

CARE ECONOMY RESEARCH INSTITUTE



Care Economy
Research Institute

2024- 2025



REPORT



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FOREWORD

DEPUTY VICE-CHANCELLOR RESEARCH AND INDUSTRY ENGAGEMENT

As we look back on the past 18 months at the Care Economy Research Institute (CERI), I am proud of the opportunities it has created and the hard work and dedication of the team in addressing challenges that span the full scope of the care economy.

The work of the Institute reinforces what we have long understood—that both paid and unpaid care are central to our economic growth, and that nearly all Australians and their communities are affected by care in its many forms. Through a multi-disciplinary approach and forging impactful industry partnerships, we are bringing together health and social care research to reshape the narrative around care and its profound impact on human development and economic security.

Though there are many noteworthy achievements, highlights from this year include how our research collaborations with industry have sparked positive change. This was demonstrated by pioneering projects such as the Victorian Virtual Emergency Department (VVED) initiative, which has transformed the delivery of emergency care and that allows non-urgent patients access to emergency care from anywhere in Victoria, 24 hours a day.

The VVED was a winner at the Australian Financial Review's 2024 Higher Education Awards in the Industry Engagement category. It is an Australian-first service, bringing together La Trobe University's leading digital and research expertise with the real-time needs of Northern Health patients to reshape the delivery of emergency care.

Other examples include the invitation to CERI to be involved in the development of the care economy roadmap for the Malaysian Government and the framework for the Commonwealth National Care and Support Taskforce.

A final mention goes to the successful awarding of \$35 million to the Care Economy CRC, which will be located at La Trobe and will foster collaboration with wide-ranging stakeholders from across Australia including private and public companies, partner universities, councils of social service, regulators, government agencies, consumer peak bodies and community groups. Congratulations to all on this wonderful achievement.

I want to express my gratitude to everyone who has contributed to the success of CERI. I look forward to researchers, supporters and leaders breaking new ground in the year ahead to create better outcomes for all and shape a stronger future across the care economy.

Professor Chris Pakes

Deputy Vice-Chancellor Research and Industry Engagement



DIRECTOR'S FOREWORD

2024 and 2025 marked a significant milestone for the Care Economy Research Institute, as our growth to over *150 research members and 120 industry partnerships* surpassed our initial expectations since our establishment in mid 2023. This significant progress underscores the importance of the care economy as Australia's largest and fastest-growing industry, highlighting the urgent need for us to unite and tackle its biggest challenges.

Our research leadership and efforts in defining the scope and significance of the care economy, making visible the often-unseen data on health and social care, fostering collaborative research across international borders, and developing critical industry partnerships formed the foundation of our collective work.

Key achievements highlighted in this report include:

Pioneering Progress: We were proud to be awarded \$35 million in federal funding to set up the Care Economy Cooperative Research Centre (CRC). This \$129 million, 10-year initiative brings together 60 organisations from across Australia to collaborate on advancing care technologies, developing data-driven solutions, and driving workforce innovation—addressing urgent challenges like rising demand and critical skills shortages in the sector.

Building Alliances: The Institute has enhanced its collaborative efforts with like-minded organisations across both the government, public and private sectors, both in Australia and internationally, including the United Kingdom, Canada, the United States, and ASEAN nations.

Driving Impact: Our research continues to tackle the most urgent challenges facing health and care workforces, as well as the delivery of services. We share some of our key achievements and results of research translation in this report and on our website.

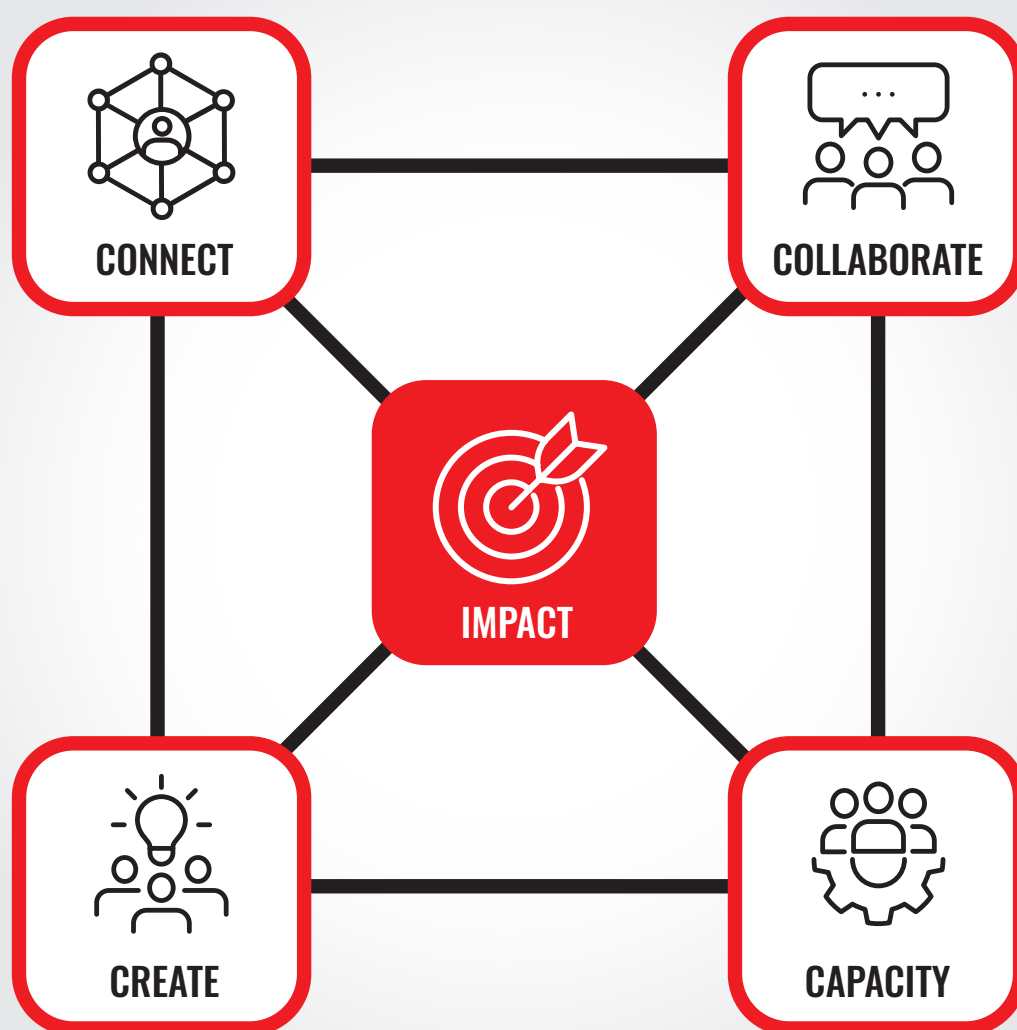
Exploring New Approaches: We remain focused on integrating technology and translating best practice evidence in 'care,' with exciting new projects underway in the AI, machine-learning and digital health sectors.

