

# e-News

## May/June 2022

### 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 patient and public involvement program

It has been a busy time for this program as we work to enhance the involvement of patients and the public in palliative care research. With our desire to develop the evidence base to underpin these practices for the palliative care discipline, we were interested to understand and scope what is currently occurring, and to collate some successful approaches. This has involved interviewing key leaders, consumers, researchers and experts – locally and abroad – both from within our field and also drawing on the expertise of other related areas of healthcare that are perhaps a little further along in similar endeavours!



Alongside two of our wonderful public collaborators Christine and Avi, we have also been deeply immersed in a scoping review to help us establish what level of involvement is currently occurring across palliative care research internationally.

Our most exciting news is that we will soon be calling for Expressions of Interest from interested community members who have a passion for improving the quality of care for people with serious illness. This process will see us engage a broader group of patients and public who will be trained and supported to contribute their voices – in the first instance informing palliative care research. If you have consumers within your networks who have a relevant lived experience with palliative care as a patient, carer or advocate, please reach out to us so we can share this call widely for interested people to self-nominate.

If you would like to keep in touch with this work, or for more information, we would love to hear from you. Contact our fabulous and friendly PPI Program Coordinator – Dr Stacey Panozzo at [stacey.panozzo@svha.org.au](mailto:stacey.panozzo@svha.org.au).

**Dr Anna Collins – PPI Program Lead**

## Update on PCRN Victorian PhD Palliative Care Student Group

We have received great interest in establishing the Victorian PhD Palliative Care Student Group and we will be having an initial meeting of the group in due course.

## Update on PCRN Virtual Journal Club

We would like to convey our appreciation to those who have expressed interest in establishing this new initiative – the PCRN Virtual Journal Club. The first virtual journal club meeting is currently in the process of being scheduled.



**Dame Quentin Bryce**  
palliative care nursing  
research fund

APPLICATIONS ARE NOW OPEN



The Dame Quentin Bryce Palliative Care Nursing Research Fund is used to support research costs associated with research into Palliative Care nursing. The funds will support research in palliative care that will improve quality of care for people diagnosed with advanced disease and their families/caregivers. The funds are offered by the Centre for Palliative Care (c/o St Vincent's Hospital) and the Department of Nursing, The University of Melbourne.

Students can apply for up to 30K per annum for funds to support Graduate Research. Funding may be requested to assist you to help complete a Masters of Philosophy (MPhil) or a Doctor of Philosophy (PhD). Some examples of this could be: Publication costs, conference attendance, supplementing your cost of living so you can go full-time, enrolment in coursework/professional development related to thesis, data collection or analysis costs.

Existing scholarship holders are eligible to apply (though please check the terms and conditions of your scholarship before applying).

Applications close on **25<sup>th</sup> June 2022**. Please see the website [here](#) for more information and send any enquiries to [shs-research@unimelb.edu.au](mailto:shs-research@unimelb.edu.au)

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## 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](mailto: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).

## Featured PCRN Member

**Voula Kallianis** (Social Worker, St Vincent's Hospital Melbourne) introduces herself and her work in her own words:



*"My name is Voula Kallianis and I am a social worker with over 30 years of experience.*

*I have worked in hospital social work for most of my career; however, I also have experience in the community as a youth worker and community development worker dealing with multicultural affairs. I have worked in obstetrics, gynaecology and rehabilitation. I am currently working in an inpatient palliative care unit at St Vincent's Hospital Melbourne where I work closely with patients and their families.*

*My qualifications include Bachelor of Arts, Bachelor of Social Work and Masters of Social Work (via research) at the University of Melbourne.*

*My thesis focused on supporting patients being discharged from the palliative care unit to a residential aged care facility, and exploring strategies that could be implemented to ensure a smooth transition.*

*Additionally, I provide annual teaching at Melbourne University to social work students in a subject titled "Assessing Risk and Vulnerability".*

*I am also an Associate Investigator for the "Psilocybin Assisted Psychotherapy for the Treatment of Depression and Anxiety Associated with Life Threatening Illness" and my particular role in this trial is as the qualitative research interviewer. This role is very exciting as it includes recording the expectations and experiences of the consumers before the commencement of the trial, during the trial and after the completion of the trial.*

