL

Professor Sanchia Aranda

CEO, Cancer Council Australia, Sydney, NSW

Professor Michael Chapman

Director of Palliative Care at Canberra Hospital and Health Services, ACT

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

Associate Professor Jodie Ellis

Department Head Nutrition and Dietetics, Calvary Hospital

Associate Professor Caleb Ferguson

Western Sydney University

Associate Professor Philip Good

Professor Christopher Hayward

Consultant Cardiologist, St Vincent's Clinic and St Vincent's Private Hospital Sydney, NSW

Professor Lawrence Lam

Vice President (Academic) Tung Wah college Hong Kong

Associate Professor Brian Le

Royal Melbourne Hospital

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

Dr Sandra Lynch

Director of the Institute for Ethics and Society, Notre Dame University Sydney

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 Jennifer Philip

Chair of Palliative Medicine at University of Melbourne and St Vincent's Hospital

Professor Tim Shaw

Professor of eHealth, Director Research in Implementation Science and eHealth Charles Perkins Centre, University of Sydney, NSW

INTERNATIONAL

Professor Patricia Davidson

Dean Nursing, John Hopkins University

Professor Thomas Fischer

Professor 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

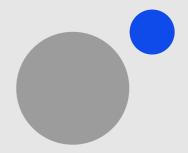
Deputy Director of the NIHR CLAHRC (Collaboration for Leadership in Applied Health Research and Care), East of England, UK

Professor Miriam Johnson

Professor of Palliative Medicine, Director of the Wolfson Palliative Care Research Centre, Hull York Medical School, Hull, UK



HONORARY ASSOCIATES



Dr Penelope Abbott

General Practitioner, Sydney West Aboriginal Health Service (SWAHS), Mt Druitt, NSW

Kimberley Bardsley

Nurse Practitioner, St Vincent's Hospital Sydney, NSW

Kristin Bindley

Western Sydney Local Health Service

Dr Chakra Budhathoki

Assistant Professor, Department of Acute and Chronic Care, School of Nursing, Johns Hopkins University, Baltimore, USA

Dr Mark Buhagiar

Andrew Donkor

Ross Drake

Starship Childrens Health

Dr Peter Eastman

Palliative Care Consultant, Barwon Health, Melbourne Health, VIC

Dr Magnus Ekstrom

Consultant, Department of Medicine, Blekinge Hospital, Sweden

Merrilee Kessler

University of New South Wales, Sydney, NSW

Dr Irina Kinchin

Senior Researcher, Trinity College Ireland

Dr Amanda Landers

Dr Matsuoka Hiromichi

Kinki University, Japan

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 Angela Rao

Clinical Nurse Specialist, Calvary Healthcare, NSW

Stephen Peterson

Consumer representative

Roslyn Prichard

University of Sunshine Coast, QLD

Davinia Seah

Senior Lecturer, Sacred Heart Health Service, NSW

Dr Caitlin Sheehan

Staff Specialist, Palliative Care, Calvary Health Care, NSW

Ben Smith

Maridulu Budyari Gumal, SPHERE

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

Rowena Tucker

SPHERE

Dr Amy Waters

Staff Specialist, Palliative Care, St George Hospital, NSW

Carol Whitfield

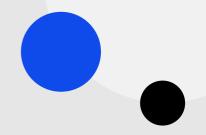
Nurse Practitioner, St Vincent's Hospital Sydney, NSW

Dr Claudia Virdun

Queensland University of Technology, QLD

Robert Zecchin

Nursing Unit Manager, Area Cardiac Rehabilitation, NSW





THE "SILENT EPIDEMIC" OF GRIEF DURING THE COVID-19 PANDEMIC



Professor Liz Lobb

Adjunct Professor of Palliative Care

As the death rates from COVID-19 rise around the world, researchers are beginning to identify what has been called the "silent epidemic" of grief.

Bereavement during the COVID-19 pandemic, whether attributable to the virus or not, presents many additional risk factors for poorer mental health. These include the public health measures of social distancing, personal protective equipment requirements, border closures, limits on visitors to hospital and residential aged care facilities, and reduced physical contact at funerals.

Although successful in reducing the spread of the virus and overall number of deaths, the public health measures have disrupted not only the way we live, but the way in which we die and grieve.

One of the largest national studies on bereavement undertaken in Australia during the COVID-19 pandemic has collected preliminary data in 2021 from over 1,500 bereaved people. Results indicate that of people bereaved at least 12 months, a third were experiencing ongoing severe grief reactions, and moderate to severe levels of depression and anxiety.

While the research suggests that overtime, most people find ways of living with their loss and the distress it causes, data indicates that 7 to 10% of bereaved people will experience chronic and disabling grief, which impacts their ability to function in their daily life and is linked with substantial mental and physical health morbidity.

How COVID-19 will impact grief related distress is the focus of a growing body of international research. Liz Lobb, Adjunct Professor of Palliative Care from the Faculty of Health together with other UTS researchers will use the information collected from the National COVID-19 bereavement project to develop a plan for bereavement support during the COVID-19 pandemic and any future pandemics.



PALLIATIVE CARE CLINICAL STUDIES COLLABORATIVE (PACCSC)

CANCER SYMPTOM TRIALS (CST)

IMPACCT TRIALS
COORDINATION CENTRE
(ITCC)



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 trial conduct support through the IMPACCT Trials Coordination Centre (ITCC).

PaCCSC

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

- O 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.

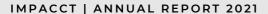
CST

One of fourteen Cancer Cooperative Trials Groups (CCTGs) provided with infrastructure support by Cancer Australia. Through clinical trials, CST research's options for improved management of cancer symptoms by identifying accessible, affordable and appropriate medicines and therapies for people with cancer.

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 coordination team.



NEW LEADERSHIP FOR PaCCSC

Professor Meera Agar is delighted to announce that Associate Professor Brian Le and Dr Tim Luckett are the newly appointed Co-Chairs of PaCCSC.

Professor David Currow, founding Chief Investigator of PaCCSC, is stepping down after 15 years as he takes up his new position as Deputy Vice Chancellor (Health and Sustainable Futures) at the University of Wollongong.

Under David's leadership, the PaCCSC national and international membership has continued to grow to over 250 members, who have developed a strong program of clinical research, including six new trials currently in start-up.

We are pleased to welcome Brian and Tim who with their combined experience will embrace the future opportunities and challenges we face as a collaborative of members, clinicians and consumers.

The nature, volume and complexity of conducting clinical research coupled with a strategic imperative to expand into non-traditional populations and clinical areas led us to appoint Brian and Tim who will work together to steer PaCCSC safely and strategically into the future.

With Brian and Tim at the helm, PaCCSC will continue to receive the same high-level support of the IMPACCT Trials Coordination Centre (ITCC) under the leadership of the National Manager, Linda Brown.

Congratulations to Brian and Tim!



Dr Tim Luckett



Associate
Professor Brian Le

Paccsc, cst & itcc team



Linda Brown, MBus, BBus (Mgmt)

PaCCSC/CST National Manager

Linda is responsible for implementing the PaCCSC and CST strategic and operational plans as well as financial management and stakeholder engagement. She provides professional leadership and management of the research network as well as ongoing development of the research program and oversight of PaCCSC, CST and ITCC. Linda also leads the IMPACCT Consumer Advisory Group (CAG), which includes consumers with particular interest, knowledge, and skills in clinical trial research.

RESEARCH SUPPORT

Belinda Fazekas, BN

National Project Officer

Jessie Hao, PhD, MMed, BMed,

Research Assistant - Trials

Jane Hunt, RN

Rapid Program and Rapid Paediatric Program Coordinator

Linda James

Project Officer

Jessie Lourdesamy, BSc (Hons)

Research Assistant – Trials (Departed Jan 2021)

Yinyin Phyo, MPhil, BBioTech, BBus (Marketing)

Research Assistant

Grace Prael, BA, BMedSci (Hons)

PaCCSC Research Assistant - Writer

Manraaj Sidhu, BMedSc, BSc (Hons)

Research Assistant - Data

Charmain Strauss, PhD, BBiomedSci

Research Assistant - Trials

Vanessa Yenson, PhD, BHealthSci, BBMSc(Hons)

CST Research Assistant - Writer

Paccsc Governance

Paccsc governance is part of the IMPACCT governance structure including the IMPACCT Scientific Advisory Committee. In 2021, this also included the Joint Paccsc/CST Trials Management Committee and study-specific Data and Safety Monitoring Committees.

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 by colleagues and the community.