Amplifying Change: We continue to ensure the voices of our care participants, carers, care providers, researchers, and other stakeholders are heard in government discussions, with their recommendations reflected in frameworks and policies.

It has been an honour to lead the Institute to make a difference to the communities that we serve. My heartfelt congratulations once again to our dedicated staff, members, students, stakeholders, and industry partners who continue to believe in and contribute to our success in creating a sustainable and compassionate care economy. I'm deeply proud of what we've accomplished together.

Professor Irene Blackberry

Director, Care Economy Research Institute and
Chair, John Richards Centre for Rural Ageing Research



We believe that the scope of the care economy encompasses all essential **social, health, and wellbeing support services** provided to individuals of all ages, abilities, and diverse backgrounds. Our perspective emphasises the lived experiences of all those involved in care, highlighting both the challenges and benefits of caring for individuals, communities, and broader society. We view caregiving as crucial for enhancing workforce productivity, and future-proofing economic growth, while serving as a foundation for advancing systemic gender equality.

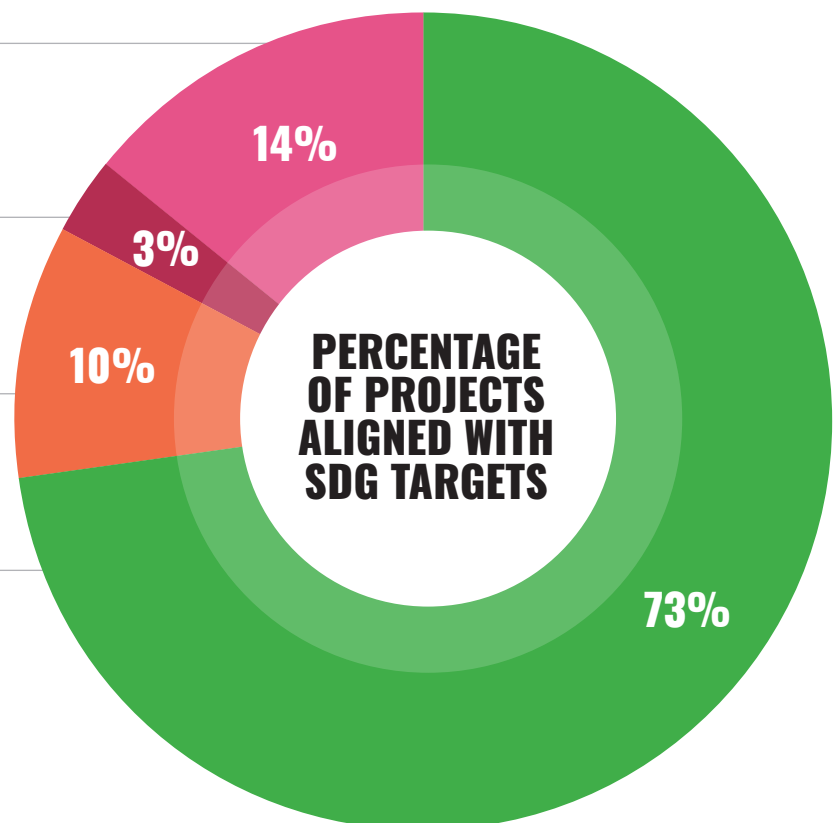
VISION

Our vision is to improve care participants' health and wellbeing and to drive economic growth across the health and social care sectors.

MISSION

Our mission is to provide an ecosystem and platform for researchers, consumers and industry partners to co-design, transform, and implement the next generation of services across the care economy, into an optimal, innovative and equitable 21st century model of care.

RESEARCH IMPACT



Our researchers and industry partners are collaborating to deliver against the UN Sustainable Development Goals.

EXAMPLES OF RESEARCH IMPACT

Green Connect Dementia Respite	A not-for-profit pilot project delivering dementia inclusive nature-based activities and respite care. This service, which is supported by La Trobe researchers, was recently recognised as an innovative first of its kind at the 2024 Future Ageing Conference .	
'Voices from the Field' Toolkits	The Indigo 4Ms Age-Friendly Health Care toolkits are the latest addition to the resources supporting integrated and comprehensive care for older people living in rural north-east Victoria and build on the collaborative efforts of La Trobe researchers and the ten consortium partners.	
The Victorian Virtual Emergency Department (VVED)	A collaboration between La Trobe researchers and Northern Health to triage patients with non-life-threatening emergencies virtually to relieve pressure on emergency waiting rooms and treat people from the comfort of their home. Winning the Industry Engagement category at the Australian Financial Review's 2024 Higher Education Awards , the VVED has helped 86% of its patients avoid a trip to the hospital.	
Factors Affecting Community Treatment Orders Research Study	This first of its kind study examines the disproportionate impact of community treatment orders (CTOs) on certain groups in Australia. A team including La Trobe researchers have contributed to the World Health Organisation's Guidance on Mental Health Policy and Strategic Action Plan as well as a submission to the New Zealand Parliament on Mental Health Legislative Reform .	
Equally Well Consumer Resource	This resource was co-designed by a team of researchers and people with lived experience to support users to advocate for their healthcare needs in appointments with doctors and specialists. By supporting people to prepare for appointments, the resource equips users to cut through barriers in clinical settings and prioritise their needs.	
Lived Experience Capacity Building and Mentoring Program	A pilot initiative aimed at building researchers' confidence and capability to meaningfully engage lived experience experts in research, positioning La Trobe to lead in best-practice public involvement. More meaningful public involvement makes research more relevant, inclusive, and better aligned with the real needs and priorities of the communities it aims to support.	
The Care Data Portal	This initiative has been developed by La Trobe researchers to simplify access to existing care data and identify gaps in datasets relating to informal care networks and carers. Creating a framework for under-researched aspects of the care economy, the Care Data Portal will support future research and policy development.	
Patient Voice Report 2025	A collaboration between Patients Australia and La Trobe researchers examining Australians' experiences with out-of-pocket costs for GP, specialist care, and hospital stays. The report explores the financial strain, decision-making impacts, and perceptions of fairness, transparency, and reform, while amplifying patient voices to support advocacy for more affordable, accessible, and equitable healthcare.	

