

PALLIATIVE CARE IN PRISONS PROJECT

UTS: IMPACCT



Message from Project Lead

PROFESSOR JANE PHILLIPS

Welcome to the sixth issue of the Palliative Care in Prisons (PiP) Project Newsletter.

This Newsletter profiles another of our Project Investigators Professor John Scott, Head of the School of Justice at the Queensland University of Technology. John is a sociologist who has worked on a range of drug supply, public health and justice issues. We also introduce Ms Monique Hooper, a nurse practitioner based in Brisbane who is joining the PiP Project as a higher degree research student, with her studies focusing on the project's co-design element to strengthen palliative care delivery in our prisons.

Behind the scenes it has been a busy time for the PiP Project team as they have prepared and submitted ethics applications simultaneously in the Australian Capital Territory, South Australia, Victoria, and Queensland, while completing the final step for approval of data collection in New South Wales. I am pleased to report that on 28 April 2022 we received the final approval to enable data collection in New South Wales, which will commence in early May. This is a significant breakthrough for the project, as securing ethics and governance approval in this state alone has involved five separate applications and taken 12 months to achieve.

Earlier in the week we also received approval from Central Adelaide Local Health Network Human Research Ethics Committee, South Australia which is another huge project win. This application was approved under the National Mutual Acceptance Scheme, meaning we can proceed straight to governance approvals for several other states and territories, rather than having to make full submissions. I would like to thank all the Project Partners and Investigators from these states and territories for the critical role they have played in progressing these complex applications.

In late 2021, Monique Hooper and I undertook a tour of Wolston Correction Centre in Brisbane and met with the correctional services and justice health team. During this visit we gained insights into the challenges and opportunities to improve the delivery of palliative care in this facility, and look forward to working with the team once we have secured Queensland ethics approval.

The team will be presenting two abstracts at the virtual Palliative Care Nurses Australia conference. Ms Kim Offner, PiP Project Manager will present on the challenges of gaining national ethics approval to collect data nationally that will inform understanding of palliative and end of life care in Australian prisons. Project Officer and PhD candidate Isabelle Schaefer will present on the findings of her meta-synthesis on the perceptions and experiences of people in prisons about palliative and end of life care, which was published in Palliative Medicine in December 2021.

Earlier this year, Isabelle also undertook a scholarship program at the Deeble Institute for Health Policy Research. As part of the program, she developed an Issues Brief advocating for the development of national data collection about the degree of palliative care need, and quality of palliative care service delivery in Australian prisons, which will be published in May.

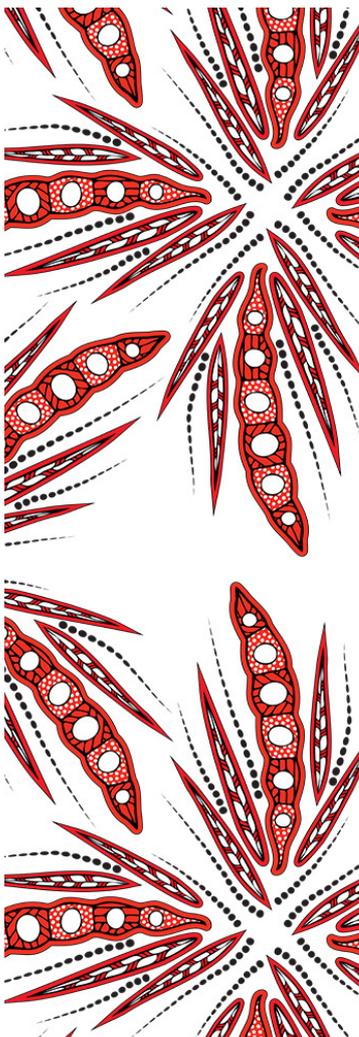
The next few months promise to be busy for the PiP Project as we begin baseline data collection and work towards receiving approval to enable data collection to commence in other jurisdictions.

