Calvary

Research in the times of COVID-19

Palliative and End of Life Care Research Institute Activity Report

2019-2022

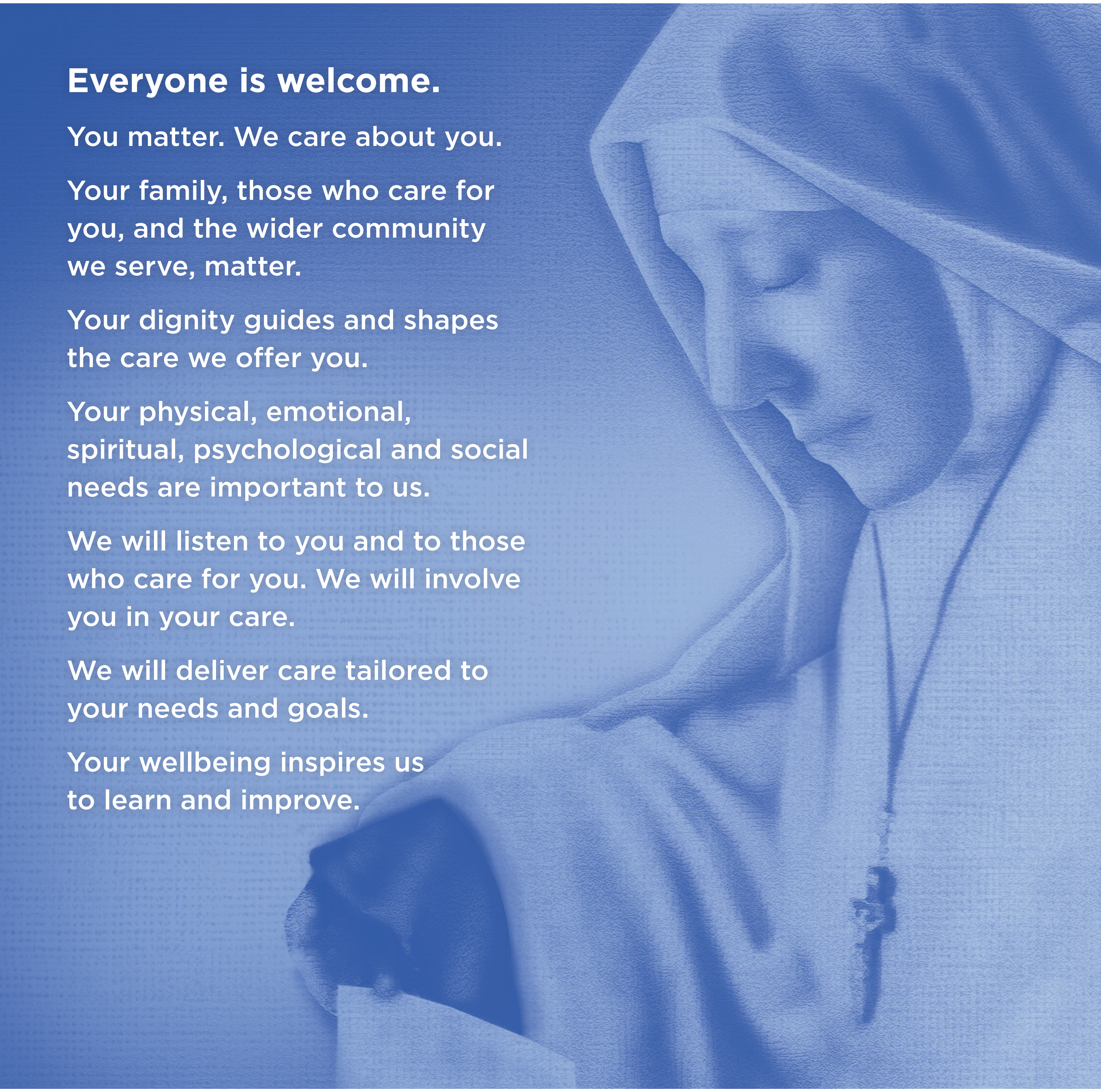
Continuing the Mission of the Sisters of the Little Company of Mary

Hospitality | Healing | Stewardship | Respect

Spirit of Calvary

Being for others

Hospitality
Healing
Stewardship
Respect



Everyone is welcome.

You matter. We care about you.

Your family, those who care for you, and the wider community we serve, matter.

Your dignity guides and shapes the care we offer you.

Your physical, emotional, spiritual, psychological and social needs are important to us.

We will listen to you and to those who care for you. We will involve you in your care.

We will deliver care tailored to your needs and goals.

Your wellbeing inspires us to learn and improve.

Continuing the Mission of the Sisters of the Little Company of Mary

About us

About Calvary

Founded in 1885 by the Sisters of the Little Company of Mary, Calvary is a charitable, not-for-profit, Catholic health care organisation.

Our mission is to provide quality, compassionate health care to the most vulnerable, including those reaching the end of their life.

With over 18,000 staff and volunteers, we have a national network of 14 Public and Private Hospitals, 72 Residential Care and Retirement Communities and 19 Community Care service centres.

About the Research Institute

Palliative care patients and their families deserve the best possible care that we can give them.

Formed in 2017, the Calvary Palliative and End of Life Care Research Institute connects researchers from specialist palliative care services in Calvary's public hospital network.

There is a growing body of research being conducted through the Calvary network of palliative care services on managing symptoms such as pain, nausea, breathlessness and delirium.

There is also psycho-social research to investigate the experiences of patients, their families and friends.

Social change has had an enormous impact on how and where people die and Calvary's palliative care services bring a depth of experience as well as evidence-based expertise, particularly for our clients in residential aged care.

Through the Institute, Calvary is able to:

- highlight excellence in palliative and end of life care research
- support collaboration between clinicians and researchers
- demonstrate the benefits of research outcomes
- put research into practice
- share research with the wider industry stakeholders.

Contents

Acknowledgement of Country

Calvary acknowledges the Traditional Custodians and Owners of the lands on which all our services operate, commits to Closing the Gap and to the ongoing journey of Reconciliation.

Message from Martin Bowles

National Chief Executive Officer

Welcome to the Research Activity Report (2019-2022) - Research in the times of COVID-19, for the Calvary Palliative and End of Life Care Research Institute.

Established from the passion of our palliative care clinicians and researchers to deliver high quality, evidence-based care, the Institute provides a virtual collaborative framework for researchers and clinicians from the specialist palliative care services across our four public hospitals.

Calvary is one of Australia's largest providers of specialist palliative care. With last year's acquisition of the Japara aged care business, Calvary now operates 72 residential aged care and retirement homes, 14 public and private hospitals, 19 community care service centres and virtual care services (My Home Hospital and COVID Care at Home) across all states and territories. This diverse service offering—a microcosm of the Australian health and aged care system—offers new and exciting growth opportunities and partnerships for the Institute.

The important work of the Institute reflects an onus of Calvary's Strategic Intent to continue to build respectful, collaborative relationships with patients, residents, clients, families and community partners from which we can further develop and improve our integrated and innovative, compassionate and person-centred models of care. This goal is central to our mission, particularly at this time of COVID-19 pandemic, government implementation of the recommendations of the Royal Commission into Aged Care, and the introduction of voluntary assisted dying in a number of jurisdictions.

We know that the highest quality person-centred care is best supported by robust research, the translation of that research into practice and continual service improvement and innovation. This edition of the Research Activity Report highlights the achievements of the Institute despite the challenges brought about by the COVID-19 pandemic. The primary focus included research on the experience of those bereaved during the COVID-19 pandemic, palliative care in the community setting, research addressing the spiritual dimensions in palliative care and neurodegenerative disorder research, along with a number of other important research projects.

Current and future Calvary-led research regarding palliative and end of life care, aligned with our strategic objectives, will be critical to the success of the organisation's growth strategy.

Finally, I would like to recognise and thank the outgoing Chair of the Institute, Professor Nicholas Glasgow. Nick has been Chair of the Institute from 2019 to 2022 and in this time has achieved remarkable results in maintaining strong engagement across our palliative and end of life care research network. We wish Nick all the best for the next step in his journey and extend our sincere thanks for his integrity and commitment in performing this important role during a time of unprecedented challenge for the health sector.

MARTIN BOWLES AO PSM

Message from Nicholas Glasgow

Research Institute Chair

I am pleased to present this Research Report for the Calvary Palliative and End of Life Care Research Institute.

As Martin has said, research is an integral part of the strategic directions Calvary is taking, and this report is testament to the many research activities in palliative and end of life care underway across the Calvary network.

The COVID-19 pandemic came to Australia in the first quarter of 2020 and continues today as I write. No one knew quite how it was going to affect Australia at that time. Health services (including primary, secondary and higher levels of care, as well as palliative care) and residential aged care facilities were among the first to experience the full brunt of this novel virus. Australia is fortunate to have relatively high immunisation rates, but despite this there are significant numbers of new cases on a daily basis, and, sadly for families, loved ones and friends, continuing deaths as well.

The pandemic had direct impacts on research in two main ways.

First, many research activities were required to cease because of the various restrictions health services had to put in place as part of the response to COVID-19 to minimise transmission. This meant that most research, including clinical trials underway in palliative care settings, stopped. Some research activities were able to continue in a modified form, often making use of the telehealth platforms for clinical consultations that rapidly evolved and have continued over the course of the pandemic. An example of this is highlighted later in this report, in the study looking at the implementation of a tool to systematically assess psycho-existential distress in palliative care patients.

