

e-News November 2021

About the PCRN

The purpose of the Palliative Care Research Network (PCRN) is to foster the evolution of collaborative scholarly inquiry in palliative care in Australia.

Objectives:

- 1. Influence the development of a critical mass of palliative care scholars in Australia.
- 2. Develop programs of research that focus on improving the quality of palliative care.
- 3. Facilitate opportunities to build relationships for collaboration and mentorship.
- 4. Raise awareness of grant opportunities, research training and research findings.

The PCRN is supported by the Department of Health, Victoria, Australia and administered by The Centre for Palliative Care (a Collaborative Centre of St Vincent's Hospital and The University of Melbourne).

Update on PCRN consumer & community involvement program

The *"Program to enhance consumer and community involvement (CCI) in palliative care in Australia"* is progressing well. We have been busy in the past months partnering together with our consumer representatives, Christine Hofmeyer and Avi Paluch, to identify, prioritise and inform the design of Phase 1, a baseline mapping to gain an understanding of the current CCI activity in palliative care.

Please join us on Thursday 25 November for our PCRN Forum to learn more about the importance of partnering together with consumers and community members in palliative care (see further details on the next page).

For more information on the PCRN consumer & community involvement program, please contact Dr Stacey Panozzo at stacey.panozzo@svha.org.au







Upcoming PCRN Event PCRN Forum (Webinar) – Thursday 25 November 2021

"Partnering with consumers to improve palliative care"

This discussion with Stacey Panozzo, Joanne Britto, Christine Hofmeyer and Avi Paluch will reflect on opportunities for consumer and community involvement (CCI) in palliative care and share a new program of work that seeks to explore, develop and implement a program to enhance CCI in palliative care in Australia.



Dr Stacey Panozzo Research Fellow, PCRN Consumer & Community Involvement Program

Stacev Panozzo is the Project Officer for the PCRN consumer & community involvement program. She is a Research Fellow working with Palliative Nexus, St Vincent's Hospital, Peter MacCallum Cancer Centre and The University of Melbourne. Stacey is a researcher whose particular areas of interest include improving supportive and palliative care access and delivery for patient groups experiencing vulnerability. Stacey is a member of the Health Equity Working Group for the VCCC. Twitter: @palmed nexus



Dr Joanne Britto Manager – Consumer Involvement, Victorian Comprehensive Cancer Centre Alliance

Dr Joanne Britto is the Consumer Involvement Manager at the Victorian Comprehensive Cancer Centre Alliance. With 25 years' experience in medical research, Joanne actively embeds the consumer perspective into program design and implementation through initiatives that formalise the role of consumers and establish effective partnerships.



Mrs Christine Hofmeyer Consumer Representative, PCRN Consumer & Community Involvement Program

Christine Hofmeyer has worked as a palliative care nurse consultant for 27 years. She has been involved in providing palliative care for patients, their caregivers and family, together with informing service and policy development at a local and state-wide level. Christine has experienced being a carer for several family members with life limiting illness and palliative care needs. She believes it is essential to ensure consumers' and carers' views and experiences are heard and integrated into research, policy development and service improvements.



Mr Avi Paluch Consumer Representative, PCRN Consumer & Community Involvement Program

Avi Paluch cared for his wife Gita who lived with cancer for 12 years. This presented a whole new set of challenges as he worked to navigate and juggle so many different roles. Yet while he faced challenges, Avi believes there were also incredible rewards in being a carer for his wife. Avi has now trained as a grief counsellor to support other carers. He believes it is important for people to understand more about palliative care.

This PCRN Forum will be facilitated by: Prof Peter Hudson (Director, Centre for Palliative Care, St Vincent's Hospital Melbourne and University of Melbourne) and Prof Jennifer Philip (Chair of Palliative Medicine, Director of Palliative Nexus, University of Melbourne, St Vincent's Hospital and in collaboration with the Victorian Comprehensive Cancer Centre).

Forum Details

- Date: Thursday, 25th November 2021
- **Time:** 4:00pm 4:45pm AEDT
- **RSVP:** This is a free event. Register online via the event website here.

(This Forum will be delivered online – link details will be sent to your registered email address 24 hours prior to the event).

For further enquiries, please contact pcrnv@svha.org.au



PCRN PhD Studentship – Apply Now!

A full-time graduate research studentship is available for a suitable PhD candidate with a nursing, medicine or allied health degree. The studentship is offered by the Palliative Care Research Network (PCRN), which is administered by the Centre for Palliative Care c/o St Vincent's Hospital and Collaborative Centre of the University of Melbourne. We are seeking a PhD candidate with an interest in research focussed on the involvement of patients, family carers and the public in improving palliative care.

