

PALLIATIVE CARE IN PRISONS PROJECT

QUT IN PARTNERSHIP WITH UTS: IMPACCT



Message from Project Lead

PROFESSOR JANE PHILLIPS

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

As we move towards the end of the year it has been a busy time for the project team, with ethics applications in several states now almost complete. Since our previous newsletter, we have received ethical Approval from the Western Australia Department of Justice Research Application and Advisory Committee (RAAC) and the Northern Territory Health HREC, and have submitted applications to Northern Territory Correctional Services, the Western Australian Aboriginal Health Ethics Committee and Tasmania Prison Health Service Research and Evaluation Committee. Preparation to collect data in South Australia and Victoria is well underway, with work to commence in the ACT in early 2023.

We have also conducted the Palliative Care Organisational Self-Assessment Telephone Survey in NSW, with representatives from Correctional and Justice Health Services and commenced collection of NSW hospital admission data.

In this newsletter, we introduce two of our project partners. Dr Jocelyn Jones from Curtin University, a Nyoongar woman with Wadjuk, Ballardong and Palyku connections to land in Western Australia. Jocelyn has contributed to invaluable research in Australian prisons, including consultation with and perspectives of people in prison regarding their healthcare priorities. Jocelyn played a key role in guiding the development of the PiP Project application to the Western Australia Aboriginal Health Ethics Committee and is a member of the National Aboriginal and Torres Strait Islander Leadership Group. Dr Tamsin Bryan leads the Palliative Care Consultation Service at St Vincent's Hospital Melbourne, and is a Site Principal Investigator for the PiP Project.

I would like to take this opportunity to farewell and thank Professor Liz Lobb for her involvement as an Investigator on the Project. Liz is retiring as Professor of Palliative Care (Allied Health) at Calvary Health Care Kogarah. Liz has worked clinically as a bereavement counsellor for 25 years, and led research in psycho-oncology and palliative care research for over 20 years. Her contribution to and support of the Palliative Care in Prisons Project has been greatly appreciated and we wish her every happiness in her retirement.

Thank you, as always, to all our investigators and project partners for providing their insight and expertise as we navigate transition into data collection. Wishing you all the very best over the upcoming holiday season.

Kind regards,

Jane Phillips

PROJECT PARTNER BIOGRAPHIES

DR JOCELYN JONES PhD, MAE

Dr Jones, a Wadjuk, Nyoongar woman from WA, is an epidemiologist and early career researcher with extensive experience working in health and justice, Aboriginal community-controlled health organisations and senior management in government. Jocelyn has expertise in both qualitative and quantitative research methods, and over the last decade has made significant contributions to Aboriginal health and social wellbeing through her work with Aboriginal female prisoners and juvenile detainees, mental health, child protection and maternal and child health. She has led high quality research and played a key role overseeing data analyses, interpreting results, conceptualisation of publications and dissemination of results.

Jocelyn is currently leading the adaptation of a mainstream high intensity violence program for incarcerated women. The program *Beyond Violence* was developed in the US and Jocelyn is responsible for adapting the program to ensure it is culturally safe for Aboriginal women. Jocelyn has also conducted community-based research with Aboriginal mothers and service providers documenting their challenges and barriers to access and provision of services. She has been key to consultations and negotiations with other Aboriginal leaders in the community around elements of various research projects, and has mentored and built capacity of non-Aboriginal researchers through provision of cultural mentorship.

Jocelyn's expertise in the prison health system has been acknowledged through her ongoing involvement in Office of the Inspector of Custodial Services prison inspections as an expert health consultant. She advises government through membership on the Closing the Gap, Justice Policy Partnership, the National Prisoner Health Data Collection committees and the National Aboriginal and Torres Strait Islander Custodial Working Party. Jocelyn is a current member of the Indigenous Data Network National Steering Committee.