Care Economy Scoping Review	This review, undertaken by researchers at La Trobe, explores global understandings of the care economy highlighting how it is defined, undervalued, and heavily dependent on informal or invisible labour. By shedding light on these dynamics, the study aims to reshape the narrative around care and influence the direction of global <u>care economy</u> initiatives.	
Online Training for Informal Carers Narrative Review	A cross-disciplinary initiative exploring the availability and effectiveness of free, accessible training for <u>informal carers</u> in Australia. By assessing existing support and the impact of e-learning, the findings informed La Trobe University's recommendations for the National Carer's Strategy.	
Aged Care Workforce Shortages	A study undertaken by La Trobe researchers estimating the sector <u>workforce shortages</u> facing rural and remote areas alongside the challenges of complex care needs and limited services. This research provides rigorous evidence for planning and policy development of equitable aged care service delivery.	
Ovens Murray Area: Community Needs Assessment	A collaborative research project undertaken by La Trobe researchers with Ovens Murray Child and Family Services Alliance to prioritise critical social issues facing the local government area and identify localities with particularly high needs. This <u>practical tool</u> is designed to help service providers, policymakers, and community leaders move from individual responses to collective impact.	
What Works in Youth Violence Report	La Trobe University and the Department of Families, Fairness and Housing (Ovens Murray – East Division) conducted research to guide strategic investment in youth services. The <u>report</u> identifies evidence-based responses to youth violence, supporting more integrated, effective local services to create lasting, positive change in the lives of at-risk young people.	
Government of Malaysia Care Economy Roadmap	An international collaboration between La Trobe and The Asia Foundation supporting the Malaysian's Government launch of their <u>Care Economy Roadmap</u> during their ASEAN Chair term. This roadmap will be launched at the Care Conference in Malaysia on the International Day of Care and Support later in 2025.	
Care Conference and Home-Based Care Survey	This first-of-its-kind survey maps home-based care models across life stages in Malaysia and Australia, identifying service gaps and improvement opportunities, and will be presented at an ASEAN Care Conference that brings together key stakeholders across the care economy.	
Long Term Aged Care Handbook	An international collaboration of authors examining the impact of an ageing population worldwide. Contributions from La Trobe researchers on <u>projected service gaps</u> in Australia inform a global overview of care systems, identifying key challenges and highlighting ongoing improvements and funding strategies. This handbook will support the development of evidence-based policies for the care of older adults.	

OUR TEAM



Professor Irene Blackberry,
Director



Dr Anne-Marie Laslett,
Associate Director,
Graduate Researchers



Dr Chris Maylea,
Associate Director,
Partnerships, Community
and Industry Engagement