I look forward to working with Investigators and Project Partners as we progress with these next steps for the Project.

Kind regards,

Jane Phillips

Wambinya Update: Focus on Aboriginal and Torres Strait Islander people



The work on Wambinya strategies to convey Aboriginal and Torres Strait Islander people's experiences of palliative care in prison continue including via a fellowship from the Human Rights Centre at Berkeley Law, University of California, in partnership with Croakey Health Media and Mibbinbah Spirit Healing. The fellowship supports writer Lucy Meyer to co-produce with Megan Williams articles for the online environment. This extends Croakey's previous work on the [#JustJustice series](#) of public health journalism articles and the publication [#JustJustice: Rewriting the Roles of Journalism in Indigenous Health](#).

Lucy has gathered a range of resources to support and inspire the work, such as through yarns with local Aboriginal and Torres Strait Islander family, Elders and service providers.

Lucy found an interesting resource from the Global Investigative Journalism Network conference. They held a panel on groundbreaking work by Indigenous reporters from around the world, including Australia – the Guardian's [Deaths Inside team](#). [Here's a piece](#) covering what happened at the event and panellists' insights.

We plan to hold a panel discussion and potentially explore family journey stories; we are working slowly but steadily in amongst other tasks so if you would like to share your experience or connect us to others, do get in touch – megan.williams@uts.edu.au.

Megan's place of work, the UTS School of Public Health Girra Maa Indigenous Health Discipline, has new artwork that you might see on some of the UTS Palliative Care in Prison Project materials, by Dubbo Wiradjuri artist Nathan Peckham signifying the diverse yet unifying and very useful wattle seed.

MEDIA WATCH: END OF LIFE CARE IN THE PRISON ENVIRONMENT

Media Watch by the Palliative Care Network collates a list of news and peer-reviewed articles on topics of interest to the palliative care community. In their issue from January 2022, Media Watch published a Backgrounder on End of Life Care in the Prison Environment, which you can download [here](#).

Publications from this issue include:

- 'End-of-life care in prisons,' Penal Reform International (p.2)
- 'Death and dying in carceral America...', Medical Anthropology Quarterly (p.2)
- 'Large-scale evaluation of a computer-based learning program...', International Journal of Prison Health (p.4)
- 'Compassion hard to come by in broken prison system,' Courier Express (p.9)
- 'Broken "compassionate release rules strand Pennsylvania's sickest prisoners...', Pittsburgh Post-Gazette (p.9)
- 'Caring for the terminally ill in prison,' University of Melbourne (p.10)
- 'The Fragmented picture of social care for older people in German prisons,' Journal of Aging & social Policy (p.13)

PALLIATIVE CARE EDUCATION OPPORTUNITIES: NORTHERN TERRITORY

The Program of Experience in the Palliative Approach (PEPA) is a national organisation seeking to provide free short observational placements in palliative care settings to build skills in providing a palliative approach to care, and educational opportunities.

Applications for a PEPA placement (2-5 days) are currently open in the Northern Territory for placements based in Darwin and Alice Springs. The application form can be found [here](#).

PEPA NT is also running a series of free 2 hour workshops on a Palliative Approach to Care starting on Thursday 2 June from 1:30-3:30pm. The workshops cover a range of topics including principles of palliative care, providing care, communication, Advance Care Planning, End of life care and ethical issues. Register [here](#) by 17 June to secure a place.

You can find more information about PEPA placements and workshops in your state or territory by visiting the [PEPA website](#).



ENSURING THE QUALITY OF PALLIATIVE CARE IN AUSTRALIA'S PRISONS: ISSUES BRIEF

Isabelle Schaefer

In early 2022, I spent six weeks with the Deeble Institute for Health Policy Research to develop a policy Issues Brief focused on palliative care in Australian prisons. An Issues Brief is designed to provide a short, accessible, objective publication for policymakers that synthesises and interprets evidence for an area of health policy, and makes evidence-based recommendations.