IMPACCT Scientific Advisory Committee (including PaCCSC)

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

Professor David Currow

Chair

Professor Meera Agar

IMPACCT Director

Linda Brown

PaCCSC/CST National Manager

Professor Debra Anderson

Dean, Faculty of Health

Dr Paula Cronin

Senior Research Fellow, Centre for Health Economics Research and Evaluation

Dr Sopany Saing

Research Fellow, Centre for Health Economics Research and Evaluation

Dr Sungwon Chang

Biostatistician

Imelda Gilmore

Consumer representative

Associate Professor Brian Le

PaCCSC Co-Chair

Dr Tim Luckett

Senior Lecturer, IMPACCT and PaCCSC Co-Chair (Acting Chair last guarter 2021)

Dr Mariana Sousa

PaCCSC and Chancellor's Postdocroal Research Fellow

Vanessa Moore

Secretariat/observer

Joint PaCCSC/CST Trials Management Committee (TMC)

The Trials Management
Committee was responsible for
the development, review and
oversight of issues specific to
each study, including recruitment,
outcomes and milestones. This
committee was dissolved at the
end of 2021 and will be replaced
with a new Paccsc/cst Site
Investigator Forum.

Data and Safety Monitoring Committees

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.

Site Representation

Peter Allcroft

Southern Adelaide Palliative Care Service, SA

Michael Chapman

The Canberra Hospital, ACT

Marie Claire Francisco

Braeside Hospital

Peter Eastman

Barwon Health, VIC

Katherine Clark

Northern Sydney LHD, NSW

Philip Good

Mater Health/St Vincent's Private Hospital (Brisbane), QLD

Sutharsha Kanathigoda

Calvary Bruce, Clare Holland House. ACT

Brian Le

Royal Melbourne Hospital, VIC

Melanie Lovell

Greenwich Hospital, NSW

Christine McDonald

Austin Health, VIC

Jennifer Philip

St Vincent's Hospital Melbourne, VIC

Jessica Lee

Concord Hospital, NSW

Megan Ritchie

Concord Hospital, NSW

Despina Seccombe

Liverpool Hospital, NSW

Caitlin Sheehan

Calvary Health Care Kogarah, NSW

Other Members

Douglas Bellamy

Nurse Representative (Cancer), NSW

<Vacancy>

Nurse Representative (Palliative Care)

Brian Ensor

New Zealand Representative, NZ

Lisa Mounsey

Advanced Trainee Representative

David Currow

PaCCSC Lead Investigator, NSW

Meera Agar

CST Chair, NSW

Jane Phillips

Chair TMC, LifeSpace

Coordinating Principal Investigator

(CPI), CPAS CPI, QLD

Linda Brown

Paccsc/cst National Manager,

Belinda Fazekas

ITCC National Project Manager, NSW

Aileen Collier

PRESERVE-NZ CPI

Annmarie Hosie

PRESERVE CPI, NSW

Jessica Lee

LICPain CPI

Raj Aggarwal

UP Study Co-CPI

Thang Du Huynh

UP Study Co-CPI

Nicola Atkin

Lorazepam for Anxiety Study CPI

Ruwani Mendis

INCA Study CPI

Gemma Ingham

Management of Fatigue Co-CPI

Kat Urban

Management of Fatigue Co-CPI

Deidre Morgan

Rehabilitation in PC Toileting Co-

Celia Marston

Rehabilitation in PC Toileting Co-

Natasha Smallwood

HiFlow in PC CPI

CST GOVERNANCE

CST is governed by a Management Advisory Committee and a Scientific Advisory Committee. In 2021, the governance structure also included study-specific Trial Management Committees as well as 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)

The Management Advisory

Committee is responsible for the strategic governance of CST.

Professor Meera Agar

Chair

Professor Jane Phillips

Cancer Nursing Expert, Deputy Chair

Professor Jennifer Philip

CST External Investigator

Professor Katherine Clark

CST External Investigator

Professor David Currow

PaCCSC Chief Investigator

Associate Professor Brian Le

PaCCSC Co-Chair

Dr Tim Luckett

PaCCSC Co-Chair

Professor Lloyd Sansom

IMPACCT (including PaCCSC) Management Advisory Board

Chair

Professor Richard Head

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

Associate Professor Cristina Caperchione

Allied Health Expert

Dr Christopher Steer

Regional Australia Cancer Trials Expert

Dr Rayan Saleh Moussa

Early Career Researcher

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

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

Membership

Professor Richard Head

Chair

Associate Professor Brian Le

Palliative Care representative, Deputy Chair

Professor Meera Agar

CST MAC Chair

Professor Rosalie Viney

Health Economist

Associate Professor Brendan Mulhern

Cancer Quality of Life Expert Service Team (CQUEST) (second half of 2021)

Dr Belinda Butcher

Biostatistician

Dr Rachel Campbell

Quality of Life National Technical Service (nominee) (second half of 2020)

Associate Professor Joel Rhee

Primary Care expert

Professor Phyllis Butow

Psycho-oncology expert

Dr Aaron Wong

Early- to mid-career representative

Dr Michael Chapman

Geriatric oncology expert

Andrea Cross

Consumer representative

(Vacancy)

Radiation oncologist with supportive care/symptom

expertise

(Vacancy)

Medical oncologist with supportive care/symptom expertise

Joint PaCCSC/CST Trials Management Committee

In 2021, a Trial Management Committee was 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.



PACCSC & CST ANNUAL RESEARCH FORUM

Our principal annual event, the PaCCSC & CST Annual Research Forum was held online for the first time on 11 and 12 March 2021. The forum brought together speakers and guests with interests in palliative care and cancer symptom management. The theme was Clinical trials in a changing world, putting the spotlight on common challenges faced here in Australia and overseas.

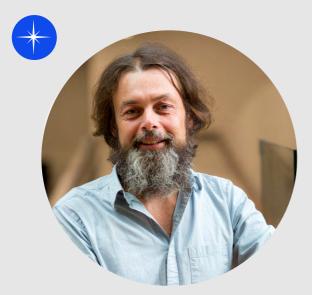
Our keynote speaker, Professor R Sean Morrison (pictured), Director of the USA National Palliative Care Research Center, gave an insightful presentation on palliative care research in the United States. We also heard from Professor Christine Ritchie, Minaker Chair in Geriatrics and Director of Research for the Division of Palliative Care and Geriatric Medicine at Massachusetts General Hospital, and Dr Michael Dougan, Assistant Professor of Medicine and Director of Immunotherapy Mucosal Toxicities Program at Massachusetts General Hospital. It was a great privilege to have three excellent international speakers at the forum.

Here in Australia, we were joined by Stefan Harrer, Chief Innovation Officer of Digital Health CRC joined us to talk about technological developments in telehealth delivery, and Hayley Burridge, Melanoma Nurse Consultant at The Alfred who conducted an engaging discussion with Tamara Dawson, founder of the Melanoma & Skin Cancer Advocacy network (MSCAN).

Thank you for all the participants, consumers and staff who attended



Professor R Sean Morrison







A QUALITATIVE STUDY ON CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

Luckett T, Roberts M, Swami V, Smith T, Cho JG, Klimkeit E, et al. Maintenance of non-pharmacological strategies 6 months after patients with chronic obstructive pulmonary disease (COPD) attend a breathlessness service: a qualitative study. BMJ Open. 2021;11(5):e050149.

This study followed up patients with chronic obstructive pulmonary disease (COPD) 6 months after they completed a breathlessness self-management program with the Westmead Breathlessness Service (WBS). This program teaches patients to use non-pharmacological strategies for chronic breathlessness like breathing techniques, pacing, positioning and the hand-held fan. Immediately after completing the program, nearly all 41 patients we interviewed reported benefits in the form of reduced breathlessness and/or increased confidence and daily functioning. Six months later, however, interviews with 32 (78%) of these patients found benefits had only partially been sustained. While most patients were still practising one or more WBS strategy, many had lost confidence and struggled to maintain motivation and hope. A 'chaos narrative' had become prevalent, in which patients recounted events over the previous 6 months without a sense of sequence or agency. This contrasted with the 'quest narrative' that had been prevalent 6 months earlier, in which patients talked in terms of life goals and asserted a greater degree of control over how breathlessness impacted their emotional wellbeing and daily functioning. Some patients even struggled to remember much about the WBS program, despite having enthused about it 6 months earlier. Interestingly, much of the initial praise had been directed at supportive relationships patients had forged with WBS clinicians, which one man summed up as "encouraging you to do better for yourself". These findings made us think that some form of regular 'top-up coaching' might be needed to sustain the effects of the program.



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.