Professor James Boyd,
Domain Lead,
Care Technology



Professor Meg Morris,
Co-Domain Lead,
Care Workforce



Dr Rachel Winterton,
Co-Domain Lead,
Care Workforce



Dr Sarah MacLean,
Co-Domain Lead,
Care Experience



Professor Lisa Brophy,
Co-Domain Lead,
Care Experience



Professor Leeanne Carey,
Domain Lead,
Care Delivery



Professor Alex Maritz,
Domain Lead,
Care Economics,
Social and Policy



Jennifer Boak,
Research Fellow



Karen Barclay,
Research Officer



Kate Syme-Lamont,
Research Officer



Anna Joske,
Senior Admin Officer



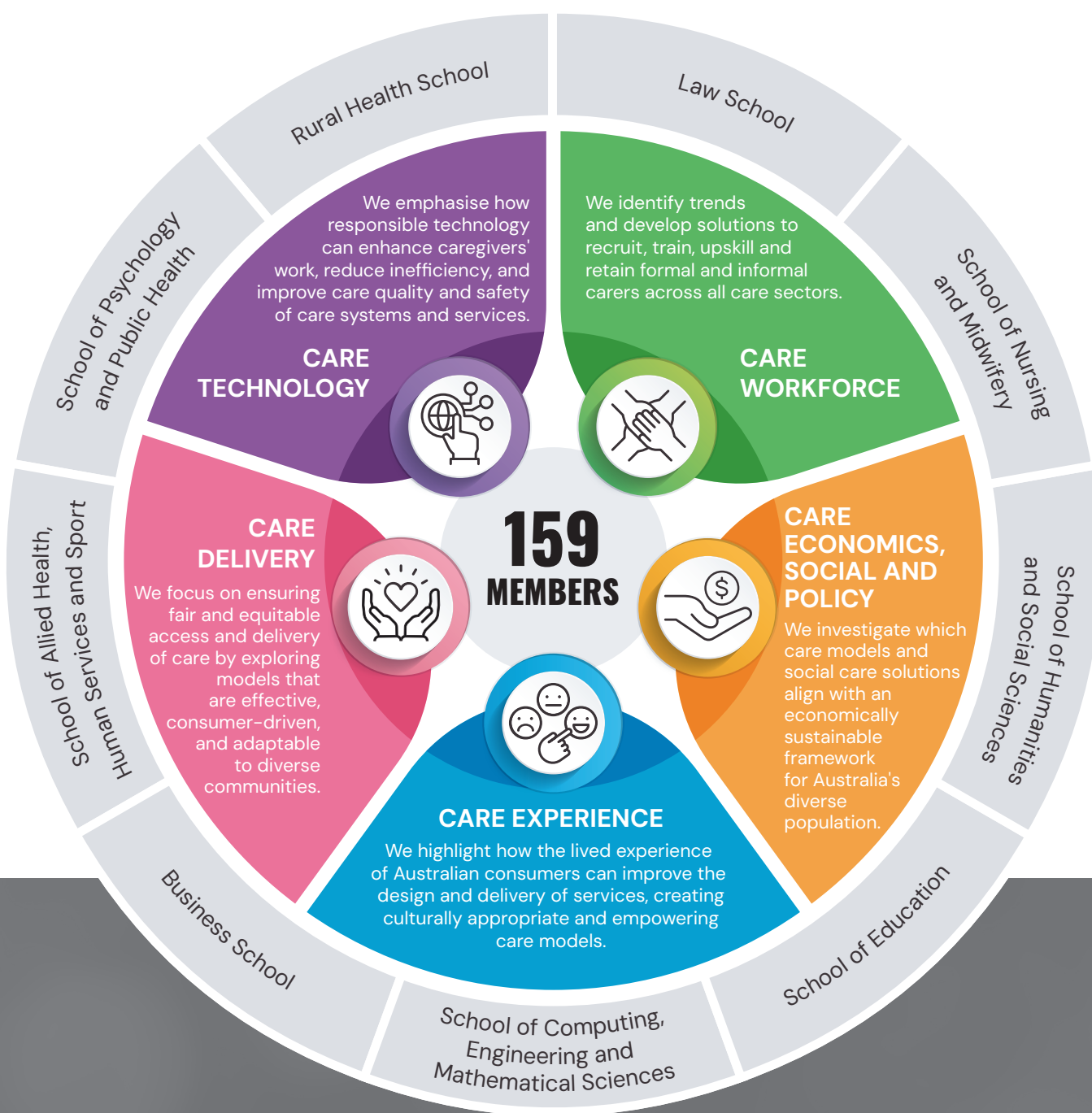
Clair Overy,
Manager

Dr Stacey Rich,
Research Fellow
(June 2023 to June 2024)

Gayle Erwin,
Senior Admin Officer
(September 2023 to
July 2024)

Makayla Grace,
Senior Project Officer
(September 2023 to
May 2024)

OUR RESEARCH DOMAINS



Our world-leading researchers conduct major research programs to co-create innovation and evidence with people with lived experience and industry partners. We recognise that the major challenges facing the care economy sit across five broad domains. Tackling these in a whole systems approach means we can work towards achieving positive outcomes and better impact.

SNAPSHOT OF ACHIEVEMENTS



134

RESEARCH
PROJECTS



1074

ARTICLES
(74% IN Q1 JOURNALS)