Second, because this was a novel coronavirus, an enormous amount of research was rapidly commissioned and prosecuted around the globe to understand the virus and inform public health and clinical responses. New vaccines were developed, tested, and rolled out in remarkably compressed timeframes compared to what had been typical in vaccine development. Studies on transmission mechanisms, disease trajectories and potential treatments to name a few examples, all mushroomed and results were distilled into a rapidly expanding evidence base. Research specifically on the impact of the virus on aspects of palliative and end of life care were among the studies commissioned. An example of this is also highlighted in this report through the Medical Futures Fund grant Professor Liz Lobb and colleagues won to study the impact of COVID-19 on bereavement.

The way research has informed the pandemic response underscores more generally the vital role research plays in developing both policy and practice in health care.

For this reason, at the national level Calvary is focused on strengthening research across all its services. Research and innovation are essential to continuous quality improvement in health care, including palliative and end of life care.

The Institute has continued to have regular monthly teleconferences among the four specialist palliative care lead sites at Calvary Health Care Bethlehem, Victoria, Calvary Public Hospital Bruce, ACT and Calvary Mater Newcastle and Calvary Health Care Kogarah in New South Wales. I am very grateful to my colleagues who have taken on the role of representing those sites when the Institute meets. Prof Liz Lobb from Kogarah, who has also deputised for me when I have been unable to attend, Dr Sarah Moberley from Newcastle, and Dr Christopher Grossman from Bethlehem. Our discussions have been warm, constructive, and focused. Thank you.

Early in 2019, Naomi McGowan, National Manager Palliative and End of Life Care moved on from Calvary. Naomi played a key role in ensuring the Institute kept progressing, including leaving clear plans for future directions the Institute could consider. Thank you Naomi for all you did for the Institute.

We were very pleased that the support for the Institute that Naomi had provided continued with the appointment of Diana Ferrao as Project Coordinator. Part of Diana's role is to coordinate the monthly meetings and support the development of various activities of the Institute including this report. She has done great work. Thank you Diana.

Finally, to the National Leadership Team at Calvary, my sincere thanks for your support of research within Calvary.

Research is hard work. It is often undertaken in peoples' own time, rather than in designated research hours. This report is testimony to the incredible established and emerging research talent that is found among those working in Calvary services. I thank them for their work.

This will be my last report. I am retiring, having enjoyed a thoroughly satisfying clinical academic career since I came to Canberra in 1997. I began part-time work at Clare Holland House soon after arriving and have continued to have links with Calvary throughout the years. I am grateful for the colleagues I have worked with at Calvary for their encouragement, support and friendship. To all of you, as well as those working and supporting the Institute – thank you. I am sure the future for the Institute is bright.

NICHOLAS GLASGOW

Research in the Times of COVID-19

Medical Research Futures Fund (MRFF) Grant

The "silent pandemic" of grief during the COVID-19 pandemic

One of the largest National studies on bereavement in Australia during the COVID-19 pandemic is being undertaken by Professor Liz Lobb, Calvary Palliative and End of Life Care Research Institute's Site Lead at Calvary Health Care Kogarah.

Funded by the Medical Research Futures Fund (MRFF), with Associate Investigators from the Institute including Professor Nicholas Glasgow, Dr Rachel Hughes, Dr Sarah Moberley and Dr Christopher Grossman, this study will document the experience of those bereaved during the COVID-19 pandemic and identify their short and long term support needs.

Data was collected between 2021 and 2022 from more than 2,700 bereaved people and 100 people were interviewed. Interviews with Multi-Cultural Health Workers and Aboriginal & Torres Strait Islander Health Workers are underway. Their views are sought as they have-multi-faceted roles being a community member, as well as a conduit between health services and their Communities.

As the death rates from COVID-19 rise around the world – currently at 6.25 million - researchers are beginning to identify what has been called the "silent pandemic" of grief. In Australia, to date there have been more than 10,000 deaths.

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 hospitals and residential aged care facilities, and reduced physical contact at funerals. Additionally in Australia, deaths during COVID-19 occurred in a milieu of loss upon loss on the back of the catastrophic east coast bushfires, prolonged drought, and floods, meaning many people are managing these multiple losses.

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. Preliminary data from this MRFF study shows 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 seven to 10 per cent of bereaved people will experience chronic and disabling grief, which impacts their ability to function in their daily lives and is linked with substantial mental and physical health morbidity.

The information from this on-going study will be used to develop a national action plan for bereavement support during the COVID-19 pandemic and any future pandemics.

BEREAVEMENT
DURING COVID-19

University of Technology Sydney Research Team

DR SERRA IVYNIAN
Project Manager

SARA ROBERTS
Research Assistant

KIMBERLY JONES
Research Assistant

Chief Investigators: Prof Liz Lobb, Dr Fiona Maccallum, Prof Meera Agar, Prof Jane Phillips, Prof Lauren Breen, Dr Tim Luckett, Prof Michelle DiGiacomo, Prof Jennifer Phillip, Prof Jennifer Tieman, Dr Annamarie Hosie.

Associate Investigators: Dr Nicholas Glasgow, Dr Sarah Moberley, Dr Rachel Hughes, Dr Christopher Grossman, Ms Imelda Gilmore, Prof Ann Dadich, Ms Janeane Harlum, Ms Katie Snell, Dr Irina Kinchin, Dr Sungwon Chang.

Julie Anne Rose (Aboriginal Palliative Care Coordinator, Calvary Mater Newcastle), Leonie Garvey (Manager Aboriginal Health Unit, Greater Newcastle Sector Aboriginal Health Unit), Sarah Moberley (Senior Research Fellow, Calvary Mater Newcastle)

Palliative Care in the Community Setting

Miromullia Project (Awabakal language, continue to take care of)

PROJECT LEAD: JULIE ANNE ROSE

In 2021, Calvary Mater Newcastle had the opportunity to pause and reflect on how palliative care was being delivered to its local Aboriginal and / or Torres Strait Islander communities. It was identified that a model of care culturally safe and effective for Indigenous communities, as well as staff, was best informed through the understanding of needs, preferences and experiences of the communities. Consulting with the Aboriginal Health Unit and local Land Councils, a partnership was developed to consult with the community to create a best practice framework for care. Further, it was agreed that it was acceptable and optimal that this project was undertaken within a research framework to ensure the process was ethical and meaningful, that the voices of community members were respected and represented authentically.

Steps completed to date:

- employment of an Aboriginal Project Coordinator, Julie Anne Rose
- establishment of an Aboriginal Advisory Group
- co-design of methodological approach in consultation with Aboriginal Advisory Groups and academic bodies
- attainment of ethical clearance from the National Aboriginal Health and Medical Research Council and local ethics committees
- established community survey and community and health professional yarning.

Lessons learnt from this approach so far have highlighted the need for such a project to have a strong Aboriginal Lead and strong community support. It is hoped that this project will continue to facilitate collaborative relationships across services to improve experiences and meet the needs of patients, families and communities accessing specialist palliative care. It is also hoped that the consultative research model may prove translatable and inform ongoing culturally safe service design models.

Sarah Moberley (Senior Research Fellow,), Dianne Foot (Care Coordinator), Peter Kozaczynski (Clinical Nurse Consultant), Helen Box (Clinical Trial Coordinator), Jessica Scaife (Nursing Unit Manager) all Department of Palliative Care, Calvary Mater Newcastle

Palliative Care in the Community Setting

Medical Research Futures Fund (MRFF) Grant - HPC3 (Hunter Palliative Community Coordinated Care)

Understanding need to enhance care in preferred place for patients and carers

PROJECT LEAD: JESSICA SCAIFE

Supported through a MRFF grant in partnership with NSW Regional Health Partners, a randomised control trial is underway to identify best practice community palliative care service delivery and explore the role of care coordination in specialist palliative care. The research is designed to understand need in patients and carers, and the impact of earlier identification of distress and unmet need on the ability for patients to receive care in their preferred place.

Hunter Palliative Community Coordinated Care (known as HPC3) is a partnership with University of Newcastle, Hunter New England LHD, Hunter Medical Research Institute and Calvary Community Care.

Health economic evaluation and comprehensive cost consequence analysis has been embedded in the research design to better inform ongoing service development in specialist palliative care.

Recruitment to this study commenced in May 2021 and within 11 months we have achieved the milestone of full participant recruitment (n=500).

The study is expected to be completed by December 2022.

Spiritual and existential dimensions of Palliative and End of Life Care

The practice of palliative care is focused on providing "whole person" care – that is, care that addresses all aspects of our humanity including physical needs (like some kinds of pain or constipation or nausea) social needs (like supporting families, carers and friends as end of life approaches) and psychological needs (such as depression or anxiety). Another very important aspect to consider are spiritual or existential concerns a person may have. Although this is very well recognised as being important, it is also the case that there may be less attention to these kinds of issues for a variety of reasons including patients not knowing if they are appropriate to raise, or clinicians feeling ill-prepared to explore these issues and respond to them if they are present.

Professor David Kissane from the University of Notre Dame has led a body of research work over the years that investigates psychological, spiritual and existential matters at the end of life. From the outcomes of this research program he developed a short questionnaire designed in a manner that makes it possible for busy clinicians to include it as part of their routine clinical work. The short questionnaire is called the Psycho-existential Symptom Assessment Scale (PeSAS). Professor Kissane is now leading a study looking at the implementation of this questionnaire in a number of palliative care services in Australia. Among these sites are Calvary Hospital palliative care services based at Kogarah in Sydney and Clare Holland House based in the ACT.