Symptom Node	Series	Population	Status	Chair
Appetite and Cachexia	Mirtazapine	Palliative Care	Open	Dr Tina Naumovski
Breathlessness	Benzodiazepines	Palliative Care	Open	Dr Peter Allcroft
	Opiods for breathlessness	Palliative Care	Open	DI Petel Aliciott
Gut Dysfunction	Macrogol for constipation	Palliative Care	Closed/Analysis underway/Paper in draft stage	Prof Katherine Clark
Nausea	Cyclizine	Palliative Care	Open	Dr Phillip Good
	Ondansetron	Palliative Care	Start up	Bi i iiiiip Cood
Neurological Mood and Cognitive Disorders	Midazolam Mirtazapine for Depression Duloxetine for Depression Citalopram/Escitalopram for Depression	Palliative Care Palliative Care Palliative Care Palliative Care	Open Start up Start up Start up	Prof Meera Agar
	Noisy respiratory secretions Nursing Interventions	Palliative Care	Closed/Paper in draft	Prof Jane Phillips Associate Prof
Nursing Inventions	for Disorientation Nursing Interventions for Constipation	Palliative Care Palliative Care	Open Pilot	Annmarie Hosie Penny West/ Prof Katherine Clark
	Dressings for Cutaneous Malignant Wounds	Palliative Care	Open	Prof Elizabeth Harry
	Amitriptyline	Palliative Care	Closed/Paper submitted	Prof David Currow
Pain	NSAIDS	Palliative Care	Open	Dr Jessica Lee
	Methadone	Palliative Care	Open	Dr Philip Good
Fatigue	Dexamethasone	Palliative Care	Closed/Paper in draft	Dr Kat Urban/ Dr Gemma Ingham
	Temazepam for Insomnia	Palliative Care	Open	
Sleep	Melatonin for Insomnia	Palliative Care	Open	Ruwani Mendis



17th World Congress of the European Association for Palliative Care (EAPC)

Variations in practice: paracentesis in malignant ascites.

Currow, D., Rowett, D., Doogue, M., Brown, L., Agar, M., & Hunt, J., Seah, D.

60th Australian Society for Medical Research (ASMR) National Scientific Conference

UTS Rapid Program - A prospective observational study of palliative care and cancer symptom management interventions - understanding the burden of the adverse effects.

J. Hunt, D. Currow, L. Brown, M. Doogue, D. Rowett, C. Sheehan.

Oceanic Palliative Care Conference (OPCC) 2021

RAPID Program— Effectiveness of Paracentesis for malignant ascites at different time points

D. Seah, S. Chang, D. Rowett, M. Doogue, L. Brown, M. Agar, J. Hunt.

RAPID Program– Variations in practice of Paracentesis for malignant ascites.

D. Seah, S. Chang, D. Rowett, M. Doogue, L. Brown, M. Agar, J. Hunt, D. Currow.

Pharmacovigilance in hospice/palliative care: Net effect of cyclizine for nausea and vomiting. R. McNeill, J. Hunt, D. Currow, M. Doogue, D. Rowett, T. Nguyen, S. Chang, Y. Phyo.

Symptom Node	Series	Population	Status	Chair
	Ascitic Taps	Palliative Care	Closed/Paper submitted	Dr Davinia Seah
Intervention Series	Diuretics for Lymphoedema	Palliative and supportive care	Open	Dr Beth Russell
	Intrathecal Catheters	Palliative and supportive care	Pilot phase	Dr Alix Dumitrescu/ Kate Reed-Cox
	Medical Cannabis	Palliative and supportive care	Open	Prof Jennifer Philip
Extraordinary Series	Gabapentin/Pregabalin for itch and restless legs	Renal supportive care	Open	Dr Nina Vogel
	Adult telehealth	Palliative Care	Open	Prof Jennifer Philip
Aged care	Cefalexin for Soft Tissue/ Wound Infections	Aged Care	Pilot	Prof Debra
series	Cefalexin for Urinary Tract Infections	Aged Care	Pilot	Rowett



Publications submitted to peer review journals

- 1. Currow, D., Rowett, D., Doogue, M., Hussein, A., Digges, M., Chang, S., Allan, S., Boland, J., Sinnarajah, A., Agar, M. Pharmacovigilance in hospice / palliative care: net effect of amitriptyline or nortriptyline on neuropathic pain. UTS/IMPACCT rapid program
- 2. Seah, D., Chang, S., Rowett, D., Doogue, M., Brown, L., Agar, M., & Hunt, J., Currow, D. Treatment variation in patients managed with paracentesis for malignancy-related ascites: A prospective observational study in the palliative care setting.
- 3. Agar, M., Chang, S., Amgarth-Duff, I., Garcia, M., Hunt, J., Phillips, J., Sinnarajah, A., Fainsinger, R. UTS Rapid Program – Results of the Hypodermoclysis Series

RAPID PAEDIATRIC PROGRAM

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
Breathlessness	Opiods for breathlessness	Paediatric Palliative Care	Open	A/Prof Marianne Phillips
Extraordinary Series	Paediatric Telehealth Medicinal Cannabis	Paediatric Palliative and Supportive Care	Open Open	Dr Martha Mherekumombe Dr Anthony Herbert
Nausea	Cyclizine	Paediatric Palliative Care	Open	Dr Sid Vemuri
Pain	Gabapentinoids Methadone	Paediatric Palliative Care Paediatric Palliative Care	Closed/Drafting paper Start up	Dr Ross Drake Dr Shih-Ling Liaw
Rapid Chronic Pain Program	Ketamine for Chronic Non- Cancer Pain Ketamine for Cancer Related Mucositis Pain Gabapentinoids for Chronic Pain	Paediatric Pain Management Paediatric Pain Management Paediatric Pain Management	Open Open Start up	Dr Ross Drake



Presentations

17th World Congress of the European Association for Palliative Care (EAPC)

Rapid Paediatric Program-Gabapentinoids for Pain.

R. Drake, J. Hunt, A. Herbert, J. Hynson, D. Currow, M. Doogue, M. Phillips, M. Cossich, D. Rowett.

14th Asia Pacific Hospice Palliative Care (APHC) Conference

Rapid Paediatric Program- Opioids for Breathlessness.

R. Drake, J. Hunt, A. Herbert, J. Hynson, D. Currow, M. Doogue, M. Phillips, M. Cossich, D. Rowett, P. Heng, M. Mherekumombe.

Oceanic Palliative Care Conference (OPCC) 2021

Rapid Paediatric Program – Results of the first series - Gabapentinoids for

R. Drake, J. Hunt, A. Herbert, J. Hynson, D. Currow, M. Doogue, M. Phillips, M. Cossich, D. Rowett.

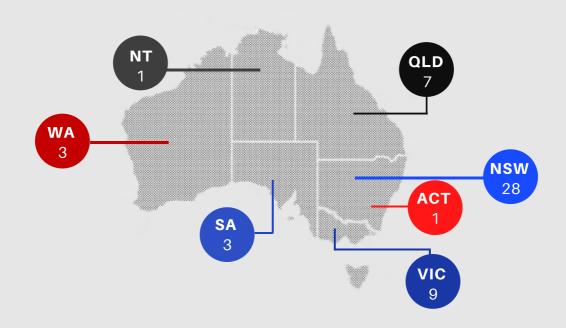
RAPID SITES





Australian Rapid Program

52 sites





International Rapid Program

10 countries | 84 active sites

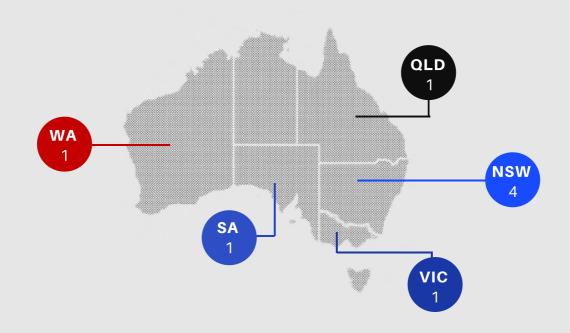


RAPID PAEDIATRIC SITES



Australian Paediatric Program

8 sites





International Paediatric Program

9 countries | 19 sites





TEACHING AND LEARNING

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.

New Subjects Developed

- Clinical Assessment in Palliative
- Pharmacology in Palliative Care
- Optimising end-of-life communication
- Optimising end-of-life communication within complex and diverse situations

First Graduations in 2021

Masters - 2 students **Graduate Certificate** 9 students

Subjects & Number of Students Completed

New Contributors in Teaching & **Subject Development**

> Nicole Knox Mariana De Sousa Fiona Turk





centred care (28 students) Optimising wellbeing for people living with advanced disease (7



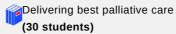
students) Generating evidence to improve palliative care outcomes (10 students)



Optimising end-of-life communication within complex and diverse situations (10 students)

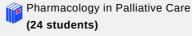


Optimising end-of-life communication (10 students)

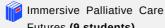




Complex Symptom Management (28 students)



Ethical Dimensions of



Futures (9 students) Palliative Care (10 students)





Translating evidence into change (8 students)



Clinical Assessment in Palliative Care (24 students)







Louise Hickman



DiGiacomo



Deborah Parker



Tim Luckett







Mariana De Sousa





POSTGRADUATE STORY

I AM PASSIONATE ABOUT KEEPING 'NURSING' IN NURSING

Mary Roberts

Master of Palliative Care





I'm a registered nurse with 30+ years of experience, working in respiratory medicine. I have a passion for treating all patients like they are your mother, father, husband, wife, brother, sister or child. I am also passionate about keeping the 'nursing' in nursing. It doesn't matter how technologically advanced nursing practice becomes, it's important to remember you are treating a person, with a family, friends, a history, a story. We cannot lose sight of the person and the 'care' they need.