Please see here for more information on the studentship being offered, including on how to apply.

Application closing date: 3rd December 2021.

Introducing The Nicole King Scholarship

This annual scholarship has been established by Nicole King's family in her memory. Nicole was a Lecturer in the Department of Nursing at The University of Melbourne and clinical educator at Peter MacCallum Cancer Centre until her untimely death in 2011. The Scholarship honors Nicole's contribution to cancer and palliative care nursing and her passion for scholarship and research in the discipline. The Nicole King Scholarship is available to Graduate Research students (MPhil or PhD) with a focus on Cancer and Palliative care nursing. For details about this scholarship please access the link here. **Application closing date: 30th November 2021**.

New Prizes for Australian Death Studies Research

The Australian Death Studies Society is proud to launch three new annual prizes, for best Student Paper, Dissertation, and Creative Work.

The Australian Death Studies Society (ADSS) was founded in 2020 and aims to foster the development of high quality scholarship about dying, death, and body disposal within Australia. The subject matter of death touches all aspects of human experience, and this is reflected in the multidisciplinary nature of our membership.

We welcome submissions for these prizes from scholars of diverse disciplinary backgrounds, including (but not limited to) anthropology, design, history, law, medicine, philosophy, palliative care, sociology, taphonomy and forensic sciences, and media studies.

Applications for the prizes are due 1st **December 2021**. Please see the website here for guidelines and send any enquiries to info@deathstudies.org.





Call out to supervisors of current PhD candidates focused on palliative care or related areas

As part of an initiative that we are undertaking, we would like to identify the primary supervisors of current PhD or Professional Doctorate candidates in Victoria whose projects are focused on palliative care or related areas.

We have a collaborative idea for consideration, and we would highly value PhD supervisors' perspectives on this.

If you are a primary supervisor of a current Victorian-based PhD/Doctoral candidate(s) and willing to have a preliminary discussion to find out more, please contact us at pcrnv@svha.org.au.

Thank you for considering this and we look forward to hearing from you.

Professor Peter Hudson and Professor Jennifer Philip (Co-leads, PCRN)

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Improving how we assess the quality of death and dying through the 'QualDeath' project



QualDeath is a new collaborative project led by the Centre for Palliative Care, St Vincent's Hospital, to develop a systematic process to assess the quality of dying in hospital for patients with advanced cancer. Researchers will soon begin collecting data about existing appraisal practices from those working with patients at the end-of-life. Ultimately, project will contribute to improving how hospitalised patients and their families experience dying and bereavement.

To learn more about the project including how to get involved, visit the website here or email hannah.gould@svha.org.au.

Promoting collaboration amongst members

In order to promote collaboration amongst PCRN members, we have attached a *membership listing (detailing members' affiliations, email address, and areas of research interest) with this edition of e-newsletter. We encourage you to contact other members with similar interests in order to promote collaboration.

Please note that this membership listing is intended for PCRN members' information only and is not for redistribution.

*Note: Only PCRN members who have provided consent for their details to be published are included on the list.

If you would like to become a member, please refer to the 'Membership' section of this newsletter.

Would you like to be profiled in the PCRN e-News?

One of the key objectives of the PCRN is to facilitate opportunities to build relationships for collaboration in palliative care research. To help enable this we would like to offer members the opportunity to be profiled in the PCRN e-News. One member will be profiled within each edition.

If you are interested in being considered, please provide the details below to pcrnv@svha.org.au with the subject 'PCRN member profile'.

Please provide the following details: Your Name, Professional Role/Title, Discipline, Institution, City/ Country, Specific area of interest in palliative care research and your Email address (so that other members can contact you directly).





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 Medicine - 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 (AIIHPC) – to subscribe to mailing list go to the website.

Palliative Medicine Research Review - to subscribe email: kathy@researchreview.com.au.

Upcoming Funding Opportunities 2021/2022

PCRN PhD Studentship

For more information visit the website Closing date: 3 December 2021

James N Kirby Foundation

(various grant opportunities)

For more information visit the website Closing date: TBC (applications for 2022 funding will open in Nov 2021)

John T Reid Charitable Trusts

For more information visit the website Closing date: TBC (application enquiries for 2022 funding will open in Jan 2022)

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

Nicole King Scholarship

For more information visit the website Closing date: 30 November 2021





Upcoming Conferences

Please note: due to COVID-19, please check the relevant conference websites for the most recent updates/ information on conference status and dates.

