



e-News

September 2017

About the PCRN

The purpose of the Palliative Care Research Network (PCRN) is to develop a platform for sustainable research collaboration. The PCRN is currently funded by the Victorian Cancer Agency and 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 organisation.

Writing Workshop 2018 – Call for Expressions of Interest

Writing research papers does not come naturally to most of us and the process of moving from research idea to published manuscript can be a daunting one, however the primary task of a researcher is the communication of technical results to the broader scientific community. Whether in written or oral form, scientific communication is a critical step in the scientific method and is the key driver of movement within a scientific field. Therefore, the construction of a written scientific manuscript must not be taken lightly. The typical research paper is a highly codified rhetorical form, and knowledge of the rules goes a long way toward writing a paper that will get accepted in a peer-reviewed journal. The PCRN is seeking interest in potentially planning a writing workshop in mid-2018 on 'how to write a paper: guide and advice on getting published'. **If you are interested, please email pcrnv@svha.org.au (subject heading: EOI – Writing Workshop) by Friday 24 November 2017 with the following details: your full name, affiliation and current role, and what you wish to get out of such a workshop.**

PCRN Project Update

Family meetings for hospitalized palliative care patients: Benefits and resource implications

Family meetings are recommended as standard practice, as a means whereby health professionals, together with family carers and patients (where able) discuss goals of care, site of care options, psychosocial issues, and plans for the future. These encounters are not usually provided consistently or systematically, nor are they conducted according to best available evidence. The primary aim of the study is to assess the effect of a structured family meeting (SFM) on patient and family outcomes. In particular we are examining the effect of an SFM on the family carer's level of psychological distress and quality of life and on the patient's care at the end of life and hospital usage at the end of life. The study also aims to determine when the most appropriate time is to provide a SFM and the resource implications of implementing SFM meetings into routine practice.

This is a multi-site project, conducted over three clinical sites, including St Vincent's Hospital, the Royal Melbourne Hospital and the Austin Hospital. Patients and their primary family carer are being recruited to the study. The target sample size is approximately 100 in each of the control and intervention groups. We have already recruited 108 patients to the control group (who receive standard care) and 80 patients to the intervention group (who receive standard care plus a SFM). We are currently only recruiting to the intervention group at all three sites.

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Family meetings for hospitalized palliative care patients: Benefits and resource implications

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A small qualitative component includes inviting 10 carers who receive a SFM to participate in an interview to comment on their experience of the SFM and any possible outcomes. At the end of the study, focus groups will also be conducted with health professionals to obtain their feedback on their involvement in the SFMs.

Data collection will be complete by the end of 2017 and project completion due in June 2018. For further information please refer to the study protocol which has been published:

Hudson P, Girgis A, Mitchell G, Philip J, Parker D, Currow D, Liew D, Thomas K, et al. (2015). Benefits and resource implications of family meetings for hospitalized palliative care patients: research protocol. *BMC Palliative Care* 14(1):73.

Travel Report from Lucy Forrest – a 2017 PCRN Travel Grant Recipient

I wish to extend my sincere thanks to PCRN for supporting my attendance at the World Congress of Music Therapy in Tsukuba Japan, in July 2017.

The World Congress of Music Therapy is held every three years, and in recent years has been held in Vienna/Krems, Austria (2014), Seoul South Korea (2011), Buenos Aires Argentina (2008), Brisbane Australia (2005) and Oxford England (2002). The benefit of the Congress being held in different continents and countries is that it allows the global music therapy community to see how music therapy is practised in different countries and cultures, and within different philosophical and theoretical frameworks. Whilst in Japan, I was able to meet with Japanese music therapists and researchers to learn more about palliative care music therapy in Japan, and to talk about ethical and practical considerations in undertaking research in palliative care within Japanese culture. This opportunity has increased my awareness of cultural considerations in both working clinically and conducting research with people of Japanese background.