There were two reasons I chose to study this degree, one professional and one personal. Professionally, I do a lot of work in Breathlessness, I run clinics, I participate in research and I teach. I felt that despite my years of experience, I lacked 'legitimacy' as I had no formal qualifications in the field. Little did I know how much more I would gain from doing the course! Personally, I had just experienced the passing of a family member in not so ideal circumstances. I was distraught by the lack of care they received and in order to change practice — I thought it's better to do it within, so getting a qualification in Palliative Care seemed to be the correct path.

I'm learning things that I never expected to. It's all really clinically relevant and can be implemented into every day practice. Being challenged by something other than the day to day issues has been great. Balancing it during COVID-19, not so great!

The advice I have for anyone considering the Graduate Certificate in Palliative Care is to...just do it! I was worried about studying again after a break of over 20years but the lecturers are great. Very supportive! They are more than happy to guide you along the way. The opportunity to mix (online) with other students from a range of experiences, workplaces, geography etc. is also amazing and adds to the learning experience.



HIGHER DEGREE RESEARCH STUDENTS

CURRENT PHD STUDENTS

Peter Allcroft

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

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

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

Claire Fraser

Palliative care competency models: What specific competencies do nurses require to provide quality palliative care in regional, rural and remote Australia

Supervisors: Jane Phillips Louise Hickman

Natalie Govind

Palliative care and stroke Supervisors: Louise Hickman, Jane Phillips

Ramkumar Govindaraj

Evaluating the impact of using patientreported outcomes in oncology clinical practice

Supervisors: David Currow, Meera Agar

Malorie Hall

Pre-operative nutrition support in heart and lung transplant patients

Supervisors: Sally Inglis, Peter Macdonald

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 preadmission

Supervisors: Deborah Parker, Louise Hickman

Alison Hession

"I see dead people" - End-of-Life visions, experiences of patients, families and caregivers in an acute care hospital Supervisors: Tim Luckett, David Currow, Michael Barbato

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

Celia Marston

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

Lucinda Morris

Optimising clinical decision making for elderly cancer patients undergoing radiation therapy

Supervisors: Meera Agar, Sandra Turner, Jane Phillips

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

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

Isabelle Schaefer

An evaluation and gap analysis of access to best evidence-based care for people with palliative care needs in Australian prisons

Supervisors: Jane Phillips, Michelle DiGiacomo, Nicole Heneka, Stacy Panozzo

Davinia Seah

Health Service Utilisation at the End of Life

Supervisors: David Currow, Kathy Eagar

Mia Taylen-Smith

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

Eric Torgbenu

Identifying Opportunities to Strengthen Care for People with Cancer-related Lymphoedema Living in Lowand Middleincome Countries

Supervisors: Tim Luckett, Mark Buhagiar, Jane Phillips

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

MASTERS BY RESEARCH

Elizabeth Turner

Experiences of Spontaneous Coronary Artery Dissection

Supervisors: Michelle DiGiacomo, Serra Ivynian, Louise Hickman

SUBMITTED

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

Elyn Montgomery

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

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

COMPLETED

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, Gideon Caplan

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 postcaring at end of life in Western Sydney Supervisors: Michelle DiGiacomo, Joanne Lewis, Jo Travaglia

Julee McDonagh

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

Glenn Paull

Care resynchronisation: A nursing delivery platform for coordinated costefficient inpatient management of chronic heart failure in Australia

Supervisors: Patricia Davidson, Phillip Newton

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 Salamonson, Rochelle Wynne

OTHER UNIVERSITIES (COMPLETED)

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 Salamonson, Lucie Ramjan, Sungwon Chang

Ninik Yunitri (UMJ)

Mental Health intervention among high school students in Indonesia

Supervisors: Lawrence Lam, Mary K Lam





PURSUING CHANGE FOR CARERS WITH WELFARE NEEDS

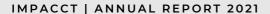
UTS PhD graduate and honorary Clinical Fellow (IMPACCT), Dr Kristin Bindley, explores the effects of public policy and systems for carers of people with life-limiting illness



Caring for someone with a life-limiting illness (such as cancer, or motor-neurone disease) may have significant social, physical and psychological impacts. Implications may unfold while caring, however they may also reverberate long after the person being cared for has died. "Among a range of concerns, financial strain is common for carers for varied reasons, such as in situations where carers have to cease or reduce their paid work to provide care," Dr Kristin Bindley explains. "This means that some carers need to seek government income support, such as a Centrelink payment, as well as other forms of social welfare."

Kristin has a background in social work, and currently works as the Bereavement Counsellor and Clinical Lead for the Bereavement Service within Supportive & Palliative Care in Western Sydney – a region associated with high levels of relative socioeconomic disadvantage. Kristin's PhD evolved from an issue identified through her practice, where she often encountered carers who were negotiating challenging aspects of policy related to income support and public housing, following the death of the person for whom they provided care. "Alongside often intense grief, some carers with complex mental health backgrounds or physical health issues were struggling to deal with fall out related to their welfare needs in bereavement. Some had experienced a large drop in the rate of their income support payment," Kristin says. "Others were feeling overwhelmed that government policy might require them to relocate from their public housing property soon after the death, or to actively look for a new job in early bereavement. This often increased distress, and had an especially detrimental impact upon their grieving."

Kristin completed her PhD under the primary supervision of A/Prof. Michelle DiGiacomo, within IMPACCT (Improving Palliative, Aged and Chronic Care through Clinical Research and Translation) in the Faculty of Health at UTS, with co-supervision by Prof. Joanne Travaglia and A/Prof Joanne Lewis. Kristin's research sought to inform approaches that might improve the caring and bereavement experience of carers of people with life-limiting illnesses, who interact with welfare policy and public organisations during and following informal care provision. "Often, research has focussed on the economic costs of caring and the psychological aspects of complex bereavement," explains Kristin. "The impact of structures and systems upon carers in the context of life-limiting illness has largely been overlooked – and this includes social policy and processes that are already known to generally contribute to inequity, especially in welfare states similar to ours in Australia."







"My hope is that this work supports initiatives and advocacy that cultivate networks of care across sectors, and 'grief literate' organisations and workers"

Kristin's PhD study involved interviews with bereaved carers, health professionals in palliative care, and welfare workers within government agencies responsible for coordinating income support and public housing, in Western Sydney. She found that carers experienced a range of burdens related to complex policy requirements, highly virtualised processes, and low rates of income support.

"Many carers spent considerable time and energy navigating systems. Some manage to do this fairly well, however others are disadvantaged to a greater degree due to personal factors such as their level of English literacy, their mental health, their capacity to deal with systems, or their way of grieving." Kristin's research demonstrated that being disadvantaged in system navigation may contribute to inequity through increased financial insecurity, housing instability, and negative psychological outcomes.

There were also consequences for health professionals and welfare workers. "Many workers shared with me their sense of helplessness when trying to assist carers to manage complex welfare systems, and their frustration with being 'policy-bound' in circumstances where outcomes did not seem to be just or appropriate for carers, as well as other vulnerably positioned groups."

Kristin's research identified a number of recommendations. She argues that attention to promoting effective encounters between carers, and their health professionals or welfare workers, is important. Kristin suggests workers be supported to develop 'structural competency'; or the ability to recognise the way in which policy and institutions can shape social and health outcomes for individuals. However, Kristin's work ultimately highlights a need for broader review and reform of welfare policy related to carers, and connections between health and welfare systems. "This work reiterates that these systems have become highly siloed, complex, and poorly responsive to experiences such as caring at end of life," Kristin says. "My hope is that this work supports initiatives and advocacy that cultivate networks of care across sectors, and 'grief literate' organisations and workers. These are vital to supporting the most vulnerably positioned carers during and following caring."

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

Consumers

Andrea Cross
Bev Noble
Carmela Kendrick-Smith
Dea Close
Imelda Gilmore
John Stubbs
Padman Karamil
Meg Lane
Phillip Lee
Ted Moors
Stephen Peterson

Rebecca Smyth

CONSUMER ENGAGEMENT AT A GLANCE





Paccsc/cst Annual Research Forum – Melanoma consumer advocate discussion



Consumer involvement in a range of PaCCSC/ CST governance committees



Concept development workshop contributions and incubators



Consumers as Investigators of research grant funding submissions



Centre for Palliative Care -Partnering with consumers to improve palliative care study involvement



Consumers on the International Cancer Research Partnership (ICRP) Patient Engagement Program



Delphi studies -Investigating troublesome cancer symptoms for adults, children and adolescents



The vital role of the consumer in health and medical research – INSPIRE



Attendance at the Oceanic Palliative Care Conference (OPCC)



Consumer voice on the HeSANDA initiative on secondary use of data in clinical research









Philip Lee
IMPACCT Consumer

CONSUMER NEWS

CONSUMER REPRESENTATIVE EXPERIENCES OF PARTNERSHIP WITH HEALTH WORKERS IN AUSTRALIA

I am pleased to share that I was a co-author on a research article, Consumer representative experiences of partnership with health workers in Australia published in the November 2021 issue of Patient Experience Journal (PXJ), an international, multidisciplinary, and multi-method, open-access, peer-reviewed journal, focusing on understanding and improving the patient experience.