The systematic approach employed for the management of physical symptoms has been well documented and tools such as the Symptom Assessment Scale (SAS), incorporated by the Palliative Care Outcomes Collaboration (PCOC), has been successfully adopted by a majority of palliative care services nationally. SAS attempts to quantify an individual's experience of symptoms, such as for example pain, nausea, breathlessness or fatigue, using an analogue scale that ranges from no distress

expressed as zero and the maximum imagined distress as 10. Importantly, it is essential that this is from the individual patient's perspective. PeSAS is an extension to the SAS in that it employs a validated 10 item assessment of distress associated with for example anxiety, discouragement, hopelessness, pointlessness and depression recorded on the same familiar analogue scale.

As Professor Kissane and others have highlighted in their work, verifying demoralisation, disempowerment, the sense of futility and feelings of hopelessness as common experience that people may confront with a terminal illness, once recognised and addressed with various counselling interventions, then many may regain a sense of empowerment and recapture a new a sense of hope. As well, there is an opportunity to disentangle and investigate the relationship between physical and psychological distress.

Role play with simulated patients provides a safe setting in which to build experience around having conversations about psycho-existential symptoms.

Clare Holland House Experience

Though acknowledging psycho-existential assessment as 'core-business' the 'systematic' element was initially not instinctive to many. Over time and with practice the closely knit team, initially daunted by unfamiliar language, has developed their own language and style of communication that, though staying true to the 10 items on the official assessment scale, has provided the confidence to include routine psycho-existential assessment into their own brand of relevant person-centred care.

Nurses and doctors attached to the community and outpatient services have found that PeSAS assessments have not only prompted referrals to counselling services and pastoral care, but has also been a useful handover tool that provides discussion points in inter-disciplinary meetings. As of May 2022 around 132 out of a potential population of 287 or 46 per cent, have been through this routine assessment process with many ongoing depending upon the severity of their symptoms.

Recognition and acknowledgement of psycho-existential symptoms have been observed to be in many cases therapeutic for patients who have openly expressed a renewed sense of empowerment within the chaos of a palliative care journey. For example, one assessment of a patient suffering from lung cancer resulted in very high scores, particularly around anxiety and being trapped by her illness. This prompted a referral to social work for follow-up counselling.
At this session the patient confessed that '...it felt a frightening thing to say out loud at the time (express the overwhelming fear of dying from shortness of breath), but now she can without crying...now glad that it's out in the open and that the (Palliative Care) team is aware, she feels reassured that breathlessness will be able to be managed at the end of her life and is choosing to focus on this'. Furthermore, she went on to say that she is 'confident she would talk with the nurses if her distress around this arises again'. Interestingly, a repeat assessment revealed much lower scores on all items.

The concept of 'total pain', as originally recognised by founder of the modern hospice movement Dame Cicely Saunders (1918-2005), acknowledges the interaction of the domains of physical, psychological, social and spiritual distress as experienced by the individual as they navigate this 'new strange world' in which they may feel so alone. The daily challenge encountered by practitioners in palliative care is to effectively assess and provide comfort to the whole person.

Not only is this project a necessary and logical acknowledgement of World Health Organisation's early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual that is necessary in best practice palliative care, it has provided ideal opportunity for practitioners to generally improve their communication skills.

"The good physician treats the disease; the great physician treats the patient who has the disease."

Sir William Osler.

Neuro-palliative Care

Calvary Health Care Bethlehem (CHCB) has specialised in providing services for people with progressive neurological diseases for more than 30 years. In 2009, The Victoria Department of Health designated the neurology service at CHCB as a 'state-wide service', based on the Subacute Capability Framework and it is known as the Statewide Progressive Neurological Disease Service (SPNDS).

In 2012, the Statewide Progressive Neurological Disease Service Project (2012 – 2016) validated a model for specialists, regional clinics, telehealth and secondary consultation providing neuropalliative rehabilitation to Victorians living with a progressive neurological disease (PND). As a part of the project, a PND service was set up and evaluated in Barwon and the Southwest region. The outcomes supported the hypothesis that "an integrated model is beneficial and can be delivered equitably in metropolitan and regional settings".

In 2019, the Victorian Government awarded CHCB a Palliative Care Service and Innovation and Development Grant as a means to continue this important research and model of care development. Work began with Bethlehem researchers in areas including: reviewing existing models of care structures, approaching key patient, family and professional caregiver stakeholders and implementing and designing a new model of neuro-palliative care for services in Victoria to aspire to.

The 'My Neuro-Palliative Care' Project was designed to gather information on the lived-experience of patients and carers who are receiving care from both SPNDS and local providers, including the local Victorian palliative care services. The project gathered evidence around what patients and families need; what patients think is important in their care; what are the current gaps in the system and what the barriers are to providing a more integrated model of care. Collectively we explored options for improvement, drawing on published evidence to design a new model of neuro-palliative care. In the final phase of the project, this new model was piloted and evaluated in both metropolitan and regional locations in Victoria.

The My Neuro-Palliative Care project team aim to deliver:

- Consumer's perspectives on neuro-palliative care delivery in Victoria.
- An evaluation of the use of shared needs assessment and care planning documents to support interprofessional collaborative care across different sectors and organisations.
- Guidelines for the use of telehealth in interprofessional, collaborative neuro-palliative care.
- A Framework for action on education and research in neuropalliative care—inclusive of consumers, clinicians, service providers and researchers.

PHASE 1

Review and evaluation of the current model of care: the lived experience of current neuro-palliative care

- January 2020 to October 2020. Calvary Research Ethics and Ethics Committee approval no. 61429
- 18 patients/carers participated in semi-structured interviews
- Review of the current published literature and relevant policy documents
- Survey of neurological and palliative care staff at Calvary HealthCare Bethlehem

PHASE 2

Collaboration and co-design of the new model of neuro-palliative care

- November 2020 to March 2021. Monash HREC multi-site ethics submission: 66873
- Survey of Victorian palliative care providers
- Focus groups with six self-nominated palliative care services (four metropolitan and two regional services)
- Semi-structured interviews with representatives of GPs, neurological organisations, NDIS providers and other providers involved in the care of people with PNDs
- Stakeholders co-design new model of neuro-palliative care, develop the protocol for implementing the pilot study and agree on outcome measures

PHASE 3

Evaluation and implementation of the new model of neuro-palliative care

- April 2021-January 2022. Monash HREC multi-site ethics submission: 76058
- Piloted and evaluated across an 'episode of care' for each patient/carer participant
- Complete reports and publications. Dissemination of findings

In 2022, the project is now entering its end stages with reports and publications being drafted and the model of care being presented to stakeholders from across the State (including but not limited to: Bendigo Health, Eastern Palliative Care, Eastern Health, Albury Wodonga Health & Mercy Palliative Care). It is hoped that the Government will adopt and recommend this model of care for health services for PND patients. Bethlehem-based researchers are planning further works in this area to bolster awareness, resources and implementation of the new care models of neuro-palliative care work around Australia.

ACADEMIC RESEARCH CENTRES

Calvary Public Hospital Bruce

Clare Holland House

Calvary Public Hospital Bruce has continued to support research and innovation in palliative and end of life care for over a decade through the Calvary Centre for Research in Palliative Care based at Clare Holland House. Professor Nicholas Glasgow is the third person to lead this Centre. He follows Professor Liz Forbat and before her, the inaugural Director Dr John Rosenberg, who was appointed in 2011.

During the terms of both Professor Forbat and Dr Rosenburg, the Centre was a partnership between Calvary Public Hospital Bruce and the Australian Catholic University. In 2018, the Australian Catholic University decided to not renew this partnership, but Calvary Public Hospital Bruce continued its support of research and innovation. This is a testimony to Calvary Public Hospital Bruce's commitment to the value and importance of research activities being embedded in clinical service delivery as a way of continuously improving patient care, as well as enhancing recruitment and retention of staff. Since 2020, research at Clare Holland House has been further supported through the appointment of a Research Nurse, Dr Graham Moss.

Throughout the time the Centre has been in operation it has been involved in collaborative multidisciplinary activities with other key partners including the University of Canberra, the Australian National University, the Canberra Hospital as well as residential aged care facilities and general practitioners. The Centre has also partnered with the Palliative Care Clinical Studies Collaborative in formal research programs. These collaborative activities are essential if sound research addressing the needs of people nearing the end of life is to be successfully completed.

The government responses at both Commonwealth and Territory levels to the COVID-19 pandemic imposed considerable restrictions on the kinds of research activities that could be undertaken at Clare Holland House. None the less, research and innovation has been able to continue as the summaries below show.

Staff at Clare Holland House are all supportive of and committed to research activity being part of the fabric of service delivery provided to patients. The extent to which they individually participate varies according to the demands of their different roles. Research reported below happens because of this support, and of course, the willingness of patients, their families and carers to be involved.

As Director of the Centre, I express my sincere thanks to the leadership at Calvary Public Hospital Bruce, to Ms Amanda Keogh and Dr Suharsha Kanathigoda for their leadership of Clare Holland House, to Dr Graham Moss for all his hard work, to all the staff working at Clare Holland House, and the patients, families and carers who have contributed to the outcomes summarised in this report. They have been achieved with you all. Thank you.

About our Researchers

PROFESSOR NICHOLAS GLASGOW - EMERITUS PROFESSOR, THE AUSTRALIAN NATIONAL UNIVERSITY

Head of the Calvary Centre for Research in Palliative Care

Research interests: Health services research, chronic disease and comorbidity.
Inspiration: The opportunity to work with others to expand knowledge aimed at improving patient care.
Involved in research for: 30 years.

