



e-News

November 2019

About the PCRN

The purpose of the Palliative Care Research Network (PCRN) is to develop a platform for sustainable research collaboration. The PCRN is supported by the Department of Health and Human Services, Victoria, Australia. The Centre for Palliative Care (a Collaborative Centre of St Vincent's Hospital and The University of Melbourne) is the administering organization.

Call for Suggestions for 2020 PCRN Forum Topics & Presenters

If you have any suggestions on topics that you would like to be presented at 2020 PCRN Forums and /or speakers that you would like to hear from, please email your suggestions by **13 December 2019** to pcrnv@svha.org.au with the subject '2020 PCRN Forum Topic/Speaker Suggestion'.

PhD Studentship in Palliative Care

The Centre for Palliative Care c/o St Vincent's and The University of Melbourne is delighted to be offering a full time PhD studentship for candidates with a suitable nursing or allied health degree. We are seeking to support a PhD candidate with an interest in inter-disciplinary research in palliative care that will improve quality of care for people diagnosed with advanced disease and their families/caregivers.

For more information please see [here](#) and/or contact Prof Marie Gerdtz: gerdtzmf@unimelb.edu.au

Useful Resources in Palliative Care Research

Please find below a sample list of useful resources which you can subscribe to in order to keep up with the latest palliative care news and publications on evidence-based palliative care research.

Media Watch, created and distributed by [Barry R. Ashpole](#) – to subscribe email: barryashpole@bell.net

E-Hospice – to subscribe to e-newsletter go to the [website](#).

Briefings in Palliative, Hospice, and Pain Medicine & Management – to subscribe to table of contents go to the [website](#).

CareSearch palliative care knowledge network – to subscribe to e-newsletter go to the [website](#).

All Ireland Institute of Hospice and Palliative Care (AIHPC) – to subscribe to mailing list go to the [website](#).

PCRN Reports

Travel report from A/Prof Clare O'Callaghan – a 2019 PCRN Travel Grants recipient

This report outlines how the \$750.00 I was delighted to receive as a Travel Grant from PCRN was spent and the value that I gained from receiving the grant.

How the money was spent

The grant money was used to pay my registration fee to attend the 2019 Spiritual Care Australia Conference, held in East Melbourne, 16-19 June. The conference theme was “Setting the GPS: Finding your way in spiritual care”. I led a workshop at the conference called, “Palliative care patients’ and informal caregivers’ multifaceted and contested perspectives about optimizing spiritual care: Lessons from a qualitative inquiry”. My co-presenter was David Glenister, Coordinator of Pastoral/Spiritual Care at Melbourne Health. [Two co-authors who intended co-presenting, Natasha Michael and Xavier Symons, unfortunately needed to withdraw from the workshop]. A synopsis of presentation content follows:

A qualitative study aimed to understand palliative care patients’ and caregivers’ perspectives about optimizing spiritual care. Thirty patients and ten caregivers of patients were interviewed. Twenty-seven identified as Christian; 2 with Judaism, 1 with Buddhism/Christian, and 10 had no religion. Participants described multifaceted and contested beliefs about spirituality. While many did not resonate with spiritual care, all valued respectful staff who affirmed each individual’s worth (personhood). They were comforted and strengthened by skilled staff and the organization’s welcoming tone. Hospitality may be a helpful concept to use alongside spiritual care in pluralist palliative care settings. The findings’ transferability into clinical, organisational and environmental care will be considered.

A case study was included to illustrate the multifaceted ways that hospitality could extend spiritual well-being. It demonstrated the value of song writing for a palliative care patient with a developmental disability. Workshop participants were also invited to improvise on musical instruments.

About 50-60 people attended the workshop and robust discussion ensued, especially regarding the helpfulness of the hospitality term related to spiritual care, with pros and cons voiced. A number highlighted the importance of the findings arising from caregivers’ direct views about spiritual care in palliative care. Some also requested information about where the beautiful sounding instruments, which anyone could play, were sourced from. It is anticipated that ideas and information shared in the workshop would inform workshop participants’ spiritual care into the future.