24

HIGHER DEGREE
RESEARCH STUDENTS



18

EXTERNAL
GRANTS



\$17.8M

RESEARCH
GRANTS

\$129M

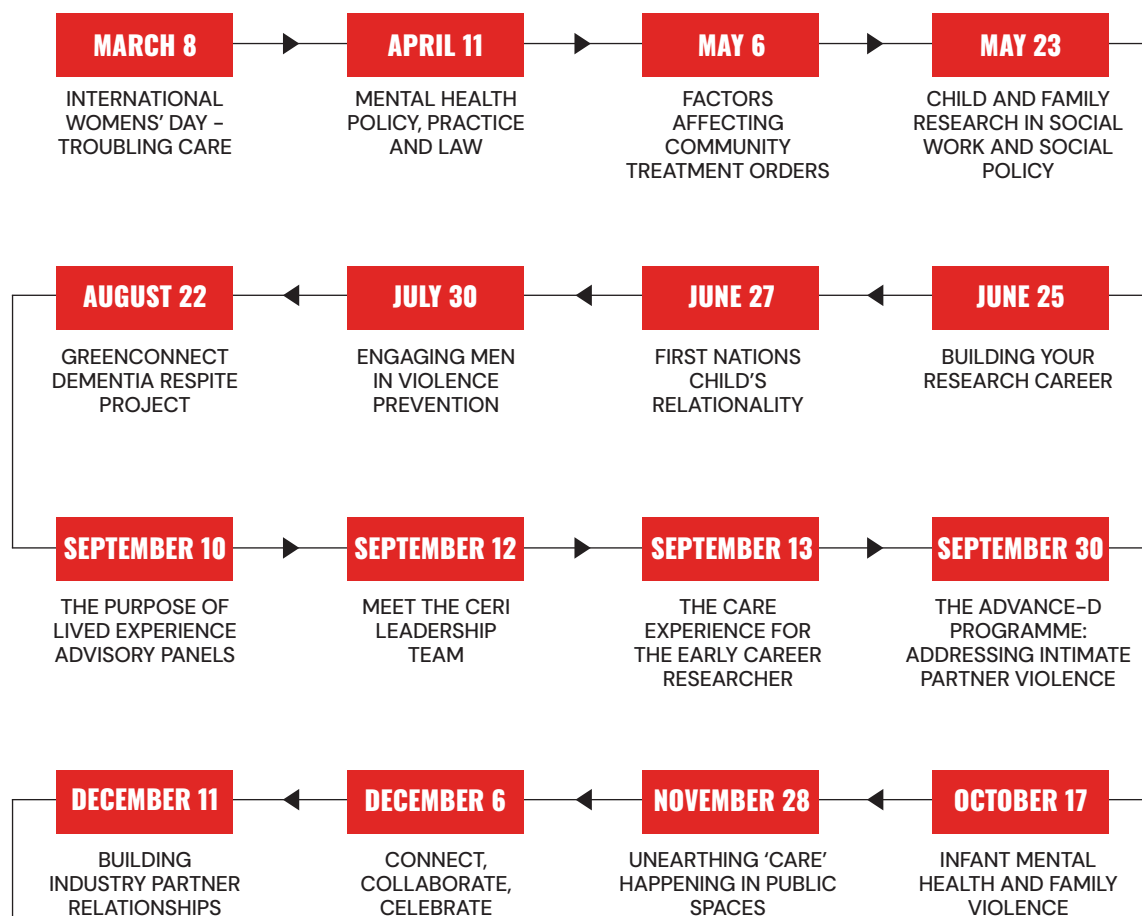
TO ESTABLISH
CARE ECONOMY
COLLABORATIVE
RESEARCH CENTRE

THE GLOBAL REACH OF OUR MEMBERS' RESEARCH COLLABORATION

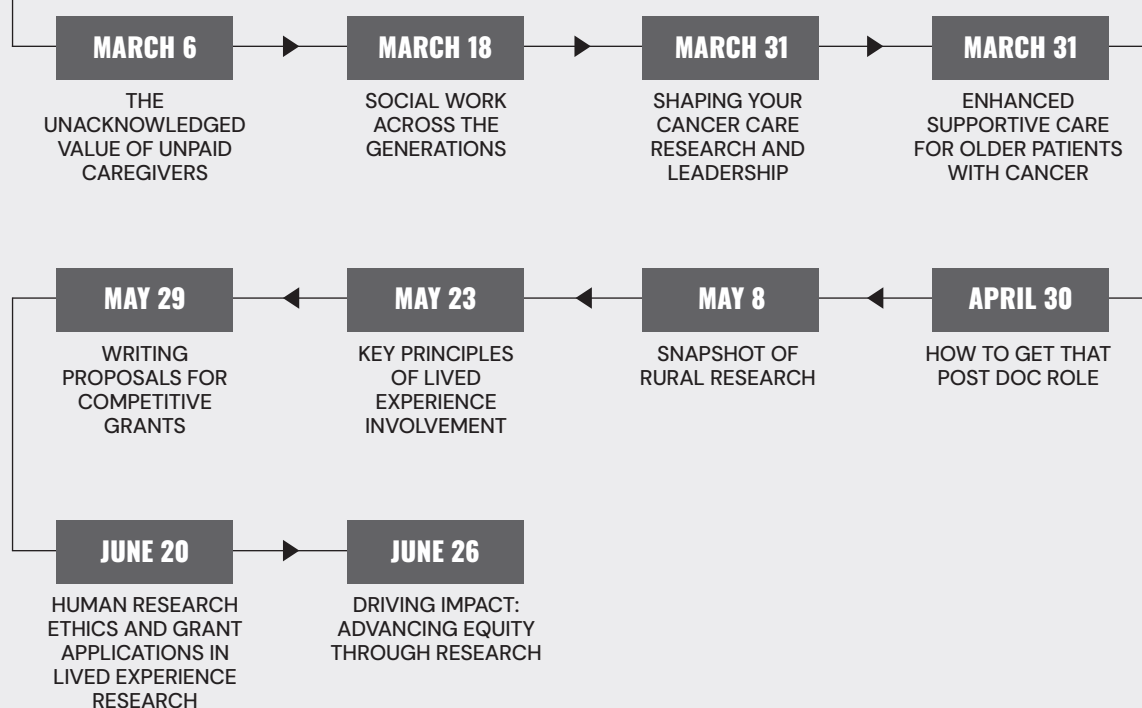


RESEARCH ENGAGEMENT

2024



2025



CARE ECONOMY COLLABORATIVE NETWORK

The Care Economy Collaborative Network (CECN), an initiative of CERl, is reshaping the way care needs are addressed in Australia. Expanding to 100 members in 2024, the network now unites academics, government entities, for-profit and not-for-profit organisations to connect and collaborate on research that is most meaningful to them.

To ensure we can sustain and strengthen this network, the Institute has launched an initiative to engage senior leaders from across care sectors, gathering their insights on what they need from the network and how we can best offer support. The findings from this analysis will guide our efforts into 2025 and beyond.

What we know so far is that the strength of the CECN lies in building connections between organisations, highlighting member capabilities, promoting knowledge sharing, and representing smaller service organisations in larger conversations. Join the network to be part of the dialogue.

Join the CECN today and realise the benefits of membership, including:

- building connections with businesses, service providers, clinicians, academics, and researchers.
- establishing Communities of Practice to address emerging issues, and to share and test novel solutions.
- participating in events, forums, and professional development opportunities be informed about the latest evidence and innovation in care.
- opportunities to participate in collaborative research projects as they arise.



113 NETWORK
MEMBERS

"It has been great partnering with the Care Economy Research Institute on important initiatives related to healthcare workforce training and digital health technology. Choice



Aged Care is a progressive organisation and in working with La Trobe, we have enjoyed collaborating with like-minded researchers who also value innovative and practical projects that are responsive to the care sector's emerging needs in supporting at-risk consumers".

Michael Bonner, CEO and Owner, Choice Aged Care & National Care Academy RTOs

"Being a part of the Care Economy Collaborative Network has broadened our adult learning centres' perspective, helping us see how our work fits into larger



research trends. It has facilitated valuable knowledge exchange, connecting us to experts and resources we might not have had access to otherwise. This collaboration has enriched our practice and allowed us to contribute more meaningfully to the broader educational landscape. We very much appreciate the time CERl staff allocated to our Professional Development Day for the Learn Local Care and Support Industry Practice Network in late 2024 and we look forward to the next step in our collaboration."

Olivia Hurrell, Partnerships Coordinator, Bass Coast Adult Learning

If you are in industry and are interested in changing care for the better, consider joining the CECN. Use the QR code to register.



CASE STUDIES

BUILT FOR BETTER AGEING: A REUSABLE WEARABLE FOR SAFER LIVING



CARE
TECHNOLOGY



Project title: **Smart wearables for fall detection in older adults**

Investigators: Dr Shanmuga Sundar Dhanabalan, Dr Andrew Tucker, Prof. Aniruddha Desai, Prof. Prakash Veeraraghavan, Prof. Irene Blackberry, Dr Tshepo Rasekaba

Timeline: January to December 2025

Location: Victoria

Partners: Sleepтите Pty Ltd



CONTEXT

Australia's population is ageing rapidly, with 4.2 million people aged 65 and over—currently 16% of the population—a proportion expected to grow to 21–23% by 2066. This demographic shift is increasing pressure on aged-care services and highlighting the need for innovative healthcare solutions. Among the most serious health risks for older adults are falls, which often result in severe injuries, hospitalisations, and a loss of independence. Smart wearables present a proactive approach by offering continuous monitoring, early fall detection, and real-time alerts to caregivers or emergency responders. These devices support safer, more independent living, reduce healthcare costs, and provide peace of mind for families. In 2020 alone, falls among older Australians cost the healthcare system over \$2.3 billion, and as the population continues to age, smart wearables play a vital role in promoting healthy, secure ageing.



APPROACH

Building on their successful collaboration, Sleepтите and La Trobe University researchers are developing discreet, privacy-preserving technologies to remotely monitor aged care residents while addressing their individual health and support needs. Their latest project focuses on a low-cost, efficient, and reusable wearable device designed to prevent and detect falls. The device is evolving into a consumer co-designed wearable device that analyses movement patterns, detects falls, and alerts carers in real time. By promoting reuse and repair, the design helps reduce electronic waste and supports more sustainable consumption habits. Through advances in wearable sensor technology and real-world testing, this research–industry collaboration is delivering practical solutions to key challenges in aged care.