DR SUHARSHA KANATHIGODA - MEDICAL DIRECTOR PALLIATIVE CARE ACT & CHH

Site Investigator

Research interests: Promoting the importance of high quality research being embedded into clinical services with the aim to improve patient outcomes.
Inspiration: Seeing research activities grow and produce results that change practice.
Involved in research for: 20 years.

GRAHAM MOSS PhD – COMMUNITY SPECIALIST PALLIATIVE CARE NURSE AT CLARE HOLLAND HOUSE IN THE ACT

Research Nurse

Research interests: Use of evidence in palliative care, health promoting palliative care and the developing field of building compassionate communities. Currently involved, with Dr Suharsha Kanathigoda Medical Director of ACT Palliative Care services and Site Investigator, in the roll out of the routine clinical assessment of psycho-existential symptoms in palliative care. This national Department of Health sponsored project is headed by Professor David Kissane from the University of Notre Dame.
Inspiration: Bearing witness to skilled and compassionate end of life care of patients and their families.
Involved in research for: 12 years.

NIKKI JOHNSTON OAM - PALLIATIVE CARE NURSE PRACTITIONER

Site Investigator

Research interests: The impact of experience of trauma on the way we die; palliative and end-of-life care in residential aged care.
Inspiration: Changing practice and policy through the conduct of high quality research.
Involved in research for: 30 years.

DR SUZANNE RAINSFORD - PALLIATIVE MEDICINE SPECIALIST, GENERAL PRACTITIONER

Site investigator; Research Fellow at the Australian National University

Research interests: The 'safe death' in rural settings, including residential aged care.
Inspiration: Improving the end-of-life experience for patients, their families, and health care professionals.
Involved in research for: 7 years.

JULIANE SAMARA - NURSE PRACTITIONER

Site investigator

Research interests: Palliative care, exercise in oncology.
Inspiration: Contributing to establishing an evidence base to provide excellent end of life care.
Involved in research for: 6 years.

Current Studies

Improving collaborative palliative care: after death reviews in residential aged care homes. **Samara, J., Dawda, P., Bail, K., O'Connor, T.**

Routine Clinical Assessment of Psycho-Existential Symptoms in Supportive and Palliative Care. **Kanathigoda, S. (CI at Calvary Bruce, CHH), Moss, G (CHH), Prof D. Kissane (UND), Prof. N. Glasgow (CHH), Prof E.A Lobb (CHCK)**

Touchpoint opportunities for everyday clinicians to make a difference in guiding patients to understand and eventually accept palliative care. **R. Bilton-Simek (CI, CHH), Prof. Karen Strickland (UC), Prof. N. Glasgow (CHH), Amanda Keogh (CHH)**

A model to strengthen capacity and coordination of palliative and end-of-life care in Cooma residential aged care – **Phase 2. Rainsford, S., Glasgow, N., Phillips, C., Hall, S.**

Literature search looking for research already published around empathic distress, compassion fatigue and resilience in health professionals. **Waterford, M.**

Publications

Strengthening advance care planning in rural residential aged care through multidisciplinary educational case conferences: A hybrid implementation-effectiveness study. Progress in Palliative Care. 29(4). 199-208, DOI-10.1080/09699260.2021.1872136. **Rainsford S, Hall Dykgraaf S, Kashim R, Phillips C, Glasgow, N.(2021)**

'Traversing difficult terrain'. Advance care planning in residential aged care through multidisciplinary case conferences: A qualitative interview study exploring the experiences of families, staff and health professionals. Palliative Medicine. 35 (6). 1148-1157. DOI- 10.1177/02692163211013250. **Rainsford S, Hall Dykgraaf S, Kashim R, Phillips C, Glasgow, N. (2021)**

Telehealth Palliative Care Needs Rounds During a Pandemic. The Journal for Nurse Practitioners. 17(3). 335-338. https://doi.org/10.1016/j.nurpra.2020.12.009. **Samara, J., Liu, W., Kroon, W., Harvie, B., Hingeley, R., Johnston, N., (2021)**

The conscious state of the dying patient: an integrative review. Palliative and Supportive Care. FirstView. Jan-13 https://doi.org/10.1017/S1478951521001541. **O'Connor, T., Paterson, C., Gibson, J., Strickland, K. (2021)**

Reducing time in acute hospitals: A stepped wedge randomised control trial of a specialist palliative care intervention in residential care homes. Palliative Medicine 34(5), 571-589 doi: 10.1177/0269216319891077. **Forbat, L., Liu, W., Koerner, J., Lam, L., Samara, J., Chapman, M., Johnston, N. (2020).**

Relative importance of clinical and sociodemographic factors in association with post-operative in-hospital deaths in colorectal cancer patients in New South Wales: An artificial neural network approach. Journal of Evaluation in Clinical Practice 26, 1389-1398 doi: 10.1111/jep.13318. **Sha, S., Du, W., Parkinson, A., Glasgow, N. (2020).**

The impact of introducing Palliative Care Needs Rounds into rural residential aged care: A quasi-experimental study. Australian Journal of Rural Health doi: 10.1111/ajr.12654. **Rainsford, S., Johnston, N., Liu, W., Glasgow, N.J. (2020).**

Palliative care needs rounds in rural residential aged care: a mixed-methods study exploring experiences and perceptions of staff and general practitioners. Progress in Palliative Care 28, 308-317 doi: 10.1080/09699260.2019.1698177. **Rainsford, S., Johnston, N., Liu, W., Glasgow, N.J., Forbat, E. (2020).**

Improved quality of death and dying in care homes: a palliative care stepped wedge randomised control trial in Australia. American Geriatrics Society 68(2), 305-312 https://doi.org/10.1111/jgs.16192. **Liu, W., Koerner, J., Lam, L., Johnston, N., Samara, J., Chapman, M., Forbat, L. (2019).**

Conference Presentations

Palliative Care Needs Rounds in residential care settings: changing government policy and funding in Australia. Oceanic Palliative Care 2021. Sept 2021. **Samara, J.**

Improving Palliative Care for Older Australians. Barossa Palliative Care Symposium. Feb 2020. **Samara, J.**

Being on the same page." A qualitative study exploring the role of multidisciplinary educational case conferences in enabling the necessary conversations that underpin advance care planning in rural nursing homes. EAPC 2020 Virtual Conference Palermo, Italy, October 2020. **Rainsford, S., Hall, S., Kasim, R., Phillips, C., Glasgow, N.**

Better lives and better deaths in aged care through specialist palliative care Needs Rounds: Results from a stepped wedge randomised controlled trial. Oceanic Palliative Care Conference, Perth, September 2019. **Forbat, L., Johnston, N., Liu, Wai-Man., Koerner, J., Chapman, M., Lam, L., Samara, J.**

Harm at End of Life. Australian College of Nurse Practitioners Dimensions in Care Conference, Perth, September 2019. **Samara, J.**

The Silicone in Residential Aged Care. Australian College of Nurse Practitioners Transforming Healthcare Conference, Perth, September 2019. **Samara, J., Johnston, N.**

Australian College of Nurse Practitioners Transforming Healthcare Conference, Perth, September 2019. **Johnston, N. Donna Diers Oration.**

Conference Posters

A qualitative study exploring rural primary palliative care from the experiences and perspectives of Australian rural general practitioners and community nurses. 11th World Research Congress of the EAPC, Palermo, Italy. **Rainsford, S., Glasgow, N., Hall, S., Phillips, C. (2020).**

"An interview is not a consultation". The dual role of clinician-researcher. Hospice UK, Liverpool, England. **Rainsford, S., Phillips, C. (2019).**

Committees

Professor Nicholas Glasgow

PaCCSSC: Member

RACP Curriculum Advisory Group: Member (For AChPM)

Australian Pharmacy Council: Councillor

Canberra Region Medical Education Council: Member PaCCSSC: Member

Review of Medical Intern Training Steering Committee: Member (AMC Nominee)

Dr Suharsha Kanathigoda

PaCCSSC: Member

ACT Palliative Care Governance Committee: Member

ACT Palliative Care Forum: Member

Alexander Maconochie Centre model of care development group: Member

RACP regional committee NSW/ACT: Deputy Chair

Nikki Johnston OAM

Clinical Leadership Forum: Member

AIVL Healthy Ageing Project Advisory Group: Member

Life Circle Australia Clinical Committee: Member

Dr Suzanne Rainsford

McGrath Foundation, Expert Reference Group - Breast Cancer Nursing Model of Care: Member

Co-ordinaire Primary Care Network, Advisory Group, Palliative and end of life care in southern NSW: Member

Expert Reference Group, Project to develop a palliative care bereavement support model 2017-2018: Member

Southern NSW Local Health District: Member PaCCSSC: Member

Juliane Samara

Australian College of Nurse Practitioners National Council: Member

ACT Chapter Australian College of Nurse Practitioners: Chair

ACT Nursing and Midwifery Leaders Network Group: Member

ACT Health Advisory Committee (Professional Colleges): Member

Cancer Nurses Society Australia Nurse Practitioner Specialist Practice Network: Member

Commonwealth Nursing and Midwifery Office Strategic Reference Group: Member

ACADEMIC RESEARCH CENTRES

Calvary Health Care Kogarah

Calvary Health Care Kogarah has been involved in clinical trials through the Palliative Care Clinical Studies Collaborative for 13 years. The past two years have been the most challenging as public health restrictions to minimise the spread of the COVID-19 virus and protect the health care workforce had a significant impact on recruitment. Nevertheless, we completed studies on Melatonin for the prevention of delirium in advanced cancer and the use of sub-cutaneous Ketamine in major depressive disorder.