A Personal Reflection

Findings from the workshop were informed by research funded in part by a PCRN project grant. It was satisfying to be able to share this information with participants on the workshop’s completion. It is also satisfying to be able to report to PCRN that their investment is informing conference presentations here in Melbourne (as well as at the Oceanic Palliative Care Conference in Perth in September and also at the European Palliative Care Conference last May; journal articles are under review and being prepared). I also found much of the conference content very interesting, especially a workshop on community spirituality and music therapy by Astrid Notarangelo, and a keynote by George Halasz. In Dr Halasz’ keynote I learned about trauma theory and its potential value to conceptualize and inform responses to trauma affected health-workers. I also learned that “SOS” is derived from “save our soul”. I hope to follow-up some of the references Dr Halasz mentioned and consider how they may inform my future work.

Thank you PCRN for your support.

A/Prof Clare O'Callaghan

Cabrini Health

Travel report from Dr Safrina Thristiawati – a 2019 PCRN Travel Grants recipient

Asia Pacific Hospice and Palliative Care Conference, Surabaya, Indonesia. 1st to 4th August 2019: A report

The conference was co-organised by the Indonesian Palliative Society (MPI) and the Asia Pacific Hospice Palliative Care Network (APHN). After the 12th APHC in Singapore in 2017, Indonesia – through The Indonesian Palliative Society – expressed their willingness to host The 13th Asia Pacific Hospice Palliative Care Conference 2019.

More than 1,000 participants from around 26 countries attended the Conference (APHC 2019) -- general practitioners, specialist doctors, nurses, pharmacists, social workers, pastoral care workers, medical and nursing students, and volunteers. All of the participants were involved in palliative care in their respected countries.

The conference programme consisted of workshops, plenary sessions, concurrent sessions and industrial symposium. The activities also included medical and industrial exhibitions.

The APHC 2019 and its related activities was supported by the Provincial Government of East Java, the Ministry of Health and the Ministry of Tourism of the Republic of Indonesia.

The title of my papers were:

1. You don't know if you don't ask: A pilot study using patient reported outcomes in a specialist palliative care service
2. What do I need to know about you as a person to give you the best care possible?

I enjoyed the conference, up-dated my knowledge on palliative care and end-of-life care and had discussions with many participants, including those from Indonesia, Malaysia, Singapore, India, China, Bangladesh and Japan.

Safrina Thristiawati, PhD.

Senior Research Officer

Calvary Health Care Kogarah, NSW

Travel report from Ms Naomi Mason – a 2019 PCRN Travel Grants recipient



Naomi Mason delivering the Ian Maddocks Lecture at 19OPCC

I was thrilled to receive a travel grant from PCRN to help me get to Perth for the inaugural Oceanic Palliative Care Conference in Perth (previously known as the Australian Palliative Care Conference – but now with an enhanced international perspective and collaboration).

Nearly 950 delegates were registered to attend and came from 20 different countries. Approximately 300 presenters and 77 sessions showcased the largest and most diverse program to date. The theme was Universal Access: Oceans of Opportunities which affirmed “Access to Palliative Care as a human right.”

Entering the Perth Convention and Exhibition Centre on day 1 of the conference, I was excited to hear the ‘Born to Sing’ choir perform ‘You Raise Me Up’ – a beautiful song that for me, captured the essence of palliative care – supporting our patients, their families, colleagues and peers in the field. Welcoming performances from Corroborree for Life and Haka for Life were stirring as they shared an important message: choosing life.

Di Darmody from ABC radio Perth proved to be an excellent MC – welcoming, warm and witty. Jane Fischer, Chair of Palliative Care Australia, shared a five point plan for action and called for us to be inspired and challenged.

A video keynote from Dr Marie-Charlotte Bouesseau from the World Health Organisation spoke of the importance of knowledge exchange and partnership to help determine the best ways to help primary care move forward and strengthen palliative care across the globe.

Dr Christian Ntuzimira from Rwanda shared fascinating and deeply moving transcultural palliative care considerations – including his belief that palliative care is a way to help his country rediscover the humanity and dignity of its people.

I enjoyed listening to Dr Frank Brennan read poetry to reflect on palliative care experiences and the elements of a patient that “remain untraversed by disease: spirit, imagination, legacy, memories and love, in all its expression.” Later, during a panel discussion, Dr Brennan shared the poem, White-water Rafting and Palliative Care by Bruce Dawe – which speaks beautifully to knowledge, uncertainty and companionship.