Attendance at the World Congress of Music Therapy 2017 allowed me to present the complete findings of my PhD research: this is the first occasion on which I have been able to present the findings in their entirety. The Congress also gave me opportunity to meet with and learn from palliative care specialists from around the world; attend specialist sessions on paediatric palliative care, neuro-palliative care, and palliative care in neonatology; and have preliminary discussions with colleagues regarding future research opportunities. Two sessions of particular interest looked at working with infants and children in palliative care following stroke; and working with adults with dementia at end-of-life, and their carers. I was also invited to review a palliative care text “Voices of the Dying and Bereaved: Music Therapy Narratives” that has recently been released by my Canadian colleagues Prof Amy Clements-Cortes and Sara Varves Klinck, international leaders in the fields of palliative care and bereavement care respectively.

From a musical perspective, I had the amazing opportunity to participate in a taiko drumming workshop that looked at traditional Japanese drumming methods and how these might be applied within a therapeutic context; and I also attended sessions that looked at Japanese, Korean, Chinese and South African folk songs for use in therapy with adults and children.

As a clinician whose research is concerned with cultural issues in practice, it was quite simply an incredible experience to go to Japan and experience a country and culture so different from Australia, and to be immersed in Japanese cultural traditions and practices and learn about how these might be applied within a clinical context.

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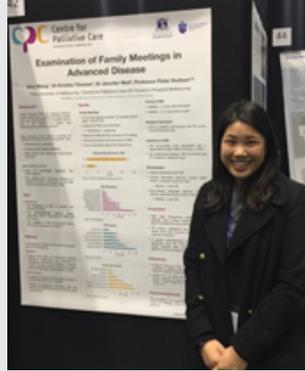
Travel Report from Lucy Forrest – a 2017 PCRN Travel Grant Recipient *Continued...*

I look forward to sharing my experiences with the palliative care and music therapy communities in Australia and internationally; and following submission of my PhD thesis shortly, I am looking to publish my research findings in a series of papers, as well as write a collaborative paper that emerged from discussions with colleagues in Japan about cultural issues at end of life.

Lucy Forrest, RMT
Music Therapist & Clinical Supervisor
Monash Health

Congratulations to Naomi Mason – Winner of the PCRN Membership Competition at the 2017 Australian Palliative Care Conference

The lucky winner of the PCRN membership competition at the recent 2017 Australian Palliative Care Conference was Naomi Mason, a palliative care researcher and social worker from Albury Wodonga Health. Naomi's prize was a \$50 Readings voucher and a bottle of red wine. Naomi's key reasons for joining the PCRN include: mentorship, networking with other researchers, collaboration opportunities, and access to funds for projects and scholarships.



Middle: The lucky competition winner, Mrs Naomi Mason and our PCRN Program Manager, Ms Soula Ganiatsas.

Right: Amy Wang (PCRN member) with her poster at the 2017 Australian Palliative Care Research Conference.

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](#).

Upcoming PCRN Event

PCRN Workshop – Thursday 26th October 2017

“Communicating research to a lay audience”

Have you ever been confounded on how you should communicate your research to the lay audience?

If you're an academic in the area of health and medicine, chances are the general public has little to no idea about the unique and exciting findings of your research. This is a shame because they want to know. The Palliative Care Research Network (PCRN) is hosting a Workshop entitled 'Communicating Research to A Lay Audience' at the [5th Australian Palliative Care Research Colloquium](#). This workshop will provide insights on how you could communicate your research to the general public in a language that is understandable to those who don't work in the medical field. In this interactive workshop, Sasha will take you through how to pitch your research to *The Conversation* (an independent source of news and views, sourced from the academic and research community and delivered direct to the public, which aims to allow for better understanding of current affairs), as well as how they edit articles there – the structure, the news pyramid and jargon busting. At the end of this process, your unique findings will have a chance to reach a much wider audience than that of academic journals.