We have now re-opened for clinical trials on appetite, breathlessness in chronic obstructive pulmonary disease, neuropathic cancer pain, inoperable bowel obstruction and constipation and led by Site PaCCSC Investigator Dr. Caitlin Sheehan and supported by our clinical trials co-ordinator Dr. Angela Rao, PhD and Erin Tracey RN.

Breathlessness is a distressing and debilitating symptom that impairs functional capacity and reduces quality of life. Timely assessment of breathlessness is essential to optimise pharmacological treatment, and to address the psychosocial issues and cognitive processes that drive breathlessness. Dr Angela Rao recently led an international collaborative quality improvement project with Stanford University, California, SPHERE Palliative Care Clinical Academic Group and the Calvary Health Care Kogarah Community Palliative Care Team. The project 'Evaluation of a multidisciplinary response to breathlessness in home community palliative care' was undertaken to improve the timeliness of breathlessness assessment for patients experiencing moderate to severe breathing-related distress. The project created new processes and changes in clinical practice including streamlined identification and review of patients who are moderately or severely distressed due to their breathlessness and ongoing education and support for staff to accurately assess and monitor breathing-related distress.

We published a seminal paper on the significance of the viewing of the body after a death in palliative care. Analysis of interviews with bereaved family members by lead author Dr Jane Mowll identified five themes including: a dual sense of the body still "holding" the person and as "just a body"; family's experiences of the body both at home and in formal care settings; expectations around the right amount of time to be with and leave the body. Our findings highlight the importance of facilitating family and individual preferences, and options around care, place, and time with the body. Focus on support from clinical and social work staff is warranted to enable the provision of informed choice and support for families to engage with the body.

At a national level, Professor Liz Lobb is involved in studies to understand the provision of palliative care in prisons; screening for psycho-social existential distress in palliative care, and understanding bereavement and mental health outcomes during the COVID-19 pandemic.

Palliative and end of life care is becoming a significant element of correctional health services due to the ageing prison population. There is currently no standardised national model of palliative care for older Australian prisoners, and limited information available regarding palliative care capabilities within correctional facilities in Australia. The study aims to co-design a palliative model of care for Australian prisoners with end of life needs inclusive of education policy, and build on the correctional health workforce's palliative care capacity through an education program for correctional clinicians in partnership with interested jurisdictional correctional-justice health services.

The second national study is the Routine Clinical Assessment of Psychosocial and Existential Symptoms in Palliative Care: A National Quality Improvement Project through Education and Supervision.

Patients with unrecognised depression, unaddressed demoralisation and unabating anxiety account for some of the most vulnerable patients in palliative care. Despite effective, evidence-based treatments being available, non-recognition has been a major barrier. The implementation of routine screening depends on clinicians' confidence and competence to discuss psycho-existential symptoms, understand them and know how to deal with them. This education and knowledge translation project will roll out educational workshops to train and upskill clinicians and train services to assess for unmet psycho-existential need.

About our Researchers

PROFESSOR LIZ LOBB - PROFESSOR OF PALLIATIVE CARE (ALLIED HEALTH)

Head of Research, Calvary Health Care Kogarah, Adjunct Professor; University of Notre Dame, Sydney and University of Technology, Sydney

Research interests: Loss, grief and bereavement in carers, in particular prolonged grief disorder.

Inspiration: Participating in research that translates directly to patient care and support for carers; supporting clinical staff to turn their clinical questions into a research concept and watching the next generation of PhD and Masters students flourish.

Involved in research for: 27 years.

DR CAITLIN SHEEHAN - PALLIATIVE CARE PHYSICIAN

Site investigator PaCCSC

Research interests: Symptom management in palliative care; research at very end of life; consent in palliative care.

Inspiration: To improve overall end of life care for patients.

Involved in research for: 13 years.

DR JODIE ELLIS - HEAD OF DEPARTMENT, DIETETICS, SPEECH PATHOLOGY AND PSYCHOLOGY

Site investigator PaCCSC

Research interests: Cachexia, nutrition impact symptoms, oral intake, the impact of food and nutrition on patients, carers and health professionals in palliative care.

Inspiration: Discovering the unknown and supporting our patients and carers to lead the most fulfilling life possible. Encouraging other clinicians and students to undertake research. Watching the next generation of researchers develop into passionate and successful researchers.

Involved in research for: 24 years.

ERIN TRACEY - REGISTERED NURSE, PALLIATIVE CARE UNIT

Research Nurse (Clinical Trials), Calvary Health Care Kogarah

Research interests: Improving patient palliative care symptoms and quality of life.

Inspiration: To improve patient outcomes and end of life experiences through expanding our current evidence base and knowledge via rigorous research.

Involved in research for: 1 year.

DR ANGELA RAO - CLINICAL NURSE SPECIALIST, CLINICAL TRIALS COORDINATOR

Adjunct Industry Fellow, Early Career Researcher, University of Technology Sydney

Research interests: Affective disorders (depression, anxiety & psycho-existential distress), meditation, palliative care, advanced cancer, end of life care, chronic illness.

Inspiration: To reduce or alleviate suffering by building the evidence base for non-pharmacological therapies in advanced cancer, chronic illness, palliative and end of life care, and support the uptake of these therapies into routine clinical care.

Involved in research for: 7 years.

Current Studies

SPHERE – Clinical Academic Palliative Care Group. **Agar, M., Chye, R., Davis, JM, Harlum, J., Trethewie, S., Parker, D., Currow, D., Luckett, T., DiGiacomo, M., Hosie, A, Kochovska., Pont, L., Ries, N., Brown, L., Fazekas, B., Cheah, S., Hickman, L., Viney, R., Wood, M., Seah, D., Stone, E., Sheehan, C. Sheahan, L., Brennan, F., Lobb, EA, Lintzeris, N., Sanderson, C., Wiltshire, J., Fernando, A., Noonan, K. Thang, DH; Aggarwal, R., Dadich, A., Hamill, K., Parker, D., et al**

Tetrahydrocannabinol (Namisol®) for anorexia in people with advanced cancer. **Agar, M., Martin, J., Currow,D., Lintzeris, N., Solowij, N., Phillips, J., Lovell, M., Noble, B., Chai, R., Lee, J., Aggarwal, R., Clark, K., Brwn, L., Naumovski, T., McLeod, P., Fazekas, B., Cheah, S., McCaffery, N., Ellis, J.,**

Improving the management of Inoperable Malignant Bowel Obstruction (IMBO Study). **Currow, D., Agar, M., Clark, K., Sheehan, C., Davis, A. Engel, A., Pather, S., Pont, L., Kinchin, I., Chang, S., Brown, L., & Brassil, M.**

Lidocaine (lignocaine) for Neuropathic Cancer Pain – Feasibility study (LiCPain). **Lee, J., Agar, M., Currow, D., Lovell, M., Phillips, J., McLachlan, Noble, B., Brown, L., McCaffrey, N.,Fazekas, B., Chye, R., Aggarwal, R., Sanderson, C., Ayoub, C., Sheehan, C., Aggerwal, G., Urban, K., Mital, D., Bhattrai, P., Linton, A.**

Identifying the mental health effects and support needs of people bereaved during and following COVID-19: A Mixed Methods Project. **Lobb, EA., Maccallum, F., Agar, M., Phillips, J., Breen, L., Philip, J., Tieman, J., Hosie, AM.,DiGiacomo, M., Luckett, T., Gilmore, I., Chang, S.., Kinchin, I., Dadick, A.,Harlum, J., Glasgow, N., Moberley,S., Hughes, R., Snell, K., Grossman, C.**

Exploring morally challenging and distressing clinical experiences among healthcare professionals in oncology and palliative care in Australia: A Qualitative Study. **Kelly, B., Stafford, L., Agar, M., Boon, K, Dhillon, H., Kissane, D., Lobb, EA., Milne, D., Phillip. J., Ratcliffe, S., Shaw, J., Turner, J.**

Routine Clinical Assessment of Psychosocial and Existential Symptoms in Palliative Care: A National Quality Implementation Project. **CIs Kissane, D., Devery, K. Lobb, EA, Chye, R., Clayton, J., Aggarwal, G., Michael, N., Poon, P., Micallef, C., William, L., Allcroft, P., Eng, D., White, A., Kanathigoda, S. Glasgow, N., Chapman, M., Good, P., Kenner, D., Yubair, Y.**

A Phase III, international, multi-centre, double-blind, dose increment, parallel-arm, randomised controlled trial of duloxetine versus pregabalin over 14 days for opioid unresponsive cancer-related neuropathic pain. **Clark, K. Matsuoka, H., Lee, J. Phillips, J. Agar, M., Currow, D., Lovell, M., Kochovska, S., Le, B., Noble, B., Brown, L., Fazekas, B.**

Better-B Study – BETter TreatmEnts for Refractory Breathlessness – An International, Multicentre, Randomised Controlled Pragmatic Trial of Mirtazapine to alleviate Breathlessness in Palliative and End of Life Care. International investigators led by **Professor Irene Higginson; Australia: Professor David Currow**

Strengthening access to best evidence based care for people with palliative care needs in Australian prisons: a national co-design and capacity building project. **Currow, D., Parker, D., Levi, C., Lintzeris, N., Lobb, E., Phillips, J. L., Philip, J., Scott, J., Abbott, P., DiGiacomo, M., Hickman, L., Kinchin, I., Luckett, T., Panozzo, S., Sanderson, C., Williams, M., Heneka, N., Schaefer, I.**

Subcutaneous Ketamine Infusion in Palliative Care Patients with Advanced Life Limiting Illnesses for Major Depressive Disorder: A Phase II Pilot Feasibility Study. **Lee, W., Sheehan, C., Stafford-Bell, F., Chye, R., Loo, C., Draper, B., Agar, M., Currow, C.**