A particular highlight was listening to Dr Jonathan Ramachenderan (Twitter: @thehealthyGP) share his story of vulnerability, self-compassion and care – and how we as clinicians working in emotionally fraught environments, might become more self-aware to strengthen ourselves in order to thrive.

The theatre of delegates hung on every word as Briony Lyle reflected on caring for her husband, Jarrod Lyle, at the end of life – with support from Palliative Care Nurse, Kerrie Fitzpatrick. “Everybody needs an Aunty Kerrie” – for support and in navigating a complex system and time.

I was honoured to deliver the Ian Maddocks lecture which detailed my qualitative research into the preparedness experiences for rural and regional family palliative carers. I am grateful to an engaged audience and the lovely folk that approached me afterwards to share their responses to how we can improve our support of family carers.

The conference was exceptionally well designed and delivered. A diverse and engaging program showcased the immense work contributing to palliative care being ‘everybody’s business.’

Thanks PCRN for this wonderful opportunity!

Ms Naomi Mason

Project Officer

Albury Wodonga Health

Travel report from Dr Gursharan Singh – a 2019 PCRN Travel Grants recipient

I am grateful to PCRN for being awarded a Travel Grant to present an oral presentation at the 2019 Oceanic Palliative Care Conference held in Perth from the 10th-13th of September.

With this grant, I had the opportunity to present my PhD research findings to an audience from Australia, New Zealand and other countries in the Oceanic region such as Fiji. My research in the area of heart failure and palliative care gave me the opportunity to disseminate my findings to the research community and also improve my presentation skills as an early career researcher. Following my presentation, there were many questions from the audience and I was thrilled to be able to discuss this research area further with other researchers and health professionals in the audience.

Furthermore, the PCRN Travel Grant which facilitated my attendance at the Oceanic Palliative Care Conference gave me the opportunity to network with various researchers and academics. I was able to catch up and meet many new researchers and learn about the research that they are conducting in the areas of palliative care education and training for healthcare professionals.

The Oceanic Palliative Care Conference had keynote sessions which allowed me to learn more about palliative medicine research occurring in underdeveloped countries and research allowing greater implementation of opioids in the palliative care setting.

In conclusion, I would like to thank PCRN for the Travel Grant as it provided me with the opportunity to present my research, improve my presentation and communication skills, network with other academics and health professionals and improve my knowledge of the current state of palliative care research.

Kind Regards,

Gursharan Singh

Western Sydney University

Travel report from Mrs Katherine Pryde – a 2019 PCRN Travel Grants recipient

Firstly, I would like to sincerely thank the PCRN for awarding me the travel grant to attend and present at the 2019 Oceanic Palliative Care Conference (19OPCC) held in Perth from the 10th-13th of September. A personal goal of mine was to be able to present my research project at 19OPCC. However, having recently changed jobs, I was ineligible for conference funding from Cabrini Health. The travel grant was the difference between me being able to present the work personally or staying in Melbourne and delegating the presentation to someone from the research team. I am so grateful for this financial support so that I could achieve my goal.

Even though I have done many presentations before, I had never spoken at a conference. There is a level of uncertainty doing anything for the first time. Will I be able to get my message across clearly? Will I be asked tricky questions? Will I spill coffee on my white shirt right before the presentation? (The answer to that one is YES!) Thankfully I had some lovely feedback about the presentation and will feel more confident if I'm lucky enough to have another abstract accepted one day.

I was also encouraged to see that another of your grants was awarded to a Victorian Allied Health researcher, Naomi Mason. It's wonderful that organisations such as PCRN and PCA are increasingly giving a voice to allied health in palliative care.

Continued...

Travel report from Mrs Katherine Pryde – a 2019 PCRN Travel Grants recipient *continued...*

Whilst there were many inspiring presentations and posters at the conference, I think the highlight for me was the opportunity to meet with so many other like-minded clinicians and researchers. I particularly enjoyed connecting with other members of the Australian Allied Health in Palliative Care group. We first met and formed a very small group at the Cairns PCA conference in 2011. Allied health research in palliative care was even rarer at that time than it is now. How nice it was to hear about some of the work that is now being done, particularly by physiotherapists and occupational therapists. Dr Deidre Morgan (OT/Researcher, Flinders University) had lots of great ideas and was very generous with sharing her knowledge.