The published article examines and explores the consumer experience within a Local Health District (LHD), how consumer representatives engaged with staff for service improvements, their relationships with health care workers - and the systems in which they operate.

These experiences inform a practice of partnership that may be useful for other organisations wishing to engage meaningfully with consumers. I was one of three consumer representatives on the team that also included an LHD staff member and the principal investigator, the LHD Community and Consumer Partnerships Group Imaginator.

Read the article here:
pxjournal.org/journal/vol8
/iss3/8/



GRANTS AWARDED

IMPACCT/UTS LED **GRANTS**

CATEGORY 1	IM	PACCT/UTS LE
Cancer Australia	Support for Cancer Clinical Trials Program 2022-2024 Funding Round for the Multi-site Collaborative Cancer Clinical Trials Groups	\$1,249,500
	Agar M.	
CATEGORY 2	IMI	PACCT/UTS LEI
Cancer Australia	Cancer Australia Quality of Life Technical Services	\$988,425
	Mulhern B, Luckett T, Viney R, De Abreu Lourenco R, Agar M, Street D, Kenny P, Page K, Addo R, Kochovska S, Chang S, King M, Rutherford C.	
Cancer Council of Victoria	The COMET (Community Supportive Care Trials) program: enhancing supportive care trials for community dwelling people with cancer	\$493, 853
	Agar M.	
Cancer Institute NSW	Defining constipation in palliative care to estimate its prevalence: a national survey of palliative care patients and providers	\$23,964
	Agar M.	
Translational Cancer	TCRN PhD Scholarship Top-up Awards	\$5000
Research Network	Luckett, T.	
Maridulu Budyari Gumal - The Sydney Partnership for Health, Education, Research and Enterprise (SPHERE)	Send in the Elder Clowns: a qualitative study of a psychosocial intervention to improve quality of life of people with dementia in residential aged care	\$19,964
	Ellis G, DiGiacomo, M, Luckett T, Kochovska, Agar M, Currow D, Parker D, Carr R, Symons D, Warner T.	
Prostate Cancer Foundation of Australia	A mixed methods study to develop two e-learning modules on understanding and managing localised and locally advanced prostate cancer and understanding survivorship care for men living with prostate cancer	\$100,000
	Jakimowicz S, Levett-Jones T, DiGiacomo M, Green A, Maguire J, Heneka N.	
CATEGORY 3	IMP/	ACCT/UTS LED
elsinn Healthcare SA artnership Fund	Phase II, double blind, placebo controlled, parallel arm, fixed dose, multi-site study to evaluate the safety, feasibility and desirability of conducting a fully powered phase III study of anamorelin for anorexia in people with small cell lung cancer	\$867,390
	Currow D.	

INTERNAL	IMPACCT/UTS LED

UTS	Designing a Model of Intergenerational Care: Connected Living for Older and Younger Australians	\$29,557
	Parker D.	
UTS	Home aged care services in regional and rural Australia: baseline study of the drivers of quality of care and financial viability	\$35,000
	Brown D, Parker D.	
UTS Faculty of Health Equipment Grant	Bright Light therapy devices and associated equipment	\$4,368
	Saleh Moussa, R.	
UTS ECR Research Capabilities Development Initiative	Supporting the implementation of evidence-based prostate cancer survivorship interventions into clinical practice: A co-design implementation study	\$19,928
	Heneka N, Chambers S, DiGiacomo M.	

COLLABORATIVE GRANTS LED BY OTHER AREAS OR INSTITUTIONS

MRFF Medical Research Future Fund	Understanding the contribution of Aboriginal and Torres Strait Islander culture and wellbeing to health: Implementation of the What Matters 2 Adults (WM2A) wellbeing measure	\$998, 036
	Howard K, Garvey G, Dickson M, Anderson K, Roder D, Martin R, Cutmore B, Jackson J, Jones N, Currow D .	
NHMRC Targeted Call for Research into End of Life Care	A randomised trial of a carer end of life planning intervention (CEPLI) in people dying with dementia.	\$1,486,232
	Arendts G, Chenoweth L, Hayes B, Etherton-Beer C, Spilsbury K, Howard K, Campbell E, Celenza A, Agar M , Pearce K, Schnitzer L and Asha S.	
NHMRC Ideas Grant	Driving quality in delirium care through a patient-centred monitoring system in palliative care	\$503,477
	Hosie A, Agar M, Hawkins F, Johnson C, Walpole G, Moffat P, Casey P, Cook A, Chye R, Oehme J.	
NHMRC	Deciphering the heterogeneity of chronic breathlessness: implications for more personalised management of the symptom	\$1,500,000

Currow, D.

CATEGORY 1

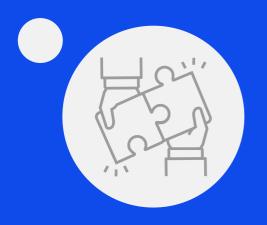
COLLABORATIVE GRANTS

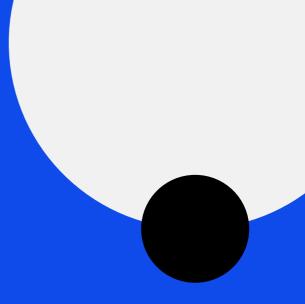
CATEGORY 2	COLLABOR	PATIVE GRANTS
Cancer Institute NSW	The APRICA program – Accelerated translational research in PRImary Liver Cancer	\$4,000,000
	McCaughan G, Zekry A, Reddel, R, Chant, K, Clarke, S, Liauw W, Nagrial A, Agar M . et al.	
Prostate Cancer Foundation of Australia	Co-designing a new implementation model for delivering support and education to carers of people living with dementia	\$100,000
	WSU - Harris. DiGiacomo M (CIC)	
SPHERE Implementation and Translation Funding Scheme: Age and Aging	How can people with dementia and their caregivers be supported by the built environment?	\$37,000
	WSU – Karmacoska. DiGiacomo M (CIE)	
CATEGORY 3	COLLABORATI	VE GRANTS
Aged Care Quality and Safety Commission	Qualitative Communications Research into the aged care home service sector	\$142,568
	Mills C, Parker D.	
Health Research Board Ireland	Measures of wellbeing for use in economic evaluation: valuing and assessing health outcomes in Ireland	€244,455
	Kitchin I, Walshe V, Coast J, Normand C, Viney R, Elliott R, Mulhern B, Kinghorn P, Currow D , Tobin K.	
Integrated Living	Evaluation of the Integrated Health Systems Demonstrator	\$100,000
	Brown D, Parker D.	
University of Hull	Improving Appropriate Access and Availability of Opioids for Cancer-related Pain Control in India: bridging the gap between policy and practice	£30,000
	Clark J, Johnson M, Currow D.	
INTERNAL	COLLABOR	PATIVE GRANTS
QUT CHT Grant Enabling Scheme	Adapting a tool to measure experience of care in people with serious illness in the Australian hospital setting to inform a multi-site stepped wedge cluster randomised	\$50,000

controlled trial.

Virdun C, Phillips J, **Luckett T,** Button E, Yates P.







COLLABORATIONS AND EXTERNAL ENGAGEMENT



COLLABORATIONS AND ENGAGEMENT

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.





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.

EXTERNAL ACADEMIC APPOINTMENTS

Professor Meera Agar

- Conjoint Associate Professor, South West Sydney Clinical School, University of New South Wales, Sydney, NSW
- O Visiting palliative care specialist, HammondCare, South West Sydney
- Honorary Associate, University of Sydney

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
- O Honorary Professor, School of Medicine, University of Sydney
- O Honorary Senior Associate, Sax Institute Associate

Professor Michelle DiGiacomo

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

Professor Deborah Parker

- O 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

Dr Sungwon Chang

Adjunct Fellow, Western Sydney University, NSW

EDITORIAL ROLES

Professor Meera Agar

Age and Ageing

BMC Geriatrics

BMC Palliative Care

Canadian Medical Association Journal

Critical Care Medicine

European Journal of Heart Failure

European Journal of Preventive Cardiology

European Respiratory Journal

Genetics in Medicine

International Journal of Nursing Studies

JAMA

Journal of Clinical Oncology

Journal of Clinical Psychopharmacology

Journal of the American Geriatrics Society

Lancet Oncology

Medical Journal of Australia

Nature reviews

Palliative Medicine

Thorax

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 Tim Luckett

Academic Editor, PLOS One



Editorial Board, International Journal of Healthcare

Editorial Board, Journal of Alternative, Complementary & Integrative Medicine Editorial Board, Journal of Cardiology and Therapy