*As part of my current role within the Social Work Department at St Vincent's Hospital Melbourne, I have been involved in a research project that identifies and explores the impact of family violence on patients presenting to the hospital during the COVID 19 pandemic. A data mining approach using an electronic audit tool was used and two focus groups were held with clinicians. The audit tool was used to inform anticipated pandemic related factors, exploring emerging risk factors as well as protective factors. A qualitative thematic analysis was undertaken of the retrospective audit data as well as the clinician focus groups. The research team is currently in the process of collating and analysing results, and we anticipate a publication in 2022.*

*As a clinician, one requires great mentoring and support when undertaking research and the Social Work Department at St Vincent's Hospital Melbourne where I work has been instrumental in this.*

*I enjoy my role as a social worker in the palliative care unit and providing emotional/grief support to patients and families with empathy and grace. It certainly is a privileged role.*

*I see the value of research in this space as it can inform and improve our practice, enables us to share knowledge, and increase collaboration with key stakeholders such as with other clinicians and research institutions."*

If you would like to know more about Voula and her work, contact her directly at [Voula.Kallianis@svha.org.au](mailto:Voula.Kallianis@svha.org.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.

**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 (AIHPC)** – to subscribe to mailing list go to the [website](#).

**Palliative Medicine Research Review** – to subscribe email: [kathy@researchreview.com.au](mailto:kathy@researchreview.com.au).

## Upcoming Funding Opportunities 2022/2023

### Dame Quentin Bryce Palliative Care Nursing Research Fund

For more information visit the [website](#)  
Closing date: 25 June 2022

### Bethlehem Griffiths Research Foundation

For more information visit the [website](#)  
Closing date: TBC (next funding round open in mid-June 2022)

### John T Reid Charitable Trusts

For more information visit the [website](#)  
Closing date: TBC (next funding round open in June/July 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

### Cancer Australia – Priority-driven Collaborative Cancer Research Scheme (PdCCRS): Clinical Trials and Cohort Studies Scheme

For more information visit the [website](#)  
Closing date: 24 August 2022

## 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

#### 3<sup>rd</sup> and 4<sup>th</sup> Sapporo Conference for Palliative and Supportive Care in Cancer

Dates: July 21-23, 2022  
Location: Sapporo, Japan  
[\[Website\]](#)

#### 23<sup>rd</sup> International Congress on Palliative Care

Dates: October 18-21, 2022  
Location: Montreal, Canada  
[\[Website\]](#)

#### 7<sup>th</sup> Public Health Palliative Care International (PHPCI) Conference

Dates: September 20-23, 2022  
Location: Bruges, Belgium  
[\[Website\]](#)

#### 2<sup>nd</sup> Annual Meeting of the International Neuropalliative Care Society (INPCS)

Dates: November 10-12, 2022  
Location: Virtual  
[\[Website\]](#)

#### 2022 World Cancer Congress

Dates: October 17-20, 2022  
Location: Geneva, Switzerland  
[\[Website\]](#)

### National

#### Redesigning Deathcare Conference

Dates: October 27-29, 2022  
Location: Hybrid – Virtual/ Melbourne, VIC  
[\[Website\]](#)

## 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](mailto:pcrnv@svha.org.au) with the subject 'PCR N Newsletter - article to share' and we will feature the publication in an upcoming edition.

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Philip J, Wawryk O, Pasanen L, Wong A, Schwetlik S, Collins A. (E-Pub 21 Feb 2022). "Telehealth in outpatient delivery of palliative care: a prospective survey evaluation by patients and clinicians". *Internal Medicine Journal*. doi: 10.1111/imj.15721.

### What is already known about the topic?

In Australia during the COVID-19 pandemic new funding models were introduced to support telehealth consultations, resulting in their widescale adoption in palliative care service delivery. Clarity around the clinical circumstances and patient populations that might be most appropriate for telehealth models was required.