CONSULTATION WITH PEOPLE IN PRISON ABOUT THEIR HEALTH PRIORITIES

As part of her social justice work, Jocelyn has co-authored an article describing consultation of people in prison about their health priorities to inform research priority-setting. Increased focus on care equity and participation of under-served populations in decision-making about health priorities led Jocelyn and her co-authors to use an innovative strategy for stakeholder consultation with people in prison.

'Citizen's juries' were convened in which representatives of a community (selected prisons) come together to advocate for community issues that were of collective importance. Six prisons in NSW and QLD participated in the priority-setting exercise, with 50 participants engaging in six citizen's juries lasting seven to eight hours. Juries were asked to discuss and rank health priorities within their facility that should be a priority for future research and action.

Juries in all six facilities nominated Mental Health as the most pressing issue, citing the need for better access to medication and specialists, leadership and peer support, and education and awareness on trauma issues. Other priorities included alcohol and drug issues, health education, cognitive and intellectual disabilities, and health-care services.

This work presents a novel and rigorous strategy to seek detailed and meaningful input from people in prison about their perspectives on health and healthcare. The article, published in the *Lancet: Public Health* journal can be found [here](#).

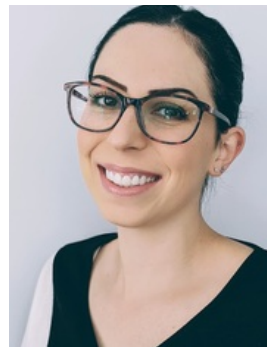


SPEAK UP: THE IMPORTANCE OF SPEECH PATHOLOGY IN PALLIATIVE CARE

Speech Pathology Australia's podcast 'Speak Up' this year explored the role of speech pathology in palliative care and its importance in maintaining communication and swallowing in patients nearing the end of life.

Dr Laura Chahda (photo on left, University of Melbourne) and Dr Lindsay Carey (photo on right, La Trobe University) talk with Senior Speech Pathologists Lisa Terry and Samantha Bradley (Monash Health), discuss the findings of their article "Speech-language pathologists and adult palliative care in Australia". Using a mixed methods approach, the authors conducted a scoping literature review, demographic survey of speech and language pathologists and semi-structured interviews to explore the perspectives and experiences of speech and language pathologists in providing speech pathology to people with palliative care needs.

If you would like to listen to the podcast, you can find it [here](#). If you would like to read the published article, you can find it [here](#).



PROJECT PARTNER BIOGRAPHY

DR TAMSIN BRYAN

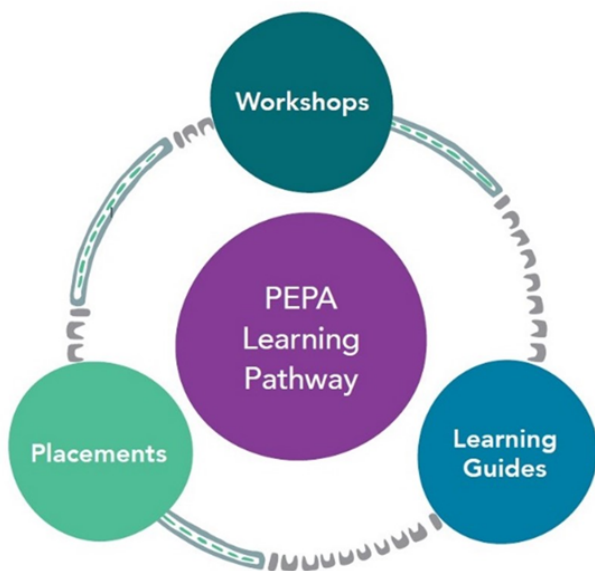
Dr Tamsin Bryan is a Palliative Medicine Physician at St Vincent's Hospital Melbourne where she has been the lead physician for the Palliative Care Consultation Service for 13 years. She has an interest in the provision of equitable and high-quality palliative and end of life care for under-served patient groups, in particular those experiencing incarcerated. Tamsin has extensive experience in the provision of palliative care for prisoner patients admitted to the St Vincent's Hospital maximum security prison ward.