International

1st Annual Meeting of the International

Neuropalliative Care Society (INPCS) Dates: November 4-6, 2021 Location: Virtual [Website]

14th Asia Pacific Hospice Conference Dates: November 13-14, 2021 Location: Virtual [Website]

11th International Seminar of the European Palliative Care Research Centre in collaboration with the Norwegian Cancer Society - Next generation palliative care research

Dates: December 2-3, 2021 Location: Virtual [Website]

3rd and 4th Sapporo Conference for Palliative and Supportive Care in Cancer Dates: July 21-23, 2022 Location: Sapporo, Japan

[Website]

7th Public Health Palliative Care International (PHPCI) Conference

Dates: September 20-23, 2022 Location: Bruges, Belgium [Website]

2022 World Cancer Congress

Dates: October 17-20, 2022 Location: Geneva, Switzerland [Website]

23rd International Congress on Palliative Care

Dates: October 18-21, 2022 Location: Montréal, Canada [Website]

<u>National</u>

48th Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting Dates: November 16-18, 2021 Location: Melbourne, VIC [Website]

2022 Palliative Care Nurses Australia (PCNA) Conference Dates: May 1-4, 2022 Location: Virtual [Website]





Recent articles published by PCRN members

In each edition we aim to feature recently published articles by PCRN members. If you have published in a peer reviewed journal recently and the subject matter is relevant to the PCRN objectives and community (for example articles that relate to enhancing evidence-based palliative care) then please email pcrnv@svha.org.au with the subject 'PCRN Newsletter - article to share' and we will feature the publication in an upcoming edition.

Seah D, Marco D, Philip J, Sands MB. "The epidemiology of death and symptoms: Planning for populationbased palliative care". In: Cherny NI, Fallon MT, Kaasa S, Portenoy RK, Currow DC. (eds) Oxford Textbook of Palliative Medicine 6th Ed. Oxford University Press, 2021: 55–68. ISBN: 9780198821328. Doi: 10.1093/ med/9780198821328.003.0007.

What is already known about the topic?

Despite the advances of medicine, many illnesses continue to evade cure. Chronic, progressive, incurable illness is a major cause of disability, distress, suffering, and, ultimately, death. This is true for many causes of cancer, AIDS, and other disorders of vital organs. Such progressive, chronic diseases are most common in late adulthood and old age, but they occur at all ages. Disease-modifying treatments and the relief of suffering through symptom management, care planning, and family support are central to care, and these four domains are core goals of palliative care.

What does this paper add & what are the implications for practitioners?

This chapter offers an overview of how epidemiological studies may be used to clarify the population/s of people who may benefit from palliative care, to assist the planning for how services may meet the needs of people towards the end of life. Symptoms associated with a series of common, progressive, chronic illnesses will be discussed, thereby further facilitating planning for individual patients and for services.

Ulrick P, Panozzo S, Marco D, Collins A, Philip J. (E-Pub 17 May 2021). "End-of-life care in illicit drug users: mapping medication use". BMJ Supportive & Palliative Care. doi: 10.1136/bmjspcare-2021-002906.

What is already known about the topic?

While clinical wisdom has long provided suggested guidance around caring for people who use illicit drugs (referred to as PWUD) at the end of life, there is striking paucity of empirical evidence underpinning these practices. Understanding medications and doses required to manage symptoms at the end of life is essential to provide effective end-of-life care for these patients.

Continued...





Recent articles published by PCRN members Continued...

What does this paper add?

PWUD receive greater doses of symptom-controlling medications, particularly opioids and midazolam at the EOL. Opioid dose increases at the EOL for PWUD are of similar magnitude to comparator patients, with no exponential dose escalation.

What are the implications for practitioners?

Clinicians must be aware that end-of-life prescribing is likely to be different for PWUD, with patients possibly requiring significantly higher doses of symptom-controlling medications. This finding is particularly important since clinicians' fears around overprescribing and drug-seeking behaviours may lead to pain being undertreated in this group.

Membership

The PCRN now has 428 registered members. Individuals with a genuine interest in enhancing the development of collaborative scholarly inquiry in palliative care in Australia are encouraged to join. **Membership is free.**

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 / Share your work with other members

If your work is relevant to the PCRN community, or if you would like to share news relevant to palliative care research to the membership (i.e. call for participation in research study, sharing updates on your projects), 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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