Associate Professor Michelle DiGiacomo

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

Professor Louise Hickman

Editor in-Chief, Contemporary Nursing

Professor Sally Inglis

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





Faculty of Health, Deans Advisory Committee

Faculty of Health Board Member

Faculty of Health, Deans Management Group

Faculty of Health, Equity and Diversity Working Group

Faculty of Health, Faculty Board

Faculty of Health, Faculty Courses Committee

Faculty of Health, School of Nursing and Midwifery Research Committee

Faculty of Health Research Degrees Committee

Faculty of Health, HDR Student Assessment Chair

Faculty of Health, Research Impact Strategy Committee

Faculty of Health, Research Committee

Faculty of Health, UTS International Postgraduate Research Scholarships panel

UTS Research Working Committee, Centre for Carers Research

UTS Research Data Management Training Working Group

UTS Chancellor's Postdoctoral research fellowships committee

Graduate School of Health, Heads Advisory Committee

UTS Human Research Ethics Committee Clinical Trials Sub-committee

UTS / Prince of Wales Hospital Clinical Alignment Precinct

UTS Social Impact Framework Committee

UTS Associate Professor Promotions Committee Faculty of Health Representative

UTS Work Planning Tool Working Group



COLLABORATIONS

NSW

Art Gallery of New South Wales, codesign of workshops to explore solutions to communication difficulties related to dementia

Australian Cancer Research Foundation Oncology Alliance for the Science of Integrated Survivorship (ACRF OASIS) Centre

Blacktown & Mt Druitt Hospitals Sydney

Calvary Health Care Sydney

Cancer Institute NSW

Cancer Institute NSW – Translational Cancer Research Network

Camden Palliative Care Unit

Carers NSW

Griffith University

HammondCare

NSW Cardiovascular Research Network

NSW Ministry of Health

Palliative Care Outcomes Collaboration

Research in Implementation Science and eHealth (RISe), Sydney University

SPHERE - Sydney Partnership for Health, Education, Research and Enterprise

Aboriginal Health & Wellbeing Clinical Academic Group

Age and Ageing Clinical Academic Group Cancer Clinical Academic Group Cardiovascular Clinical Academic Group Healthy Urban Environments Clinical Academic Group

Mindgardens Clinical Academic Group Palliative Care Clinical Academic Group Respiratory, Sleep, Environmental and Occupational Health (RSEOH) Clinical Academic Group St Vincent's Hospital and/or Sacred Heart Health Service Sydney

South Western Sydney Local Health District Palliative Care Service

South Eastern Sydney Local Health District

South Eastern Sydney Translational Cancer Research Network, University of New South Wales

Translational Cancer Research Network, University of New South Wales

Uniting

University of Newcastle, Priority Research Centre for Generational Health and Ageing

University of NSW South Western Sydney Clinical School Centre for Big Data Research in Health

University of Queensland, Centre for Health Services Research

University of Sydney Brain and Mind Centre School of Medicine

Victorian Comprehensive Cancer Centre

Western Sydney University
Department of General Practice, School of
Medicine

MARCS Institute for Brain, Behaviour and Development

NICM Health Research Institute School of Nursing and Midwifery

Westmead Hospital Sydney

NATIONAL

Aged Care Services Australia

Alzheimer's Australia

Australian Association of Gerontology

Australasian Delirium Association

Australian and New Zealand Society of Palliative Medicine Australian Commission on Safety and Quality in Health Care

Australian Healthcare and Hospital Association

Blood Cancer Taskforce

Cancer Australia

Cancer Council Australia (including NSW)

Cardiac Society of Australia & New Zealand

Carers Australia

Caresearch, Flinders University

Central Adelaide Palliative Care Service

Flinders University

Leading Aged Services Australia

Melbourne University

NHMRC Centre for Research Excellence, Peripheral Arterial Disease

NHMRC Cognitive Decline Partnership Centre

Palliative Care Australia

Palliative Care Clinical Studies Collaborative

Palliative Care Nurses Australia

Patient reported outcomes working group member

Psycho-oncology Co-operative Research Group (PoCoG)

Queensland University of Technology

ITCC CLINICAL TRIAL SITES



NATIONAL

Austin Health, Melbourne Barwon Health, Geelong Braeside Hospital, Sydney Calvary Health Care Kogarah, Sydney Christchurch Hospital, New Zealand Concord Repatriation General Hospital, Sydney Hammondcare Greenwich Hospital, Sydney Liverpool Hospital, Sydney

Mater Health Services, Brisbane Royal Melbourne Hospital, Melbourne Sacred Heart, St Vincent's Hospital, Sydney Sir Charles Gairdner Hospital, Perth St Vincent's Hospital, Melbourne The Canberra Hospital, Canberra Westmead Hospital, Sydney



NTERNATIONAL

Asia Pacific Hospice and Palliative Care Network American Delirium Society, USA Asia Pacific Hospice and Palliative Care Network Bruyère and Ottawa Hospital Research Institutes Bengbu Medical College, Anhui, China Cochrane Collaboration Eindhoven University of Technology, The Netherlands

Evangelische Hochschule Dresden (EHS), Germany Guangxi Medical University, Nanning, China Hong Kong Polytechnic University, Hong Kong Hull York Medical School, University of Hull, UK International Association for the Study of Lung Cancer

International Association for Hospice and Palliative Care International Council of Women's Health Issues International Learning Collaborative connected to care

International Network for Doctoral Education in Nursing Johns Hopkins University, Baltimore

Lancaster University, UK

Lund University

Leiden University Medical Centre, Netherlands

Leiden University Medical Centre, Netherlands McGill University, Montreal, Canada McMaster University, Hamilton, Canada Multinational Association of Supportive Care in Cancer

Queens University Belfast, Ireland Stanford Primary Care and Population Health, USA Sun Yat-sen University, Guangzhou, China The Education University of Hong Kong, China Tilburg University, The Netherlands

Tung Wah College, Hong Kong

University of Auckland, New Zealand

University of Technology Auckland, New Zealand

University of Basel, Basel, Switzerland

University of California, San Francisco, USA

University of Cambridge, UK

University of Hertfordshire, UK

University of Ottawa, Canada

University of Manitoba, Canada

University of York, UK

Vanderbilt University, Nashville, USA

Vrije Universiteit Brussel, Brussels, Belgium

Wolfson Palliative Care Research Centre, University

of Hull, UK





NSW COMMITTEES

Australian Cardiac Alliance (ACvA)

Cardiac Society of Australia and New Zealand (CSANZ)

Carers NSW
Consumer and Carer Coaching Project
(3CP) Advisory Group

Carrington Care

Leigh Place

Heart Foundation NSW Cardiovascular Research Network

Improving Palliative Care through Clinical Trials NSW (ImPaCCT:NSW)

NSW Australian Association of Gerontology

NSW Ministry of Health
Palliative Care Workforce Development
Working Group

Palliative Care NSW

SPHERE (Sydney Partnership for Health, Education, Research and Enterprise)

Age and Ageing Clinical Academic Group -Quality of Life, Education and Workforce Cancer Clinical Academic Group - Living with and After Cancer

Clinical Trials: Clinician, Public and Patient Involvement Steering Committee Clinical Trials: Conduct & Enhanced Recruitment Performance Steering

Committee Mindgardens Clinical Academic Group, Steering Committee

Palliative Care Clinical Academic Group, Management Committee South Western Sydney Local Health District (SWSLHD)

Human Research Ethics Committee

Translational Cancer Research Network TCRN Executive

Workforce 2025 Flagship

NATIONAL COMMITTEES

ANZSPM Palliative Care Respiratory Special Interest Group

ANZUP Cancer trials group, Quality of Life Subcommittee

Australian Advisory Council on the Medicinal Use of Cannabis

Australian Clinical Trials Alliance (ACTA)

Advisory Council
Reference Group A – Efficient and
Effectives Clinical Trial Networks
Special Interest Group for Clinical Trial
Network Managers

Workforce Special Interest Group

Australian Association of Gerontology Culturally and Linguistically Diverse Special Interest Group

Regional, Rural and Remote AAG Special Interest Group

Housing and Built Environment Special Interest Group

Student and Early Career Professional Development and Events Group

Australasian Delirium Association

Australasian Palliative Link International

Australian Adult Cancer Pain Management Guidelines

Australian College of Nursing

Australian Diabetic Educators Association, Diabetes Research Foundation Council

Australian Hartford Consortium of Gerontological Nursing Excellence

Australian New Zealand Society of Palliative Medicine

Cancer Australia

Cancer Cooperative Trials Group – Executive Officers Network

Cancer Symptom Trials

Cardiac Society of Australia & New Zealand

Board

Cardiovascular Nurses Council, Chair Professional and Ethical Standards Committee

Scientific Committee

Scientific Programming Committee

Caresearch

palliAGED National Advisory Group National Advisory Group

Clinical Oncology Society Australia Council

Geriatric Oncology Research Working Group Geriatric Oncology Special Interest Group, Chair