An Evaluation of Palliative Care Needs Rounds in Residential Aged Care Facilities in South Eastern Sydney Local Health District: Interviews with RACF staff. **Cohen, J., Sanchez, C., Lobb, EA., Thristiawati, S.**

Randomised, double blind, placebo controlled phase III trial of oral melatonin for the prevention of delirium in hospital in people with advanced cancer. **Sheehan, C. (CI at Calvary Kogarah) PaCCSC**

The Life Space Validation Study. **Phillips, J, Sheehan, C.**

Evaluation of a multidisciplinary response to breathlessness in community palliative care: A Stanford University Collaborative Quality Improvement Project. **Rao, A., Gallagher, E., Forby, F., Sanchez, C., Sheehan, C., Hosie, A., Agar, M.**

Publications

"I dressed her up in her best dress": bereaved family members experiences of viewing the body in the context of palliative care. Qualitative Research in Health, Pages 1-8, doi.org/10.1016/j.ssmqr.2022.100058. **Mowll, J. Bindley, K., Lobb, EA., Sanderson, C. & McLeod, R (2022).**

"Supportive care of patients diagnosed with High Grade Glioma and their carers" in Australia, Journal of Neuro-oncology. **Halkett, G., Berg, M., Daudu, D., Dhillon, HM, Koh, E-S, Ownsworth, T., Lobb, EA, Phillips, J., Langbecker, D., Agar, M., Hovey, E., Moorin, R.,Nowak, AK (2022).**

Evidence of Effective Interventions for Clinically Significant Depressive Symptoms in Individuals with Extremely Short Prognoses is Lacking – Systematic Review. Letters to the Editor, Journal of Palliative Medicine, Volume 25, Page 3. **Lee, W., Pulbrook, M., Sheehan, C., Kochovska, S., Chang, S., Hosie, A. Lobb, EA, Draper, B., Agar, M., Currow, D. (2022).**

"I didn't want to remember memories of caring, but I can't help it": A qualitative study of the experiences of bereaved Iranian cancer caregivers with prolonged grief disorder, Death Studies, doi:10.1080/07481187.2022.2036270. **Salehi, D., Zarani, F. Fata, L, Sharbafchi, MR, Lobb, EA (2022).**

Improving the methods for patient-reported experience measures (PREMs) in palliative care: Findings of a cognitive interview study. Annals of Palliative Medicine. **Luckett, T., Virdun, C., Rao, A., Daly, L., Hackl, N., Willems, A. & Phillips, J.L.**

Australian specialist palliative care's response to COVID-19: An anonymous online survey of service providers. Annals of Palliative Care. 10(3). doi: 10.21037/apm-20-1760. **Luckett, T., Donkor, A., Phillips, J. Currow, D., Parker, D., Lobb, EA., Agar, M. (2021).**

To be mortal is human: Professional consensus around the need for more psychology in palliative care. BMJ Supportive & Palliative Care. doi:10.1136/bmjspcare-2021-002884. **Sansom-Daly, U.M., Lobb, E.A., Evans, H.E., Breen, L.J., Ugalde, A., Best, M., Zomerdijk, N., Beasley, E.A, Taylor, K., Clayton, J., Sharpe, L., Bartula, I., and Olver, I.(2021).**

The development of the Australian National Palliative Care Clinical Studies Collaborative 'Integrating Qualitative Research into Clinical Trials. Journal of Palliative Medicine. DOI: 10.1089/jpm.2020.0480. **Philip, J., Collins, A., Phillips, J., Morgan, D., Lobb, EA., DiGiacomo, M., Kochovska, S., Brown, L, Currow, D. (2021)**

Patients', caregivers' and clinicians' understandings of an advance care planning process: The example of ambulance palliative care plans. Annals of Palliative Medicine. 10(6). 6247-6258. doi: 10.21037/apm-21-288. **Lobb, EA. Rao, A. & Sanderson, C, (2021).**

Patients Receiving Palliative Care and Their Families' Experiences of Participating in a "Patient-Centered Family Meeting": A Qualitative Substudy of the Valuing Opinions, Individual Communication, and Experience Feasibility Trial. Palliative Medicine Reports.2(1). DOI: 10.1089/pmr.2020.0109. **Cahill, PJ, Lobb EA, Sanderson CR and Phillips JL (2021).**

Clinically Significant Depressive Symptoms are Prevalent in People with Extremely Short Prognoses – A Systematic Review. Palliative Medicine 2021: Vol 61 (1) 143-166. **Lee, W, Pulbrook, M., Sheehan, C., Kochovska, S., Chang, S., Hosie, A., Lobb, EA., Parker, D., Draper, B., Agar, M., Currow, D.**

Older person and caregiver perspectives and experiences of research participation with impaired decision-making capacity: a scoping review. The Gerontologist https://doi.org/10.1093/geront/gnaa118. **Hosie, A., Kochovska, S., Ries, N., Caplan, G., Gilmore, I., Sheehan, C. Parker, D. Sinclair, C., Collier, A., Visser, M., Xu, X., Chye, R., Lobb, EA., Sheahan, L., Brown, L., Lee, W. Sanderson, C., Amgarth-Duff, I., Green, A., Edwards, L, Agar, M. (2020).**

Standing shoulder to shoulder to tell the family what was really going on: A qualitative study exploring clinicians' perceptions of Family Meetings. Journal of Palliative Medicine https://doi.org/10.1089/jpm.2019.0380. **Cahill, P.J., Lobb, E.A., Sanderson, C.R., Phillips, J.L (2020).**

Through the eyes of the dying: Who may benefit from bereavement follow up – Semi structured interview findings. Collegian https://doi.org/10.1016/j.colegn.2019.08.003. **Phillips, J.L., Lobb, E.A., Bellemore, F., Hayes, T., Currow, D.C. (2019).**

Conference Presentations

Identifying the mental health effects and support needs of people bereaved during and following COVID-19: A Mixed Methods Project, Agency for Clinical Innovation (2022). **Lobb, EA.**

Grief and bereavement in 2022: Challenges and Opportunities, Palliative Care Nurses Association (2022). **Lobb, EA, Invited speaker.**

Residential aged care staff perspectives of the implementation of the Palliative Care Needs Rounds: A qualitative study. Palliative Care Nurses Association (2022). **Rao, A., Cohen, J. Sanchez, C., Thristiawati, S., Lobb, EA.**

Evaluation of a multidisciplinary response to breathlessness in community palliative care: A Stanford University Collaborative Quality Improvement Project", Palliative Care Nurses Association (2022). **Rao, A., Gallagher, E., Forby, F., Andrews, K., Sanchez, C., Hosie, A., Sheehan, C. & Agar, M.**

Improving the methods for patient reported experience measures (PREMs) in palliative care: Findings from a cognitive interview study. 12th World Research Congress of the European Association for Palliative Care. **Luckett, T., Virdun, C., Rao, A., Daly, L., Hackl, N., Willems, A & Phillips, J.L.**

Dignity Therapy: Empirical Foundation, Clinical Application and Patient Experiences in Australia. International Symposium on Dignity and Compassionate Care in Singapore in July, 2020 – Webinar. (2020). **Lobb, EA.**
Invited speaker.

Bereavement during COVID-19. 1st International Webinar on Spiritual Care: Centered on Death and Grief during COVID-19 University of Tehran, Iran. (2020). **Lobb, EA. Invited speaker.**

Bereavement during COVID-19. Parliamentary Friends of the Palliative Care Group. (2020). **Lobb, EA. Invited speaker.**

Bereavement during COVID-19. Liverpool Hospital Grand Rounds (2020). **Lobb, EA. Invited speaker.**

Bereavement during COVID-19. St. George Hospital Grand Rounds. (2020). **Lobb,EA. Invited speaker.**

Bereavement during COVID-19. Palliative Care Nurses Association Conference (2021). **Lobb, EA. Invited speaker.**

Self Care for the Carer in Advanced Cancer. Cancer Council, NSW (2020). **Lobb, EA. Invited podcast.**

Identifying who may benefit from bereavement follow up: Findings from a qualitative study. Oceanic Palliative Care Conference, Perth, September 2019. **Phillips, J.L. Currow, D., Lobb, E.A.**

Committees

Professor Liz Lobb

PaCCSC Cognitive and Neurological Symptom Node Sub-Committee: Member

PaCCSC Qualitative Research Sub-Committee; Member

Research and Ethics Committee - Calvary Health Care Kogarah: Chair

Research Protocol Review Committee - Calvary Health Care Kogarah: Chair

ACI Palliative Care Network Executive: Executive Committee Member

Bereavement Resource Working Group – ACI: Member

Palliative Care Home Support and Education Steering Committee - Hammond Care; Member

Management Executive – SPHERE CAG in Palliative Care: Member

Management Committee, Palliative Care NSW: Member

Palliative Care Senior Staff Committee - Calvary Health Care Kogarah: Member

Education Partnership & Communication Sub Committee, Palliative Care NSW: Member

Dr Caitlin Sheehan

PaCCSC Scientific Committee: Member

PaCCSC Trials Management Committee: Member

PaCCSC Gastrointestinal Disorders Symptom Node Subcommittee: Member

PaCCSC Cognitive and Neurological Symptom Node Subcommittee: Member

Research Protocol Review Committee - Calvary Health Care Kogarah: Member

Dr Jodie Ellis

PaCCSC Qualitative Research Sub-Committee: Member

PaCCSC Anorexia Cachexia Symptom Node Sub-Committee: Member

Research Protocol Review Committee - Calvary Health Care Kogarah: Member

Management Executive - SPHERE CAG in Palliative Care: Member

CST Scientific Advisory Committee: Member

SESLHD Allied Health Research Committee: Member

Dr Angela Rao

PaCCSC Cognitive and Neurological Disorders Symptoms Node Subcommittee: Member

CST Scientific Advisory Committee: Psycho-oncology expert

Research Protocol Review Committee: Member

Person Centred Care - Calvary Health Care Kogarah: Member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CLINICAL RESEARCH CENTRES

Calvary Health Care Bethlehem

Calvary Health Care Bethlehem has proudly continued to support research and innovation in palliative and end of life care through its temporary location in Parkdale while the Caulfield site is rebuilt. Dr Christopher Grossman is the third lead researcher for CHCB. He follows Dr Heidi Gregory and before her, Dr Scott King.