OUTCOMES

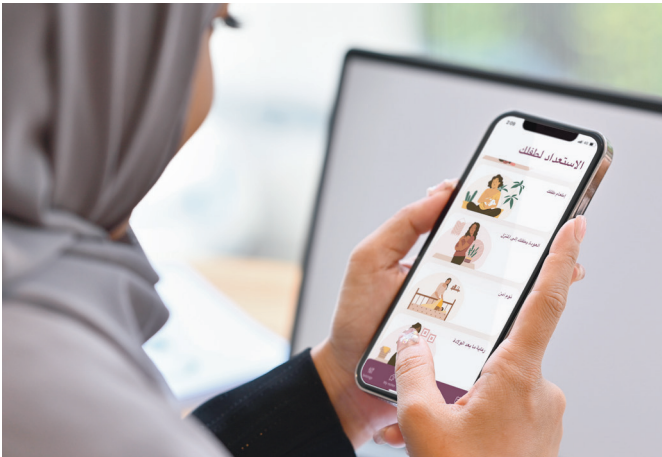
The smart wearable reduces the need for constant visual checks, easing staff workload and enabling faster responses to high-risk situations. Its intelligent alert system detects likely falls or unusual movement activity, helping carers prioritise attention where it's most needed. This leads to more efficient delivery of care and improved safety for older adults. By eliminating the need for cameras the device enhances privacy and comfort, resulting in a more dignified and less intrusive care experience in both residential and home settings. The wearable's soft, flexible design improves user comfort and supports long-term use. Importantly, the technology is scalable and cost-effective, making it suitable for widespread adoption. Beyond aged care, the platform has potential for broader medical applications, including chronic disease monitoring and rehabilitation.

"Sleepтите is committed to supporting ongoing research and development into innovative assistive technology to improve safety and wellbeing in aged and disability care."

Dr Andrew Tucker, Director Sleepтите



SCALING SMART: MULTILINGUAL MATERNAL CARE



Project title:	Mama Talk app: Scaling up for Hazaragi and Dari speaking women
Investigators:	Emma Koster, Dr Natalie Araujo, Prof. Raelene Wilding
Timeline:	June 2024 to December 2025
Location:	National
Partners:	Good Hood



CONTEXT

In Australia, 23% of the population speaks a language other than English at home, and 872,000 people report limited or no English proficiency. Government and health services often struggle to deliver timely, reliable information in languages other than English, compromising the health and safety of some of the country’s most marginalised communities. Pregnant and post-natal women are particularly vulnerable, with research highlighting a lack of language support in maternity care. This gap can lead to serious social, mental health, and obstetric risks. In Victoria, one in three women who give birth are migrants or refugees. Many of these women struggle to access essential translation and interpretation services. This systemic failure deepens health inequities and puts both mothers and babies at risk.

“There are many pregnancy apps, but MamaTalk isn’t just giving generic advice or information. It isn’t only telling me the size of a baby. It is beautifully tailored to my needs as an Arabic woman in Australia.”

Evaluation participant



APPROACH

MamaTalk is a prototype app conceptualised by Emma Koster of Good Hood in 2022. Designed for Australia’s healthcare context, it delivers accessible, culturally sensitive antenatal and postnatal information in multiple formats and languages for women from migrant, refugee, and asylum seeker backgrounds. The app was developed through a robust co-design process involving healthcare professionals, community organisations, and women from non-English speaking backgrounds, ensuring it meets diverse literacy and communication needs. Following a successful La Trobe researcher evaluation of the original Arabic-language pilot—developed with support from the Australian Red Cross Humanitech Program—additional funding was secured to expand MamaTalk. This phase has involved creating, testing and evaluating content and resources in Hazaragi and Dari.



OUTCOMES

This initiative has improved access to culturally relevant, respectful health information for underserved women during pregnancy and the postnatal period. It supports MamaTalk’s mission to enhance health literacy, foster self-advocacy, and improve outcomes for women from migrant, refugee, and asylum seeker backgrounds. Feedback from users of the Arabic pilot and ongoing Dari and Hazaragi versions has been overwhelmingly positive. Evaluations show that women not only gained confidence and agency but also used the app in creative, unexpected ways to better suit their needs—extending its usability beyond initial expectations. These outcomes highlight the app’s impact as both a health education tool and a catalyst for empowerment. Scaling the project has required sustained commitment, strong community partnerships, and creative funding, demonstrating that co-designed, community-led solutions can drive lasting, scalable impact.



CLOSER CARE: HOW PARAMEDICS ARE CHANGING COMMUNITY HEALTH



Photo courtesy of Gateway Health

Project title:	CP@clinic: Community Paramedicine in Australian Community Health
Investigators:	Prof. Evelien Spelten, Adjunct Prof. Louise Reynolds, Adjunct Assoc. Prof. Ruth Hardman, Dr Laura Hemming, Prof. Leigh Kinsman, Prof. Gina Agarwal.
Timeline:	2022 to 2027
Location:	Victoria
Partners:	Violet Vines Marshman Centre for Rural Health Research, Safer Care Victoria, Sunraysia Community Health Service, Primary Care Connect, Gateway Health, Grampians Community Health, McMaster University, Department of Family Medicine

CONTEXT

Rural and remote Australians experience significant health inequities compared to those in metropolitan areas, largely due to geographic isolation and limited access to essential healthcare services. Contributing factors include longer travel times to medical facilities, chronic shortages of healthcare professionals, reduced access to specialist and preventative care, and lower per capita healthcare funding. In this context, the *CP@clinic* model—developed by the Department of Family Medicine at McMaster University—offers a promising solution. Successfully implemented in Canada and the UK over the last decade, *CP@clinic* brings proactive, community-based healthcare to underserved populations by enabling paramedics to deliver preventative care, chronic disease monitoring, and follow-up support in non-emergency settings, relieving pressure on emergency departments and improving overall health outcomes. By realising their integration into primary care services, community paramedics can offer timely, culturally appropriate, and cost-effective care close to home.

“[CP@clinic] catches people before health problems arise [...] it’s getting to the people that really need it.” External stakeholder

APPROACH

La Trobe University researchers, together with McMaster University, adapted co-implemented and evaluated a pilot *CP@clinic* program in partnership with Sunraysia Community Health Services (SCHS). Uniquely, this version of *CP@clinic* operated outside of an ambulance jurisdiction and was delivered within a community health setting. The pilot expanded to five clinic sites across the Mildura local government area, offering free, walk-in access to healthcare for residents. A feasibility study assessed key implementation factors—including acceptability, adoption, appropriateness, fidelity, costs, penetration, and sustainability—drawing on both quantitative and qualitative data from clients, SCHS staff, and stakeholders. Based on strong feasibility findings, the program was deemed ready for broader rollout to other communities. However, ongoing data collection is needed to assess its long-term impact on health outcomes and service utilisation. There is a unique opportunity for registered paramedics to be better utilised in primary care settings, given that the current pipeline of graduating students outnumbers the available jurisdictional employment roles.