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

This study evaluated patient and physician satisfaction, acceptability and utility of outpatient palliative care provision through telehealth, and found that:

- Telehealth was generally acceptable and satisfactory, with patients providing greater positive scores than clinicians.
- Telehealth incorporating both audio and video were more acceptable and satisfactory, particularly with the presence of a carer, and during routine reviews.
- Physicians were less satisfied using telehealth when there was increasing symptom complexity across all domains (pain, psychological, and other symptoms).

The paper concluded that telehealth has high utility in palliative care practice. A future hybrid model of care comprising both face-to-face and telehealth consultations seems favoured by patients and physicians but must be accompanied by targeted support for specific patient groups to ensure equitable healthcare access. Further evaluation of telehealth during a time of fewer public health emergency measures and lower community anxiety is required to fully understand its ongoing role.

*Continued...*

## Recent articles published by PCRN members

*Continued...*

Marco DJ, Thomas K, Ivynian S, Wilding H, Parker D, Tieman J, Hudson P. (E-Pub 7 Jan 2022). "Family carer needs in advanced disease: systematic review of reviews". *BMJ Supportive & Palliative Care*. doi: 10.1136/bmjspcare-2021-003299.

### What is already known about the topic?

Family carers form the backbone of a successful home-based palliative care system. It is, therefore, not surprising that caregivers provide up to 80% of patient care needed at home. This role is generally not accompanied by formal training or financial compensation. As a result, it is not uncommon for carers to report unmet needs for information, communication, practical support, and financial assistance.

### What does this paper add?

We conducted an extensive review of current research and found the most commonly expressed needs by carers were:

1. Emotional support – needing support with personal emotions as they arise,
2. Knowledge about the disease – the desire for further information and education about the diagnosis and cause of the illness,
3. Responsibilities associated with the caregiving role – the need for education and training to gain skills in caring for someone,
4. Support with self-care – the impact of caring on the carer's quality of life, and
5. General practical support – help with daily living tasks.

Information about how carers preferred their needs be delivered included having access to professional services and support, opportunities for formal education and training, and having open channels for communication with healthcare professionals. Perhaps more importantly, carers also expressed the desire to be acknowledged for their carer role by health professionals and be actively involved in the decision-making process.

### What are the implications for practitioners?

Resourcing support services to meet the needs of family carers is an ongoing challenge. Future endeavours to meet these needs should acknowledge and encourage connections with existing care services (e.g. family GP) while also promoting awareness of other local support services. Our findings showed that it was not always clear whether carer needs were identified from direct questioning or assumptions made by researchers based on carers' 'experiences' of caregiving. As such, we need to ensure we ask carers directly about their unmet needs, so that the right support can be offered at the right time and when it is most needed.

*Continued...*



## Recent articles published by PCRN members *Continued...*

O'Connor T, Paterson C, Gibson J, Strickland K. (E-Pub 7 Oct 2021). "The conscious state of the dying patient: An integrative review". *Palliative & Supportive Care*. doi: 10.1017/S1478951521001541.

### **What is already known about the topic?**

Individualised care planning to meet the needs of the dying and their family is championed nationally and internationally. As death approaches, there is a gradual failure of all the major organs. This progressive failure of the body's systems and organs, together with the resulting physiological and metabolic changes, are precipitating factors contributing to altered consciousness in people who are imminently dying. This reduction in consciousness suggests that dying patients are less able, or completely unable, to communicate their own symptoms, needs, or levels of distress.

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

This paper highlights that although physical care needs such as pain and dyspnoea occur in the last hours and days of life, insights on how to best identify and assess these needs in the imminently dying patient who is no longer able to express their own needs, is missing. Equally, assessment of other obvious care needs such as quality of dying, suffering, psychosocial and spiritual problems, and the family were absent.

These issues raise significant uncertainty and challenges for practitioners in relation to the delivery of person-centred care; and raise significant questions about the delivery of holistic care for patients who are unable to communicate their own individual needs due to the dying process. This review adds to the call for urgent development of assessment tools to determine the care needs of dying adults with an altered level of consciousness to ensure holistic, patient-centric care.

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## Membership

The PCRN now has 450 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](mailto: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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