It is with great sadness we report that in May 2022, the team at CHBC has lost one of our key members with the death of Mr Mark Heenan. Throughout Mark's work with Clinical Services at CHBC, he was seen as a local legend and a constant source of morale for our team. Mark provided calm guidance, unconditional support and quiet reassurance to many of us over the years. He was also an avid researcher and his natural curiosity, sense of humour and dedication spurned our team on to provide better patient care. Our thoughts and best wishes are with Mark's family during this difficult time. Rest in peace, Mark.

The staff at CHCB is proud to follow the latest in evidence-based medicine and contribute to the cutting-edge of both neurological and palliative care research. Throughout 2020 to 2022, we were lucky enough to have Mr Nathan McCracken join us as a Research Nurse assisting in telehealth implementation and research in our service, with many of these findings to be presented at the upcoming ANZSPM conference in 2022. Through our collaborations with other organisations, such as: other Calvary sites nationally, Notre Dame University, Cabrini Hospital and the Palliative Care Clinical Studies Collaborative, we are continuing to work hard towards our aspirations. Our research team currently consists of specialist palliative and neurological medical staff members.

In 2021, the team at CHBC secured grants to pursue research in symptom management for Motor Neurone Disease patients and implement telehealth across our palliative care service. The further development of palliative care research at CHBC is a key strategic goal. Although relatively new and growing in palliative care research, CHBC has a strong history of research in progressive neurological diseases, particularly Huntington's disease and Motor Neurone Disease. There is increasing collaboration between specialist neurology clinicians and palliative care physicians, with a number of current joint projects.

I would like to issue a special thanks to Mr Nathan McCracken and the CHBC researchers as a whole for their hard work over the last two years. The team at CHBC would also like to thank the patients, families and staff who volunteer time to assist with research and further our knowledge of these important fields.

About our Researchers

DR CHRIS GROSSMAN - PALLIATIVE CARE SPECIALIST

Institute Site Lead

Research interests: Community palliative care service provision and development.
Inspiration: To provide excellent care to our patients and to provide the evidence base to support that care.
Involved in research for: 8 years.

DR SUSAN MATHERS - CLINICAL DIRECTOR NEUROLOGY

Site Investigator

Research interests: Models of care in neuro-palliative rehabilitation, service development and social research for people with progressive neurological diseases. Clinical trials in progressive neurological diseases.
Inspiration: Being able to combine high-quality multidisciplinary care with research activities and therapeutic trials for people with progressive neurological diseases.
Involved in research for: 15 years.

DR ROWAN HEARN - CLINICAL DIRECTOR PALLIATIVE MEDICINE RESEARCH

Site Investigator

Research interests: Carer and family support, management of depression in the end of life and Models of Care (specifically Neuro Palliative Care and Residential Aged Care).
Inspiration: Seeing research progressing from basic ideas into making real evidence-based differences in the care we provide our patients and their families.
Involved in research for: 15 years.

DR FIONA RUNACRES - PALLIATIVE CARE SPECIALIST

Site Investigator

Research interests: Provision of palliative care for patients with non-malignant disease, particularly patients with progressive neurological conditions at Calvary Health Care Bethlehem.
Inspiration: Seeing clinical practice change as a result of research, and to improve our understanding of patients' and caregivers' needs to enable better palliative care provision is the ultimate reward.
Involved in research for: 11 years.

DR SARAH LEE – NEUROLOGIST

Site Investigator

Research interests: Motor Neurone Disease, Huntington's Disease, brain machine interface, clinical trials, fronto-temporal dementia.
Inspiration: Improving quality of life by supporting patients and their carers.
Involved in research for: 8 years.

DR RUPERT STRASSER –PALLIATIVE MEDICINE SPECIALIST AND GERIATRICIAN

Site Investigator

Research interests: Palliative care for people with progressive neurological diseases and advanced care planning.
Inspiration: Understanding and improving the experience of people living with serious illness.
Involved in research for: 4 years.

Current Studies

My Neuro Palliative Care: MyNP Care – An integrated approach for people living with a progressive neurological disease – **M McPhee, S Mathers, R Hearn, C Grossman, L William, C Li.**

A Diagnostic Interview For Psychological Adjustment And Demoralisation, **Bobevski I, Kissane D, C Grossman, Burke A, Michael N.**

Opinions of carers of community palliative care patients regarding interventions and support, **Hearn R.**

An Australian Neuro-Palliative Perspective on Huntington's Disease: A Case Report, **Shah R, Lee S, Strasser R, Grossman C.**

Bereavement in the time of COVID-19 Study, **Lobb L, Agar M; DiGiacomo M, Breen L, Luckett T, Hosie A, Philip J, Maccallum F, Gilmore I, Tieman J, Dadich A, Phillips J, Glasgow N, Moberley S, Grossman, Hughes R, Kinchin I, Chang S, Harlum J.**

Palliative Medicine Specialist (PMS) clinic of Statewide Progressive Neurological Diseases (SPNDS): quality assurance database, **Strasser R, Smith A, Stefanou G, Runacres F.**

The Community CORe Project: Telehealth in Community Palliative Care Project **R Hearn, G Hessel, N McCracken, C Grossman, R Maule, A Bamford.**

MPCCC Cancer Donor Program, **D Pook, C Grossman**

End of life wishes and concerns of people with Huntington's disease and their caregivers. **Jackson, N., Mathers, S., Gluyas C., Hosken, R., Fisher, F., Gregory, H., Carlozzi N., Stout, J.**

Communication and decision-making in Motor Neurone Disease. **Paynter, C., Mathers, S., Gregory, H., Cruice, M., Vogel, A.**

A diagnostic interview for psychological adjustment and demoralisation. **Bobevski, I., Michael, N., Burke, A., Grossman, C., Kissane, D.**

THIN-PC: TeleHealth for INpatient Palliative Care. **Robinson, N., Grossman, C., Lee, S., Hearn, R.**

Role of the Palliative Medicine Specialist (PMS) in Progressive Neurological Diseases. **Strasser, R., Smith, A., Stefanou, G., Runacres, F.**

Publications

An Australian Neuro-Palliative perspective on Huntington's disease: a case report. **Shah R, Lee S, Strasser R, Grossman C (2021).**

Examining the role of specialist palliative care in geriatric care to inform collaborations: a survey on the knowledge, practice and attitudes of Geriatricians in providing palliative care. **Runacres F, Poon P, King S, Lustig J, Ugalde A (2021).**

Journey mapping as a novel approach to healthcare: a qualitative mixed methods study in palliative care. **Ly S, Runacres F & Poon P (2021).**

We couldn't have managed without your team: a collaborative palliative care response to the COVID-19 pandemic in residential aged care. **Runacres F, Steele P, Hudson J, Bills M & Poon P (2021).**

Facilitating family needs and support at the end of life in hospital: a descriptive study. **Bloomer MJ, Poon P, Runacres F., & Hutchinson AM (2021).**

Family involvement and end-of-life care needs in critical care: a retrospective descriptive study. **Bloomer MJ, Poon P, Runacres F., & Hutchinson AM (2022).**

Letter in response to top 10 tips palliative care clinicians should know about caring for patients with haematological malignancies. Palliative Medicine. https://doi.org/10.1089/jpm.2019.0561. **Lin, E., Dellit, M., Franco, M., King, S., Runacres, F., Yoong, J., Poon, P. (2020).**

Elective withdrawal of non-invasive ventilation in motor neurone disease: a neuropalliative care perspective. BMJ Supportive & Palliative Care. http://dx.doi.org/10.1136/bmjspcare-2020-002383. **Runacres, F., Hearn, R., Howe, J., Mathers, S. (2020).**

Conference Presentations

Terminal care in patients with Motor Neurone Disease. International Symposium on ALS and MND, Perth, Dec 2019). **Kulkarni A, Gregory H.**

Conference Posters

Neuro-Palliative Care - A Statewide Survey to Victorian Palliative Care Services. ANZSPM conference (SEPT 2022). **Susan Mathers, Maryanne McPhee, Rowan Hearn, Christopher Grossman, Fiona Fisher.**

Implementing a clinician-assisted vide telehealth model in a community palliative care team during peak COVID times. ANZSPM conference (SEPT 2022). **Chris Grossman, Nathan McCracken, Rowan Hearn, Gail Hessel, Alice Bamford.**

Acceptability of telehealth for initial patient assessments to a community palliative care team during peak COVID times. ANZSPM conference (SEPT 2022). **Chris Grossman, Nathan McCracken, Rowan Hearn, Gail Hessel, Alice Bacmford.**

Care of the Dying Person: Best practice principles for end of life care in Victoria. Oceanic Palliative Care Conference (Sept 2019). **Hayward, J., Boughey, M., Israel, F., Hearn, R., Couns, M.**

Committees

Rowan Hearn

Coordinating Committee of the Palliative Care Clinical Network, Safer Care Victoria, DHS, R Hearn, Member, 2021, Ext

Governance Group of the Palliative Care Clinical Network, SCV, DHS, R Hearn, Member, 2017-2020, ext

Older Person COVID 19 Experts Advisory Group, SCV, DHS, Member, 2020-2021, ext

Palliative and End Of Life Reference Group, Calvary Health Care, Member 2021, int

End of Life Monitoring Group, Catholic Health Australia, Member 2019-2021, ext

CLINICAL RESEARCH CENTRES

Calvary Mater Newcastle

The Department of Palliative Care at Calvary Mater Newcastle is a comprehensive multidisciplinary palliative care service providing clinical care to the Greater Newcastle and East Lake Macquarie areas, as well as telehealth and remote consultation services to the wider Hunter New England Local Health District. The department also provides a consultative inreach specialist palliative care service to local residential aged care facilities.