Aside from the tremendous networking opportunities in Perth, here are a few presentations / posters that I really enjoyed:

- Katrina Erny-Albrecht, CareSearch / Flinders University, Developing Skills in Evidence Based Palliative Care
- Dr Deidre Morgan, OT / Flinders University, Functional decline in the last 4 months of life
- Andrea Grindrod, Project Manager / La Trobe University, Public Health Palliative Care (PHPC): An asset-based approach that connects informal and formal networks of care
- Sally Baksa, Physiotherapist / HammondCare, The Breathlessness Program: Designed to empower palliative patients to manage and live well with breathlessness
- Dr Jordan Nguyen, CEO Psykinetic, Evolving Technology to Enhance the Future of Care

Thanks again for your support with my travel to 19OPCC.

Katherine Pryde

Physiotherapist

Allied Health, Cabrini Health

Travel report from Ms Jennifer Lowe – a 2019 PCRN Travel Grants recipient



Jennifer Lowe presenting at PHPCI 2019

As an appreciative 2019 PCRN Travel Grant Recipient, I was fortunate to attend the 6th Public Health Palliative Care International Conference held in the Blue Mountains, NSW from 13-16 of October. The conference theme was 'Compassionate Communities in Action: Reclaiming Ageing, Dying and Grieving' where I had two abstracts accepted, both as oral presentations.

In 2018, the Australasian Cemeteries and Crematoria Association had observed significant changes taking place across their sector. As a result, they commissioned the Public Health Palliative Care Unit at La Trobe University in Melbourne to conduct a study. The aim of this research was to explore the changing landscape of funerals, cemeteries and crematoria, and understand how memorialisation practices influence grief and bereavement outcomes. I was privileged to work with Associate Professor Bruce Rumbold and Professor Samar Aoun.

Continued...

Travel report from Ms Jennifer Lowe – a 2019 PCRN Travel Grants recipient *continued...*

Based on a public health approach to palliative care, the PHPCI conference provided an engaged audience with whom the research findings could be shared in a pragmatic way.

The first presentation entitled 'Bereavement support within compassionate communities: How might the death industry make a meaningful contribution?' allowed professionals from the cemetery and crematoria industry to access the academic literature pertaining to their sector for the first time; this positive feedback from the audience was certainly encouraging.

The second presentation entitled 'Memorialisation practices are changing: An industry perspective on improving service outcomes for the bereaved' focused on the bereaved consumer and was recently published in OMEGA – Journal of Death and Dying. With a background in marketing, I was able to share my unique perspective on how the death industry could forge closer relationships with their communities to improve bereavement.

As a result of attending and presenting at PHPCI 2019, I was able to gain valuable feedback from fellow researchers, clinicians and industry professionals, as well as extend my current collaborative network. I would like to express my sincere gratitude to PCRN for their support.

Kind Regards,

Jennifer Lowe | *PhD Candidate*

Public Health Palliative Care Unit

La Trobe University, Melbourne

Upcoming Funding Opportunities 2019 / 2020

Perpetual Trustees – IMPACT Grants

For more information visit the [website](#)

Closing date: 6 December 2019

Ian Potter Foundation

(various grant opportunities)

For more information visit the [website](#)

Closing date: various

Lung Foundation Australia

(various grant opportunities)

For more information visit the [website](#)

Closing date: various

John T Reid Charitable Trust

For more information visit the [website](#)

Closing date: application enquiries open on 21 January 2020

James N Kirby Foundation

(various grant opportunities)

For more information visit the [website](#)

Closing date: 14 February 2020

Upcoming Conferences

International

27th International Conference of Indian Association of Palliative Care (IAPCON 2020)

Dates: February 14-16, 2020

Location: Guwahati, India

[\[Website\]](#)

The Annual Assembly of the American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA)

Dates: March 18-21, 2020

Location: San Diego CA, USA

[\[Website\]](#)

Palliative Care Congress 2020

Dates: March 19-20, 2020

Location: Telford, UK

[\[Website\]](#)

State of the Science in Hospice and Palliative Care

Dates: March 20-22, 2020

Location: San Diego, CA, USA

[\[Website\]](#)

11th World Research Congress of the European Association of Palliative Care (EAPC 2020)

Dates: May 14-16, 2020

Location: Palermo, Italy

[\[Website\]](#)