About the Speaker

Sasha is the Deputy Editor (Health and Medicine) at *The Conversation*. She joined *The Conversation* in 2015 after working for the *Centralian Advocate* – a newspaper in Alice Springs – where she was the health and education reporter. Prior to that, she completed a Masters in Journalism and International Relations and wrote regular freelance pieces for various Australian publications.

PCRN Workshop Details

- Date:** Thursday, 26th October 2017
- Time:** 8:30 am - 10:30 am
- Venue:** Rendezvous Hotel,
328 Flinders Street, Melbourne, VIC 3000, Australia
- Cost (incl. GST):** AUD \$25.00 (light breakfast included)
- Registration:** Please register online [here](#)

For additional information, please go to the [Colloquium Website](#) or contact the event coordinator, Alfreda Soetopo, on +61 (3) 9416 0000 or by email pcrnv@svha.org.au



5th AUSTRALIAN
**PALLIATIVE CARE
RESEARCH COLLOQUIUM**
LEARN. CONNECT. COLLABORATE.
26 - 27 October 2017 Melbourne Victoria



VICTORIAN
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Upcoming PCRN Event

PCRN Forum – Thursday 30th November 2017

“Community members’ knowledge of and perceptions about the role of law at the end of life: some empirical findings”

by Professor Lindy Willmott (Queensland University of Technology, QLD)

Law can have an important role in medical decision-making at the end of life. For example, it governs whether individuals can insist on certain kinds of treatment, or having their wishes followed if they lose capacity, or whether they can receive pain relief at levels that may also hasten their death. This presentation reports on preliminary findings of empirical research into knowledge of community members about the law, as well as their perceptions about the role that law plays at the end of life.



About the Speaker

Lindy is a Director of the Australian Centre for Health Law Research which is based in the Law Faculty at the Queensland University of Technology. She publishes extensively in the health law field, including as a co-editor of a leading text in the field, *Health Law in Australia* (3rd ed, Thomson, forthcoming 2017) and specialises in the law at end of life. She has been a Chief Investigator on a number of Australian Research Council and NHMRC research projects. Between 2002 and 2007 she was a part-time member of the Queensland Civil and Administrative Tribunal. Lindy is a Board Member of Palliative Care Australia, an Associate Editor of the *Journal of Medical Ethics*, and is on the Editorial Board of the *Journal of Law and Medicine*.

PCRN Forum Details

- Date:** Thursday, 30th November 2017
- Time:** 5:00pm - 6:00pm followed by networking drinks
- Venue:** Level 2, Clinical Sciences Building,
St. Vincent’s Hospital Melbourne,
29 Regent St, Fitzroy VIC 3065
- RSVP:** This is a free event.
Please *register online by COB Wednesday 22 November 2017 to secure your place [here](#).

*This forum will be available online via a webinar and in person (please select your preference when registering).

Upcoming Funding Opportunities 2017

Alzheimer's Australia Dementia Research Foundation - 2017 Dementia Grants Program - Round 2

For more information visit the [website](#)
Closing Date: 16 October 2017

Cancer Council Victoria Postdoctoral Cancer Research Fellowships

For more information visit the [website](#)
Closing Date: 13 October 2017

Ian Potter Foundation

(various grant opportunities)
For more information visit the [website](#)
Closing Date: 20 April 2018

James N Kirby Foundation

(various grant opportunities)
For more information visit the [website](#)
Closing Date: February 2018 - date TBC
(applications open on 26 Mar 2018)

Medical Research Future Fund (MRFF) - Lifting Clinical Trials and Registries Capacity Grant Opportunity

(various grant opportunities)
For more information visit the [website](#)
Closing Date: 4 October 2017

Primary Care Collaborative Cancer Clinical Trials Group (PC4) Training Award

(various grant opportunities)
For more information visit the [website](#)
Closing Date: 27 October 2017

Upcoming Conferences

International

2017 Marie Curie Annual Palliative Care Research Conference

Dates: October 6, 2017
Location: London, UK
[\[Website\]](#)

10th World Research Congress of the European Association for Palliative Care (EAPC)