This Brief discusses the issue and consequences of the lack of data collection about palliative care need and provision in Australian prisons. Without valid, reliable data, it is difficult to understand the scope of palliative care need, trends in health and care needs, services that are currently available and priority areas for service improvement.

In the Issues Brief, I describe the limitations of health data that is currently collected about people in prison, why improving data collection would be invaluable to prison healthcare providers, and recommendations for how to improve data collection about palliative care need and service provision in Australian prisons.

I would like to thank Adjunct Associate Professor Rebecca Haddock, my supervisor from the Deeble Institute; Professor Jane Phillips, for enabling me to take on this program; and my PhD co-supervisors for their ongoing support.

PROFESSOR JOHN SCOTT

Professor John Scott is the Head of the School of Justice at Queensland University of Technology (QUT). He is a sociologist by training and his current interests intersect the fields of criminology and health sociology, making this project a good fit with his expertise. More specifically, his current research interests are in the areas of drug supply, public health, and justice issues in remote communities.

He has published widely, including 27 books and major research reports and over 100 papers and book chapters, many with leading international journals and publishers. He has also had sustained success in attracting nationally competitive grants and industry funding. One of his more recent projects, funded through the Australian Institute of Criminology, was research on justice practices in the Torres Strait Region in the far North of Australia. He has been actively involved in institutional leadership roles, including leader of a Collaborative Research Network (CRN) and extended periods acting as a head of school at QUT and University of New England.

In terms of broader service roles, he has served as a Chief Examiner with the New South Wales Board of Studies and was a member of the Community Relations Commission, New South Wales. He is currently a member of the ARC College of Experts, edits the Routledge Series Crime and Justice Studies in Asia and the Global South, Co-Edits the Journal for Crime, Justice and Social Democracy and is Vice President of the Asian Criminological Society.



MONIQUE HOOPER RN MNP IPN

Monique is a nurse practitioner who identifies as Australian Aboriginal, specifically Arrernte, Arabuna and Larrakia. She has a background of preventative health with a strong focus on chronic disease.

As a Nurse Practitioner, Monique has extensive nursing history within Primary Health Care, Aboriginal and Torres Strait Islander Health and Women's Health across South East Queensland.

Monique is completing a Master of Philosophy as part of the National Palliative Care in Prisons Project.



PRESENTATIONS AND PUBLICATIONS

- Offner K, Fielding S, Phillips JL. Navigating cross-jurisdictional research complexities: the challenges of accessing data to enable a national understanding of palliative and end of life care provision in Australian prisons. Oral Presentation, 3 May 2022, Palliative Care Nurses Association Conference.
- Schaefer I, DiGiacomo M, Heneka N, Panozzo S, Lockett T, Phillips JL. Perceptions of people in prison about the provision of person-centred palliative care: a systematic review and meta-synthesis. *Oral presentation*, 3 May 2022, Palliative Care Nurses Association Conference.
- Schaefer I, DiGiacomo M, Heneka N, Panozzo S, Lockett T, Phillips JL. *Palliative care needs and experiences of people in prison: A systematic review and meta-synthesis*. *Palliative Medicine*. 2022;36(3):443-461. doi:[10.1177/02692163211068278](https://doi.org/10.1177/02692163211068278)
- Schaefer I and Haddock R (2022). *Deeble Issues Brief No 45: Ensuring the quality of palliative care in Australia's prisons*. Australian Healthcare and Hospitals Association, Canberra, Australia.



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In partnership with:

SPHERE

Sydney Partnership for
Health, Education,
Research and Enterprise



NEXT MEETINGS

Aboriginal and Torres Strait Islander
Community Engagement Strategy Working
Group

Tuesday 26 July 2022
14:00-15:00 AEST



Correctional/ Justice Health Services
Working Group

Tuesday 17 May 2022
14:00-15:00 AEST



National Consortia Project Advisory Group

Wednesday 3 August 2022
14:00-15:30 AEST



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