Supporting a population of approximately 300,000 people, the department operates a 17-bed specialist inpatient palliative care unit, 24-hour nurse-led community outreach service supported by specialist medical practitioners and comprehensive multidisciplinary team, as well as ambulatory outpatient palliative care clinics and hospital consultative services.

The department receives approximately 1700 referrals per year.

As part of both the Calvary National network of services, and the Hunter New England Local Health District, the department is able to partner to undertake translatable research activities across health care settings, including residential aged care and primary care, as well as metropolitan, regional and rural environments. The department has a strong commitment to, and has participated in, research projects investigating models of community enablement and health / death literacy.

The department's vision is to integrate the three pillars of: best practice clinical care, evidence-based learning and development models and clinician-led research in the delivery of care to patients, carers and our wider community to enable care in preferred place, cognisant of the unique needs and preferences of all we serve.

A fundamental tenet of this model, a clinically embedded research unit, has been realised in the last three years and the site's research capability has grown, with a number of clinician-led research projects underway, in collaborative partnership with academic, clinical and community stakeholders. The department continues to strive toward improving infrastructure and capability in best practice data collection and analysis.

The department is privileged to have consumers and users of clinical and education services consulting in research design and implementation.

It is our objective that all staff in our department feel welcome to be curious and confident to contribute to improvements in care in experience for patients, carers and their peers through enquiry, research design, delivery and implementation. This will be achieved through ongoing commitment to research infrastructure embedded in clinical units.

About our Researchers

DR RACHEL HUGHES – DIRECTOR OF PALLIATIVE CARE

Research interests: Enabling optimal service development, models of care and assessment tools through clinician led research. Adaptation and evaluation of best practice learning and development models to enable change in health settings.
Inspiration: Our multidisciplinary team, who daily demonstrate curiosity and commitment to improving experience for our patients and carers, as well as their colleagues.
Involved in research for: 9 years.

JESSICA SCAIFE - NURSE UNIT MANAGER

Principal investigator Hunter Palliative Community Coordinated Care

Research interests: Workforce Design, Community Palliative Care, Specialist cancer and palliative care education programs, wellness.
Inspiration: Tangible improvements to patient outcomes, translation of evidence into practice, having the political astuteness to use evidence to inform future priorities for care.
Involved in research for: 7 years.

DR SARAH MOBERLEY – HONORARY SENIOR RESEARCH FELLOW

Research interests: The role of patients and their loved ones co-designing research programs into enhanced models of care.
Inspiration: Patient and carer stories, staff working to improve patient experience, and how simple data collection systems can direct services and improve outcomes.
Involved in research for: 12 years.

ALISHA CHAND

Project Lead, Palliative Care learning and development project

Research interests: Engaging in a human centred design approach in the early stages of developing research questions to ensure that the people we are researching for are at the centre of the process.
Inspiration: Collaboration, translating research into practice and ensuring that end users are engaged in service development and design.
Involved in research for: 7 years.

JOELLE BEVINGTON

Specialist Palliative Care redesign project lead

Research interests: Evidence-based service development and design of purposeful new solutions and alternative futures for healthcare in collaboration with service users.
Inspiration: Universal Health Coverage, where globally people have access to the health services they need, when and where they need them, without financial hardship. I have a particular interest in design and development of accessible primary care based systems and structures that act as enablers to support the community.
Involved in research for: 11 years.

FERN BESCHI, PALLIATIVE CARE PHARMACIST

Research interests: Broadening the evidence base in therapeutics to ensure best outcomes for palliative care patients.
Inspiration: My mentors who have recognised the impact of knowledge gaps on the experience of patients, their curiosity and commitment to improving outcomes through research, safety and evaluation
Involved in research for: 3 years.

RESEARCH COLLABORATORS: **Laureate Professor John Attia, University of Newcastle, Dr Helen Box, Natalie Plant**

Current Studies

Prognostic model of 12-month mortality in COPD and Liver Failure patients. **Sarah Moberley, Erin Nolan, Sarah Pullen, Rachel Hughes, Chris Oldmeadow, Katie Wynn, John Attia.**

Miromullia Project (Continue to take care of, Awabakal language): Co-designing Palliative and End of Life Care for the Newcastle Aboriginal and Torres Strait Islander Community

Palliative Care in Hunter New England: A retrospective review. Palliative Care in Hunter New England: A retrospective review. **Sarah Moberley, Rachel Hughes, Gareth Watts, John Attia.**

The implementation and effectiveness of RUN-PC Triage Tool in the Department of Palliative Care. **Sarah Moberley, Rachel Hughes, Robyn Tumeth, MayRan Saw, John Attia.**

Designing for palliative care- In-hospital methods: spatial-ise observations & photo-response interviews with patients. **McLaughlan, R., Phillip, J., Clayton, J., Kelly, B, Chye, R., Moberley, S.**

Testing an enhanced community team model to improve access and quality of palliative and end of life care provided at home. **Scaife, J., Hughes, R., Attia, J., Moberley, S., Chand, A., Kershaw, G., Kozacynski, P.**

Evaluation of training program, Quality End of Life Care for All (QELCA) ©. **Sarah Moberley, S., Hughes, R., Bevington, J.**

Professional quality of life in palliative care staff. **Moberley, S., Hughes, R., Bevington, J.**

A model of care for people with advanced non-malignant liver disease: A randomised controlled trial. **Wynne, K., Attia, J., Hughes, R., Moberley, S., Britton, B., Kerr, J., Russo, S., Dieckmann, M., Pullen, S., Palazzi, K.**

Current practices in prescription and administration, and pharmacology of subcutaneous Levetiracetam in specialist palliative care, **Fern Beschi.**

Validation of palliative care triage modelling in the local setting, **Dr Ran May Saw.**

Profile, needs and experience of brain cancer patients in the specialist palliative care inpatient setting, **Dr Laura Bird.**

A human centred design approach to education enabling palliative and end of life care in preferred place for residents of aged care facilities, **Alisha Chand.**

Publications

Research embedded in community based palliative care clinical service: feasibility, acceptability and early findings. Asia-Pacific Journal of Clinical Oncology. 17 (s8).DOI https://doi.org/10.1111/ajco.13681. **Scaife J, Box H, Kozacyznski P, Cooper K, Watts G, Attia J, Hughes R, Moberley S (2021).**

Communicating Actively Responding Empathically (CARE): Comparison of Communication Training Workshops for Health Professionals Working in Cancer Care. Journal Cancer Education (35) 54-60 10.1007/s13187-018-1439-0. PMID: 30386978. **Nixon J, Gray L, Turner J, Bernard A, Scaife J, Cartmill B. (2020).**

Communicating Actively, Responding Empathically (CARE): Perceptions of Cancer Health Professionals Attending Communication Training Workshops. **Nixon J, Turner J, Gray L, Scaife J.(2020).**

Journal Cancer Education doi:10.1007/s13187-020-01809-y.

Conference Presentations

Research embedded in community based palliative care clinical service: feasibility, acceptability and early finding. Hunter Cancer Research Symposium 2021, Translation and Impact through Collaboration. Online. (Nov 2021). **Scaife J, Box H, Kozacyznski P, Cooper K, Watts G, Attia J, Hughes R, Moberley S.**

Characteristics of Australian adolescent and young adult palliative care patients: A national study to aid definitions and services. PCOC Outcomes and Benchmarking Conference. Sydney, November 2019. **Hughes, R.**

Developing a multidisciplinary triage to improve access and outcomes for community palliative care patients. Oceanic Palliative Care Conference, Perth September 2019. **Campbell, L.**

Conference Posters

Does Palliative Care involvement affect end of life outcomes in patients with advanced chronic obstructive pulmonary disease? A retrospective mult-center observational study. ANZSPM Virtual Conference, September 2020. **Tee, H., Vogel, N., Moberley, S., Mather M., Cameron-Taylor, E., Michael, N.**

Committees

Dr Rachel Hughes

Hunter New England Palliative End of Life Care Education Committee: Chair

Hunter New England Palliative End of Life Care Committee: Member

Clinical Cancer Research Network: Member

Sarah Moberley

Calvary Mater Newcastle Clinical Trial Committee: Member

Calvary Mater Newcastle Closing the Gap Collaborative

Committee:Member

Palliative Care Clinical Studies Collaborative: Member

Hunter Cancer Research Alliance: Member

Research Development and Engagement Committee: Member

Hunter New England Human Research Ethics Committee: Member

Palliative and End Of Life Reference Group, Calvary Health Care, Member 2021, int

End of Life Monitoring Group, Catholic Health Australia, Member 2019-2021, ext

Calvary

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