OUTCOMES

The initial trial of the Australian adaptation of the *CP@clinic* program showed benefits across four areas: clients, community, paramedics, and the broader healthcare system. The evaluation found that 36% of participants had no regular GP, highlighting the model’s reach into underserved populations. Delivered in a community rather than medical setting, the program removes barriers like appointments and lack of bulk billing, creating a more accessible and welcoming environment. It also builds social connection, with community partners working alongside paramedics to run walking groups, provide food relief, and host meals. For paramedics, it offers professional development and long-term patient engagement, helping reduce burnout and improve workforce retention. The program is now expanding to four more community health services to test its effectiveness in managing chronic conditions by improving access to care, including impact on ambulance callouts and emergency department presentations.



CLIMATE, CRISIS, AND CARE: SERVICE STRAIN IN A CHANGING AUSTRALIA



Project title:	Building climate resilience in the social and community care workforce
Investigators:	Prof. Sarah MacLean, Julia de Nicola, Dr Kimberlea Cooper, Dr Heather Downey, Dr Jacqui Theobald, Dr Lisa de Kleyn, Eleanor Costello, Prof. Lauren Rickards
Timeline:	October 2023 to June 2025
Location:	National
Partners:	Alcohol and Drug Foundation (ADF)

CONTEXT

Climate change is increasingly affecting our health and social care sectors, placing new pressures on the broader care workforce who support marginalised populations. As extreme weather events, environmental degradation, and related social disruptions become more common, the care workforce is facing heightened demand for services. How this impacts people who use substances is poorly understood, but existing studies indicate that increased substance use is likely during natural disasters that are becoming more frequent, alongside unplanned substance withdrawal and exacerbated mental health conditions. These challenges are compounded by the emotional toll of supporting individuals experiencing climate-related trauma and instability, often without adequate systemic support or training. This project seeks to identify the knowledge and skills that social workers and other community sector care staff require to support community resilience and sustainability in the care workforce.

APPROACH

Building on an initial pilot study and scoping review that examined the effects of climate change and extreme weather events on substance use—finding short-term increases in alcohol and other drug (AOD) use, alongside disruptions to treatment services that compounded mental health issues and led to greater hospitalisations and vulnerability—this collaboration between La Trobe researchers and ADF is now focused on identifying the support needs of Local Drug and Alcohol Teams (LDATs) across Australia. Using a narrative approach to explore how individuals make sense of their social experiences, these frontline perspectives and insights reveal how extreme events disrupt treatment, increase service user distress, and strain already limited resources. Their narratives help reveal not only the systemic gaps and emerging pressures within the sector but also the adaptive strategies that can inform more resilient, responsive, and sustainable service models in the face of escalating climate disruptions.

OUTCOMES

While floods and other emergencies affecting the lives of potential interviewees have made recruitment to the study challenging, they have offered valuable insights into the real-time impacts on communities and care workers. Emerging themes highlight how layers of disadvantage are intensified by repeated climate-related emergencies, with grief over the loss of community and ecosystems deeply affecting people's sense of place and well-being—factors that can contribute to increased substance use. Narratives also reveal that short-term, reactive funding—often redirected to new crises—undermines long-term, generational support for highly traumatised communities. A review of international literature indicates that agencies are generally underprepared for climate emergencies, underscoring the need for further research into how local responses can better support community resilience.

“You go to a forum like that with 80 people, ... they’re all, everybody in the sector is traumatised, yeah. ... Because of the floods that they’ve really had five years of ... drought, fire, flood. We haven’t, the sector hasn’t, had a break for five years.” LDAT worker



BEYOND THE HORIZON: EMPOWERING RURAL AGED CARE WITH THE PCAT TOOLKIT



Project title:	Development and Implementation of the Palliative Care Assessment Toolkit for Rural Aged Care Facilities in Australia
Investigators:	Prof. Hanan Khalil, Prof. Evelien Spelten, Prof. Irene Blackberry, Susan O'Neill, Adjunct Assoc. Prof. Ruth Hardman
Timeline:	April 2023 to July 2024
Location:	Mildura, Victoria
Partners:	Sunraysia Community Health Service, Aged care service providers

CONTEXT

Each year, around 1,700 elderly people die in aged care settings, with fewer than 5% having advanced care directives. This leaves the majority of residents without clear plans for how they wish to die with dignity and in alignment with their values. Reports highlight inconsistencies in the provision of palliative care, particularly in rural and remote areas. Rural aged care facilities face challenges such as late referrals, insufficient staff training, and limited access to resources, often resulting in suboptimal care. High-quality palliative care was a key recommendation of the Aged Care Royal Commission, which called for improvements in this area. However, existing competency tools aren't tailored to the unique needs of rural nurses, whose scope of practice differs from their metropolitan counterparts. This research aimed to fill this gap through specialised resources and training for rural nursing practice in aged care facilities.

APPROACH

Building on previous collaboration with aged care staff and palliative care specialists, this study addressed gaps in end-of-life care, focusing on the lack of standardised assessment tools for rural settings. The project aimed to improve palliative care quality in rural facilities through implementing a structured assessment toolkit (PCAT) to enhance care planning, medication access, and staff training. Using a mixed-methods design, the study involved three phases: co-design of the toolkit, implementation, and evaluation. Baseline data was gathered through audits of decedent records and interviews with clinical staff. The toolkit developed from these findings focused on anticipatory care, advanced care planning, end-of-life care management, and staff training. Its impact was assessed through a follow-up audit after implementation.

OUTCOMES

The findings indicate significant, measurable improvements in palliative care delivery, including a rise in the initiation of end-of-life care plans (from 54% to 88%), better medication availability (from 55% to 100%), and enhanced psychological and spiritual support for residents. The PCAT incorporates best-practice guidelines for the use of anticipatory medications in end-of-life and palliative care, a checklist for palliative care nurses, and clear referral pathways. Additionally, the project included the implementation of a training and education program for aged care staff, empowering them to handle difficult conversations and ensuring proper use and integration of the toolkit. The ongoing use of the toolkit is expected to reduce unnecessary hospitalisations, alleviate distress for both residents and their carers, and optimise the use of aged care funding.

“The benefit is that people aren’t going to the hospital unnecessarily. Families are more prepared. It doesn’t come as a complete shock. The nursing team and the doctor know the patient’s wishes.”