Dates: May 24-26, 2018
Location: Bern, Switzerland
[\[Website\]](#)

National

5th Australian Palliative Care Research Colloquium

Dates: October 26-27, 2017
Location: Melbourne VIC, Australia
Registration deadline extended to 5 October 2017
[\[Website\]](#)

National

44th Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting

Dates: November 13-15, 2017
Location: Sydney, Australia
[\[Website\]](#)

6th Annual NHMRC Symposium on Research Translation

Dates: November 14-15, 2017
Location: Brisbane, Australia
[\[Website\]](#)

21st Cancer Nurses Society of Australia (CNSA) Annual Congress

Dates: June 21-23, 2018
Location: Brisbane, Australia
Abstract submissions open on 1 November 2017
[\[Website\]](#)

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.

Aoun SM, Deas K, Kristjanson LJ, Kissane DW. (2017). Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool. *Palliat Support Care*. 15(1):32-43.

Aoun S, Slatyer S, Deas K, Nikolaichuk C. (2017). Family Caregiver Participation in Palliative Care Research: Challenging the Myth. *J Pain Symptom Manage*. 53(5):851-861.

Aoun SM, Breen LJ, Oliver D, Henderson RD, Edis R, O'Connor M, Howting D, Harris R, Birks C. (2017). Family carers' experiences of receiving the news of a diagnosis of Motor Neurone Disease: A national survey. *J Neurol Sci*. 372:144-151.

Deodhar JK, Noronha V, Muckaden MA, Atreya S, Joshi A, Tandon SP, Ghoshal A, Salins NS, Patil VM, Prabhash K. (2017). A Study to Assess the Feasibility of Introducing Early Palliative Care in Ambulatory Patients with Advanced Lung Cancer. *Indian J Palliat Care*. 23(3):261-267.

Hudson P, Hall C, Boughey A, Roulston A. (2017). Bereavement support standards and bereavement care pathway for quality palliative care provision. *Palliat Support Care*. doi: 10.1017/S1478951517000451. [Epub ahead of print].

Johnston B, Flemming K, Narayanasamy MJ, Coole C, Hardy B. (2017). Patient reported outcome measures for measuring dignity in palliative and end of life care: a scoping review. *BMC Health Serv Res*. 17(1):574.

Kamal AH, Taylor DH Jr, Neely B, Harker M, Bhullar P, Morris J, Bonsignore L, Bull J. (2017). One size does not fit all: disease profiles of serious illness patients receiving specialty palliative care. *J Pain Symptom Manage*. doi: 10.1016/j.jpainsymman.2017.07.035. [Epub ahead of print]

LeBlanc TW, Sederstrom N, Spence R, von Roenn J. (2017). Palliative Care Has Come of Age. *J Oncol Pract*. doi: 10.1200/JOP.2017.026674. [Epub ahead of print]

Lewis EG, Oates LL, Rogathi J, Duinmaijer A, Shayo A, Megiroo S, Bakari B, Dewhurst F, Walker RW, Dewhurst M, Urasa S. (2017) "We never speak about death." Healthcare professionals' views on palliative care for inpatients in Tanzania: A qualitative study. *Palliat Support Care*. doi: 10.1017/S1478951517000748. [Epub ahead of print]

Li Z, Frost HR, Tosteson TD, Zhao L, Liu L, Lyons K, Chen H, Cole B, Currow D, Bakitas M. (2017). A semiparametric joint model for terminal trend of quality of life and survival in palliative care research. *Stat Med*. doi: 10.1002/sim.7445. [Epub ahead of print]

Mather H, Guo P, Firth A, Davies JM, Sykes N, Landon A, Murtagh FE. (2017). Phase of Illness in palliative care: Cross-sectional analysis of clinical data from community, hospital and hospice patients. *Palliat Med*. doi: 10.1177/0269216317727157. [Epub ahead of print]