2020 International Death, Grief and Bereavement Conference

Dates: June 1-3, 2020

Location: La Crosse WI, USA

[\[Website\]](#)

2020 World Congress of Psycho-Oncology (IPOS 2020)

Dates: June 16-19, 2020

Location: Kyoto, Japan

[\[Website\]](#)

Annual Meeting on Supportive Care in Cancer (MASCC/ISOO 2020)

Dates: June 25-27, 2020

Location: Seville, Spain

[\[Website\]](#)

24th International Philosophy of Nursing Conference IPONS. Personhood: philosophies, applications and critiques in healthcare (IPONS 2020)

Dates: August 26-28, 2020

Location: Gothenburg, Sweden

[\[Website\]](#)

National

11th Annual Palliative Care Clinical Studies Collaborative (PaCCSC) Research Forum

Dates: March 12, 2020

Location: Sydney, NSW

[\[Website\]](#)

Primary Care Collaborative Cancer Clinical Trials Group (PC4) Scientific Symposium 2020

Dates: May 29, 2020

Location: Melbourne, VIC

[\[Website\]](#)

Australian Grief and Bereavement Conference 2020

Dates: July 13-17, 2020

Location: Melbourne, VIC

[\[Website\]](#)

3rd Victorian Cancer Survivorship Conference

Dates: March 12-13, 2020

Location: Melbourne, VIC

[\[Website\]](#)

Recent Publications Relevant to PCRN Members

In each edition we will feature some recently published articles relevant to PCRN members. If you have published in a peer reviewed journal recently and the subject matter is relevant to the PCRN community, or if you come across key publications that foster evidence based palliative care, please email pcrnv@svha.org.au with the subject 'PCRN Newsletter' and we will feature the publications in an upcoming edition.

Bessen S, Jain RH, Brooks WB, Mishra M. (2019). "Sharing in hopes and worries"-a qualitative analysis of the delivery of compassionate care in palliative care and oncology at end of life. *Int J Qual Stud Health Well-being* 14(1):1622355.

Bishop CT, Mazanec P, Bullington J, Craven H, Dunkerley M, et al. (2019). Online End-of-Life Nursing Education Consortium Core Curriculum for Staff Nurses: An Education Strategy to Improve Clinical Practice. *J Hosp Palliat Nurs*. 21(6):531-539.

Breen LJ, Aoun SM, O'Connor M, Howting D, Halkett GKB. (2018). Family caregivers' perspectives on preparing for bereavement: A qualitative analysis. *J Pain Sympt Manage*. 55: 1473-1479.

Dias N, Hendricks-Ferguson VL, Wei H, Boring E, Sewell K, Haase JE. (2019). A Systematic Literature Review of the Current State of Knowledge Related to Interventions for Bereaved Parents. *Am J Hosp Palliat Care* 36(12):1124-1133.

Fukui C, Fujisaki-Sueda-Sakai M, Yokouchi N, Sumikawa Y, Horinuki F, et al. (2019). Needs of persons with dementia and their family caregivers in dementia cafés. *Aging Clin Exp Res*. 31(12):1807-1816.

O'Callaghan C, Brooker J, de Silva W, Glenister D, Melia Cert A, Symons X, Kissane D, Michael N. (2019). Patients' and Caregivers' Contested Perspectives on Spiritual Care for Those Affected by Advanced Illnesses: A Qualitative Descriptive Study. *J Pain Symptom Manage*. doi: 10.1016/j.jpainsymman.2019.08.004. [Epub ahead of print]

O'Callaghan C, Seah D, Clayton JM, Welz M, Kissane D, Georgousopoulou EN, Michael N. (2019). Palliative Caregivers' Spirituality, Views About Spiritual Care, and Associations With Spiritual Well-Being: A Mixed Methods Study. *Am J Hosp Palliat Care*. doi: 10.1177/1049909119877351. [Epub ahead of print]

Sullivan R, Ugalde A, Sinclair C, Breen LJ. (2019). Developing a research agenda for adult palliative care: A modified Delphi study. *J Palliat Med*. 22: 480-488.

Reigada C, Sapeta P, Centeno C. (2019). The value of the ethnographic approach to research issues in palliative care. *Curr Opin Support Palliat Care* 13(4):337-343.