Tele-Trials Cancer Cooperative Trials Groups Advisory Group

Cooperative Trials Group in Neurooncology

Management Advisory Committee Scientific Committee

European Association for Palliative Care Abstract Review Committee National Cancer Expert Reference Group

National Covid-19 Clinical Evidence Taskforce (NC19CET) Palliative and Aged Care Panel Guidelines Leadership Group

National Pancreatic Cancer Roadmap Steering Group, Cancer Australia

NPS MedicineWise Clinical Advisory Committee

Palliative Care Australia National Policy Advisory Committee National Standards Review Group

Palliative Care Clinical Studies Collaborative

Mood and Cognitive Disorder Symptom Node Sub-Committee Qualitative Subcommittee

Sleep Symptom Node Sub-Committee Breathlessness Symptom Node Sub-Committee

Trials Management Group

Primary Care Collaborative Cancer Clinical Trials Group Scientific Committee

Psycho-Oncology Cooperative Research Group ADAPT Implementation & RCT Working Group Depression Working Group Scientific Committee

Royal Australasian College of Physicians Adult Medicine Division Council Chapter of Palliative Medicine Committee Medicinal Cannabis Reference Group

Therapeutics Good Administration Opioid Regulation Advisory Group

Victorian Cancer Agency Research Funding Sub-committee

INTERNATIONAL COMMITTEES

American Society of Clinical Oncology Management of Dyspnea Guideline Panel

European Palliative Care Research Network, Scientific Advisory Board

European Respiratory Society Taskforce on Dyspnoea

European Respiratory Society Working group on palliative care in respiratory disease

International Association Hospice Palliative Care

International Cancer Benchmarking Program Board

International Conference of Alzheimer's Disease International 2017, Advisory Board

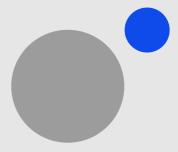
International Conference of Indian Association of Palliative Care Scientific Committee

International Palliative Care Family Carer Research Collaborative Advocate

International Research Conference Scientific and Technical Committee on Medical and Health Sciences

Scientific Committee Wolfson Palliative Care, University of Hull, UK





CONFERENCES

Agar M, Rowland C, Currow D and Marino N. 30 years of impact. Parlimentary Friends of Palliative Care Event. December 1st 2021. https://www.youtube.com/watch?v=GkyUGJqNp8Q

Agar M. In conversation (panel) Palliative Nexus Pal-Spectives series. 17th November 2021

Agar M, Bush S, Hosie A and Torke A. Symposium: Delirium and palliative care. American Delirium Society 11th Virtual Annual Conference. June 13-15 2021

Agar M. Dementia Care – the role of palliative care and symptom control. ANZSPM Medical Surgical Update (online) November 12-13th 2021.

Agar M. Delirium past. Keynote speaker. Australasian Delirium Association ASM (virtual). 8-10th September 2021.

Agar M. Keynote speaker. Advances in the management of delirium at the end of life. European Delirium Association ASM (virtual). 17-19th November 2021.

Agar M. Chairperson. Care for the older person with lung cancer (breakfast workshop session). Clinical Oncology Society of Australia ASM. November 2021

Agar M, Currow D, Doogue M, Rowett D, Seah D, Hunt J, and Brown L. Variations in practice. Paracentesis in malignant ascites.

Poster presentation, 17th World Congress of the European Association for Palliative care 6-8th October 2021.

Agar M, Nowak A, Hovey E, Barnes E, Simes J, Vardy J, Wheeler H, Leonard R, Hall M. Tim E. Phase II randomised placebo-controlled double-blind study of acetazolamide versus placebo for cerebral oedema in recurrent and/or progressive high-grade glioma requiring treatment with dexamethasone.

Oral presentation. COGNO ASM. 24- 26 October 2021

Agar M, Nowak A, Hovey E, Barnes E, Simes J, Vardy J, Wheeler H, Leonard R, Hall M. Tim E. Phase II randomised placebo-controlled double-blind study of acetazolamide versus placebo for cerebral oedema in recurrent and/or progressive high-grade glioma requiring treatment with dexamethasone.

Poster, Oceanic Palliative Care Conference, Virtual, 7-10 September 2021.

Agar M, Xuan W, Jobburn K, Maurya N, Lee J, Barclay G, Oloff A, Harlum J and Chow J. Longitudinal symptom profile of palliative care patients receiving a nurse-led end of life (PEACH) Program to support preference to die at home. Poster, Oceanic Palliative Care Conference, Virtual, 7-10 September 2021.

Agar M, Xuan W, Jobburn K, Maurya N, Lee J, Barclay G, Oloff A, Harlum J and Chow J Predictors of home death for palliative care patients receiving a nurse-led end of life (PEACH) Program.

Oral presentation, Oceanic Palliative Care Conference, Virtual, 7-10 September 2021.

Agar M, Siddiqi N, Hosie A, Boland JW, Johnson MJ, Featherstone I, Lawlor PG, Bush SH, Page V, Amgarth-Duff I, Garcia M, Disalvo D, Rose L, Del-COrS Group. Outcomes and measures of delirium interventional studies in palliative care to inform a Core Outcome Set: A systematic review.

Oral presentation, Oceanic Palliative Care Conference, Virtual, 7-10 September 2021.

Agar M, Siddiqi N, **Hosie A**, Boland JW, Johnson MJ, Featherstone I, Lawlor PG, Bush SH, Page V, **Amgarth-Duff I, Garcia M, Disalvo D,** Rose L, Del-COrS Group. Outcomes and measures of delirium interventional studies in palliative care to inform a Core Outcome Set: A systematic review.

Poster, (Virtual), 17th World Congress of the European Association for Palliative care 6-8th October 2021.

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Poster, (Virtual), 17th World Congress of the European Association for Palliative care 6-8th October 2021.

Agar M, Xuan W, Jobburn K, Maurya N, Lee J, Barclay G, Oloff A, Harlum J and Chow J. Longitudinal symptom profile of palliative care patients receiving a nurse-led end of life (PEACH) Program to support preference to die at home. Oral presentation, 17th World Congress of the European Association for Palliative care 6-8th October 2021.

McCaffrey N, Cheah S, Luckett T, Phillips J, Agar M, Davidson P, Boyle F, and Lovell M. Healthcare resource utilisation by patients with advanced cancer living with pain. An analysis from the STOP Cancer Pain trial. Oral presentation. 17th World Congress of the European Association for Palliative care 6-8th October 2021.

Bindley K, Lewis J, Travaglia J, **DiGiacomo M**. Caring, Bereavement & Bureaucracy: A Qualitative Study of Australian Social Welfare Policy and Caring in the Context of Life-limiting Illness. World Congress of the European Association for Palliative Care online, 6th-8th October 2021(Poster)

Bindley K, Lewis J, Travaglia J, **DiGiacomo M**. An intersectional exploration of Australian social welfare policy during and following caring. Oceanic Palliative Care Conference program, online. 7-10th September 2021.

Bradshaw A, Bravington A, **DiGiacomo M**. Ensuring quality in qualitative palliative care research (Workshop), Oceanic Palliative Care Conference program, online. 7-10th September 2021.

Chow J, Jobburn K, **Agar M** and Harlum J. Economic evaluation of the palliative care home support packages (PEACH) program. Poster presentation, 17th World Congress of the European Association for Palliative care 6-8th October 2021.

Currow D. Invited keynote speaker, Argentina Homecare conference. Update on cachexia-anorexia syndrome treatment, Palliative approach to breathlessness. Argentina December, 2021

Currow D. Invited speaker – parallel session. 25th Asia-Pacific Respiratory Society meeting. Oxygen for the palliation of breathlessness in people with advanced life-limiting illnesses. Tokyo November 2021

Currow, D. Discussant, Social capital and palliative care (The Australian Healthcare System).

Palliative Care Research Collaborative (USA) Investigator Development Webinar series: USA (by videoconference), November, 2021

Currow D. Invited presenter – parallel session. Opioids for chronic breathlessness - practical evidence-based prescribing: Does morphine help? Evidence for effectiveness, dose and preparations.

17th World Congress European Association of Palliative Care, Helsinki, Finland (by videoconference) October, 2021

Currow D, Rowett D, **Brown L, Agar M, Hunt J, Seah D,** Doogue M. RAPID program – Effectiveness of paracentesis for malignant ascites at different time points. Poster presentation, 17th World Congress of the European Association for Palliative care 6-8th October 2021.