More recently, her clinical work has grown to include provision of palliative care for those admitted to the St John's Inpatient Unit at Port Phillip Prison in Victoria. Tamsin has ongoing involvement in research undertaken by the Palliative Nexus research team, The University of Melbourne, focused on investigating palliative and end of life care for hospitalised prisoner patients.

Tamsin also leads an implementation and evaluation project that supports a model of best practice palliative and end of life care within the St John's Inpatient Unit at Port Phillip Prison.



The Program of Experience in the Palliative Approach (PEPA)



PEPA/IPEPA takes a strategic approach to education and training of the healthcare workforce and delivers Placements, Workshops and self-directed learning guides for priority healthcare provider groups across primary, secondary and tertiary settings. Our learning is tailored for specific health professional groups and care contexts. For more details on all their education and training initiatives, go to the [website](#).

IPEPA is a grass-roots approach to breaking down the barriers to palliative care for Aboriginal and Torres Strait Islander peoples. Informed by community, for community, IPEPA is embedding Australian Indigenous knowledges across all PEPA resources and facilitating two-way learning dedicated to building the cultural safety capacity of the non-Indigenous workforce and supporting the Aboriginal and Torres Strait Islander workforce to walk alongside those living with serious illness and at end of life.

More information about IPEPA is available [here](#).

PEPA Program of Experience in the Palliative Approach

IPEPA Indigenous Program of Experience in the Palliative Approach

Funded by the Australian Government Department of Health

REPRESENTING THE PIP PROJECT

In October, Prof Jane Phillips presented to the Maridulu Budyari Gumal (Sydney Partnership for Health, Education, Research and Enterprise) SPHERE Clinical Advisory Group Presentation day on behalf of the Palliative Care Clinical Advisory Group about the PiP Project.

Maridulu Budyari Gumal is comprised of sixteen organisations committed to research, innovation and education focusing on a wide range of pivotal health issues. During their annual reporting meeting, Jane provided members with an overview of the Project; describing its inception, planning, co-design and progress to date.

Jane and Project Manager Kim Offner also participated in the National Palliative Care Projects Grant forum in October, hosted by Palliative Care Australia. Representatives from all National Palliative Care Projects met to report on their progress, and discuss implementation, dissemination and sustainability of project outputs. The forum was a valuable opportunity to share learnings and experiences.



Maridulu Budyari Gumal
Working together for good health and wellbeing

In response to COVID-19, University of Melbourne research Group Palliative Nexus started 'Pal-spectives', a series of online seminars which showcases recent research and facilitates broader conversations about current and future palliative care. You can find a list of their previous recorded sessions [here](#).

In the latest Pal-spectives event, PiP Project Site Investigator Tamsin Bryan presented on her work with PiP Co-investigators Prof Jenny Philip and Dr Stacey Panozzo about the perceptions and experiences of clinicians who provide care to people in prison with palliative care needs while they are admitted to hospital.

Their work identified key factors that restricted the clinician's ability to advocate for a patient, and the limitations imposed by the correctional security protocols on care that was available at the end of life. Lack of clarity about protocols and responsibilities could make it difficult to facilitate care, and clinicians discussed how they manage knowledge of a person's offense with their responsibility to provide care. Late recognition of dying, difficulties in symptom management and tightly restricted family visits were also pivotal issues identified.

If you would like to hear more about this work, you can watch Tamsin's presentation [here](#), or read the published [article](#).

WEBINAR PRESENTATION FOR PALLIATIVE NEXUS



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In partnership with:

SPHERE

Sydney Partnership for
Health, Education,
Research and Enterprise



NEXT MEETINGS

Correctional/ Justice Health
Services Working Group

Tuesday 14 February 2022
14:00-15:00 AEDT



Aboriginal and Torres Strait
Islander Community
Engagement Strategy
Working Group

Tuesday 28 February 2022
14:00-15:00 AEDT



National Consortia Project
Advisory Group

Wednesday 22 March 2022
14:00-15:30 AEDT



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