Schenell R, Ozanne A, Strang S, Hensch I. (2019). Balancing between maintaining and overriding the self: Staff experiences of residents' self-determination in the palliative phases. *Int J Older People Nurs*. 14(4):e12255.

Skelton L, Guo P. (2019). Evaluating the effects of the pharmacological and nonpharmacological interventions to manage delirium symptoms in palliative care patients: systematic review. *Curr Opin Support Palliat Care* 13(4):384-391.

Tam V, You JJ, Bernacki R. (2019). Enhancing Medical Learners' Knowledge of, Comfort and Confidence in Holding Serious Illness Conversations. *Am J Hosp Palliat Care* 36(12):1096-1104.

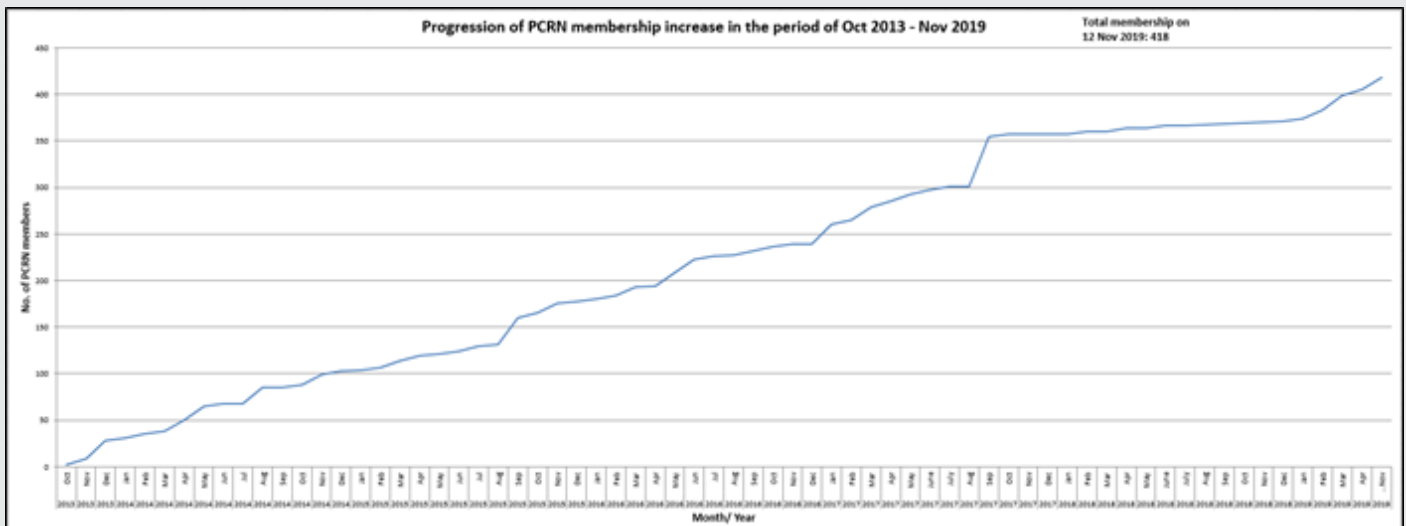
Membership

The PCRN now has 418 registered members from around Australia and other countries such as Hong Kong, India, Malawi, Norway, the UK and USA. Individuals with a genuine interest in palliative care research may become individual members of the PCRN. Membership is free and some of the *key benefits* of membership include:

- An opportunity to network and collaborate with other palliative care researchers through PCRN seminars and forums;
- If opportunities arise around PCRN / other funding, members will be notified;
- Relevant information on PCRN website;
- Opportunities to provide mentorship to junior researchers through forums / related research activity

**Please note that even though membership is open to everyone, some resources and funding may be restricted to Victorian residents only.*

To formalise your membership, please complete the [online form](#) on the PCRN website.



Forward e-news to a friend!

Please forward this newsletter to friends or colleagues interested in palliative care research. They can also sign up for [free membership](#)

Contribute to the PCRN e-News

If your work is relevant to the PCRN community, please email pcrnv@svha.org.au with the subject 'PCRN e-News submission' and we will feature your article or publication in an upcoming edition.

Unsubscribe

If you are no longer interested in receiving correspondence from us, please unsubscribe by emailing pcrnv@svha.org.au

pcrnv.com.au