Currow D. Invited Grand Rounds. When evidence meets practice... what can we learn from phase III studies in hospice / palliative care? Geriatric and Palliative Care – Massachussets General Hospital / Brigham Women's Hospital. Boston, USA (by videoconference) September, 2021

Currow, D. Invited Grand Rounds. Chronic breathlessness: silent and deadly. Lois U. and Harry R. Horvitz Palliative Care Grand Rounds, Cleveland Clinic. Cleveland, Ohio July, 2021

Currow D. Invited Plenary. Quality Palliative Care. Thai Palliative Care Association Annual Conference. Bangkok, Thailand (by videoconference) May, 2021

Currow D. Invited speaker. Assessment and pharmacological treatment of chronic breathlessness 6th McMaster International Review Course in Internal Medicine (MIRCIM 2021) Krakow, Poland (by videoconference) May, 2021

Currow D. Invited speaker. Symptom burden in mesothelioma – non-pharmacological and pharmacological management. International Mesothelioma Interest Group (iMIG) Brisbane, Australia (by videoconference) May, 2021

Currow D. Invited speaker. The evidence for prescribing opioids for breathlessness 28th International Conference of the Indian Association of Palliative Care, Patna, India (by videoconference) March, 2021

Currow D. Plenary Speaker. Is all breathlessness the same?

Parallel session speaker How science can help us to manage delirium. 16th Norwegian conference in palliative care. Oslo, Norway March, 2021 (by videoconference)

Currow D. Invited speaker, parallel session, Stream co-chair – supportive and palliative care. Cachexia – ignored and deadly International Association for the Study of Lung Cancer (IASLC) World Conference on Lung Cancer (WCLC 2021): Evidence base for symptom management stream, Singapore, Singapore. January, 2021 (by videoconference)

Currow, **Chang**, Ekström, Hutchinson, **Luckett**, **Kochovska**, Hay, Touyz, Dal Grande, Johnson. Health service utilisation in the presence of chronic breathlessness: a population survey. Oceanic Palliative Care Conference program, online. 7-10th September 2021.

DiGiacomo M, Heneka N, Disalvo D, Attwood R, **Phillips J.** Appreciating and addressing challenges of brain cancer in palliative care: clinician, patient, and carer perspectives. Cancer Nurses Society Australia Conference, Sydney, 18 November 2021.

Disalvo D, Agar M, Caplan G, Murtagh F, **Luckett T, Hickman L, Kinchin I,** Trethewie S, Sheehan C, Urban K, Cohen J and **Phillips J.** Virtual models of care for people with palliative care needs who live at home: A systematic meta-review and narrative synthesis. Poster presentation, 17th World Congress of the European Association for Palliative care 6-8th October 2021.

Fischer T, Teodorcuk A, **Hosie A and Agar M**. Symposium: Definitions, measures and intervention outcomes for agitation during illness and medical treatment. American Delirium Society 11th Virtual Annual Conference. June 13-15 2021

Hirst L, Chye R, Xuan W, **Agar M**, Razmovski-Naumovski V. A retrospective medical record review of palliative cancer patients receiving medicinal cannabis.

Oral presentation, Oceanic Palliative Care Conference, Virtual, 7-10 September 2021.

Lee W, DiGiacomo M, Draper B, **Agar M, Currow D**. Depression care in very poor prognosis setting is complex and challenging – perceptions, key barriers and potential solutions by Australian palliative care physicians and psychiatrists. Poster presentation, 17th World Congress of the European Association for Palliative care 6-8th October 2021.

Lee, W, Chang S, DiGiacomo M, Draper B, Agar M, Currow D. Dying with Depression: A mixed-methods study of clinicians' practices, challenges and solutions, Oceanic Palliative Care Conference program, online. 7-10th September 2021.

Lovell M, Phillips J, Luckett T, Lam L, McCaffrey N, Boyle F, Shaw T, Davidson P, Currow D, Cheah S, Agar M. A Cluster Randomised Controlled Trial Of Guidelines And Screening +/- Implementation Strategies To Improve Pain In Adults With Cancer. Multinational Association of Supportive Care in Cancer (MASCC) Annual meeting. 24-26 June 2021, virtual.



Presenters were awarded with <u>Winner of the Steven M. Grunberg Memorial Award for</u> excellent scientific achievement in supportive care in cancer

Luckett T, Newton-John T, **Phillips J**, Holliday S, Powell-Davies, **Lovell M**, Liauw W, Rowett D, Pearson S, **Heneka N**. Quality use of opioids in people with cancer and pain: The need to integrate care between oncology and general practice (POSTER). Cancer Nurses Society of Australia; Brisbane, Australia. 18 June 2021.

Luckett T, Roberts MM, Swami V, Smith TA, Cho J-G, Klimkeit E, Wheatley JR. Are Non-pharmacological Strategies Sustained 6 Months after Patients with Chronic Obstructive Pulmonary Disease (COPD) Attend a Breathlessness Service? A Qualitative Study. Oceanic Palliative Care Conference program, online. 7-10th September 2021.

Luckett T, Pearson M, Ferguson C, Roberts M, Dunn S, Penola D, Smith T, Swan F, **Phillips J, Currow D, Kochovska S.** Respiratory clinicians' perspectives on the hand-held fan for chronic breathlessness from COPD. Oceanic Palliative Care Conference program, online. 7-10th September 2021.

Luckett T, Roberts MM, Swami V, Smith TA, Cho J-G, Klimkeit E, Wheatley JR. Are Non-pharmacological Strategies Sustained 6 Months after Patients with Chronic Obstructive Pulmonary Disease (COPD) Attend a Breathlessness Service? A Qualitative Study (POSTER). 17th World Congress of the European Association for Palliative Care; Online. 6-8 October 2021.

McCaffrey N, Cheah S, Luckett T, Phillips J, Agar M, Davidson P, Boyle F, Currow D, Lovell M. Treatment patterns and healthcare resource utilisation by patients with advanced cancer living with pain: an analysis from the Stop Cancer PAIN Trial. 17th World Congress of the European Association for Palliative Care online, 6th-8th October 2021.

Parker, D. 2021 The Future of Dementia Care. European Association of Palliative Care 17th World Congress Online. 6-8th October

Razmovski-Naumovski V, **Luckett T, Amgarth-Duff I, Agar M.** Efficacy of medicinal cannabis for appetite-related symptoms in people with cancer: A systematic review (POSTER). Oceanic Palliative Care Conference program, online. 7-10th September 2021.

Prihartadi AS, Impelliziere Licastro G, Pearson M, Johnson MJ, **Luckett T**, Swan F. A Scoping Review of the Implementation of Non-medical Devices for the Self-management of Chronic Breathlessness. The Palliative Care Congress, Edinburgh, 25-26 March 2021.

Schaefer I, Heneka N, DiGiacomo M, Panozzo S, Luckett T, Phillips J. Determinants of palliative care provision in prison: a systematic review. Oceanic Palliative Care Conference program, online. 7-10th September 2021.

Schaefer I, Heneka N, Luckett T, Agar MR, Chambers SK, Currow DC, Halkett G, Disalvo D, Amgarth-Duff I, Anderiesz C, Phillips JL. Quality of online self-management resources for adults living with primary brain cancer and their carers: an environmental scan. Cancer Nurses Society of Australia; Brisbane, Australia. 18 June 2021.

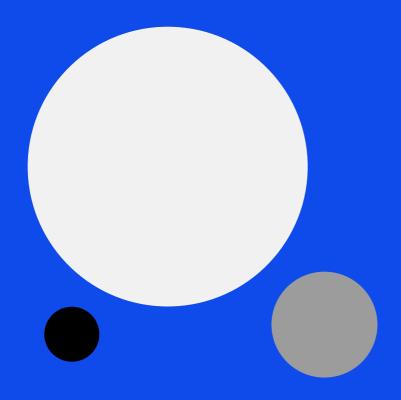
Schaefer I, Heneka N, Luckett T, Agar MR, Chambers SK, Currow DC, Halkett G, Disalvo D, Amgarth-Duff I, Anderiesz C, Phillips JL. A systematic environmental scan of online self-management resources for adults living with primary brain cancer and their carers. 17th World Congress of the European Association for Palliative Care; Online. 6-8 October, 2021.

Schaeffer I, Heneka N, Luckett T, Agar M, Chambers S, Currow D, Halkett G, Disalvo D, Amgarth-Duff I, Anderiesz C, and Phillips J. A systematic environmental scan of online self-management resources for adults living with primary brain cancer and their carers. Poster presentation, 17th World Congress of the European Association for Palliative care 6-8th October 2021.

Virdun, C, Luckett, T, Davidson, P, Lorenz, K and **Phillips, J**. Priority areas to enable optimal inpatient palliative care: a mixed methods study (POSTER). Palliative Care Australia 2021 Oceanic Conference, 7-10th September, online

Virdun, C, Luckett, T, Davidson, P, Lorenz, K and **Phillips, J.** Key areas of clinical practice that enable optimal palliative care in acute hospitals: a mixed methods study. 17th World Congress of the European Association for Palliative Care online, 6th-8th October 2021

Virdun, C, Luckett, T, Davidson, P, Lorenz, K and **Phillips, J.** Key areas of clinical practice that enable optimal inpatient palliative care: a mixed methods study. 'Champions of Change' National Nursing Forum, Australian College of Nursing. 18-20 August, 2021, Canberra.





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