Nwosu AC, Collins B, Mason S. (2017). Big Data analysis to improve care for people living with serious illness: The potential to use new emerging technology in palliative care. *Palliat Med*. doi: 10.1177/0269216317726250. [Epub ahead of print]

von Gunten CF. (2017). Palliative Care in Special Settings of Cancer Care. *J Oncol Pract*. doi: 10.1200/JOP.2017.025551. [Epub ahead of print]

Williams M, Cardona-Morrell M, Stevens P, Bey J, Smith Glasgow ME. (2017). Timing of palliative care team referrals for inpatients receiving rapid response services: A retrospective pilot study in a US hospital. *Int J Nurs Stud*. 75:147-153.

Membership

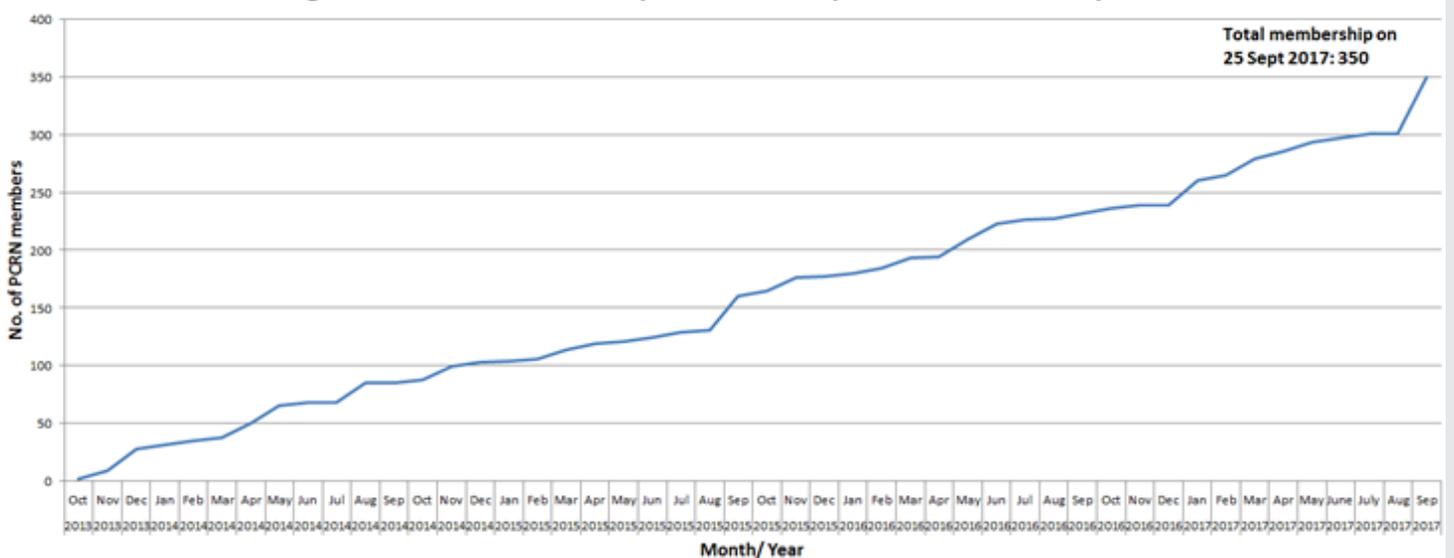
The PCRN now has 350 registered members from around Australia and other countries such as Hong Kong, India, Malawi, Norway, the UK and USA. Individuals with a genuine interest in palliative care research may become individual members of the PCRN. Membership is free and some of the *key benefits* of membership include:

- An opportunity to network and collaborate with other palliative care researchers through PCRN seminars and forums;
- Apply for a range of PCRN funding including: PhD scholarship, project and travel grants;
- Assistance in developing your research idea into a grant proposal via attendance at PCRN Concept Development Workshops;
- Opportunities to provide mentorship to junior researchers.

**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.

Progression of PCRN membership increase in the period of Oct 2013 - Sep 2017



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.

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