Mel Livens, Sunraysia



ADDRESSING HIDDEN DISABILITIES: SUPPORTING YOUNG STROKE SURVIVORS



Project title:	Co-designing a psychoeducation package to enhance psychosocial wellbeing for young adults living with stroke
Investigators:	Assoc. Prof. Dana Wong, Michaela Grech, Dr Toni Withiel, Prof. Emma Power, Prof. Ian Kneebone, Assoc. Prof. Rene Stolwyk, Dr Eirini Kontou, Mr Adrian O'Malley
Timeline:	January 2024 to 2026
Location:	Victoria
Partners:	Stroke Foundation

CONTEXT

An estimated 142,000 Australians aged 18 to 65 are living with the impact of stroke, and over half experience hidden disabilities including depression, anxiety, memory and other cognitive difficulties, and fatigue. According to the latest Stroke Foundation audit, 32% of stroke services lack access to a psychologist, so there is a need to provide other forms of information and support. Despite this, there have been no studies co-designing or evaluating psychoeducation interventions or accessible information tailored specifically for young stroke survivors. The need to address hidden disabilities in this demographic is highlighted by data from the Stroke Foundation's helpline, StrokeLine. The most frequent inquiries from callers aged 18–65 focus on fatigue (34%), followed by concerns about emotions/mood (21%) and thinking/memory/judgment (18%). Many callers seek guidance on strategies and information about available services or clinicians who can provide support.

APPROACH

To address significant service gaps, researchers and industry stakeholders have recognised the need for large-scale, easily implementable solutions specifically designed for young stroke survivors. Psychoeducation involves active communication to improve understanding of psychological, cognitive, and behavioral issues. When delivered interactively, it can enhance wellbeing, support self-management, and prevent the need for more intensive interventions. This model of care is particularly effective because it can reach large populations through online resources and telehealth sessions, making it usable for anyone with access to the internet. This project is co-designing an accessible psychoeducation package for young adult stroke survivors (aged 18–45). It includes dynamic resources like videos, podcasts, online tip sheets with chat/comment capability, and telehealth Q&A sessions to support self-management, ensuring scalability and broad accessibility. The feasibility and acceptability of these resources will then be tested in a pilot trial.

OUTCOMES

Co-designed with young stroke survivors, their support people and clinicians, this research will have both local and international impact, contributing to the evidence on the acceptability and feasibility of co-designed psychoeducation interventions. These interventions have the potential to improve client outcomes and provide additional resources for health services. By addressing the hidden challenges faced by young adults living with stroke, this project will make these invisible difficulties more visible. If it is found to be feasible and acceptable, the psychoeducation package will be made widely available to support young stroke survivors and their families.

“The psycho-social impacts of stroke are huge, not just on stroke survivors but their family members, friends and the wider community, and younger stroke survivors have unique needs.”

Dr Matthew Berryman, stroke survivor



WHERE MENTAL HEALTH AND HUMAN RIGHTS MEET



Project title:	A Human Rights Implementation Assessment for Mental Health Law and Policy
Investigators:	Assoc. Prof. Piers Gooding, Prof. Chris Maylea, Prof. Neeraj Gill, Dr Catherine Brasier, Prof. Jill Stavert
Timeline:	March 2025 to February 2028
Location:	National, with a focus on Victoria and Queensland
Partners:	Wellways Australia Limited, Edinburgh Napier University, Griffith University

CONTEXT

Individuals with mental health conditions or psychosocial disabilities, as well as their families, frequently encounter discrimination in healthcare systems and broader society, both in Australia and around the world. Mental illness can lead to significant social disadvantage, and underfunded services may fail to provide adequate support. During episodes of mental health crisis, individuals may be unable to advocate for their rights, leaving them vulnerable to violations at their most critical time. Recent Royal Commissions have highlighted how gaps in services and involuntary psychiatric interventions can violate a range of rights, including the right to the highest attainable standard of mental health. Without a tool to assess the human rights implications of mental health-related policies, practices, and laws, it becomes extremely difficult to tell whether society is improving (or going backwards) in supporting people in mental health crises.

APPROACH

During a panel discussion hosted by the Care Economy Research Institute, Professor Dainius Pūras, the former UN Special Rapporteur for the Right to the Highest Attainable Physical and Mental Health, discussed the challenge of measuring progress in mental health policy under international human rights law due to an absence of an effective indicator. This project aims to develop such a tool—a ‘CRPD indicator’—to assess Australia’s compliance with the *Convention on the Rights of Persons with Disabilities (CRPD)*. The CRPD includes a reporting mechanism requiring governments to report on their domestic implementation of the Convention. Civil society plays an important role by submitting a ‘shadow report’ that holds the government’s claims to scrutiny. While this enhances accountability, the reporting currently covers all persons with disabilities. This CRPD indicator developed in this project will specifically address rights issues in the context of mental health.

OUTCOMES

Co-developed with people affected by rights violations, the indicator assessment tool will be used by governments and a range of civil society organisations, including mental health service user associations, service providers, families, carers, and advocacy organisations. The research will involve government and regulatory stakeholders throughout the project to ensure the indicator can be readily integrated into law, policy, and practice. This new CRPD indicator will evaluate the commitment of governments to enact international human rights law in the mental health context. Ultimately, the indicator will help achieve social, economic, and cultural improvements by enhancing mental health services to better meet people’s needs, thus improving health and safety for all Australians.

“Mental health service systems have been dominated by restrictive practices, including compulsory treatments and institutionalisation, that have been shown to be harmful to both service users and their families. Wellways envisions a community where everyone can imagine and achieve their hopes and potential with freedom, dignity and choice. As an organisation we appreciate the value of having a human rights tool that can help us to align with this vision.” Gerald Reed, Director Wellways



TURNING POINTS, TOWARDS BRIGHTER TOMORROWS



Project title:	Critical moments in responses for children affected by family substance misuse
Investigators:	Prof. Anne-Marie Laslett, Prof. Sarah MacLean, Prof. Amanda Cooklin, Dr Heng Jiang, Dr Koen Smit, Prof. Kylie Lee, Eleanor Costello, Dr James Petty
Timeline:	December 2024 to June 2028
Location:	National
Partners:	Australian Drug and Alcohol Foundation, Victorian Alcohol and Drug Association, Youth Affairs Council of Victoria, Australian Institute of Family Studies, Uniting, Victoria and Tasmania, Youth Support and Advocacy Service, Monash Health, Queen's University, University of Tennessee

CONTEXT

In Australia, children and young people impacted by their families' or others' alcohol and drug (AOD) misuse often face poorer outcomes in education, welfare, health, and legal matters. For more than a third of children in the child protection system, substance misuse (including both legal and illegal drugs) by the protective parent, perpetrator, or both contributes to more serious harm. These situations typically involve multiple systems, such as child protection, juvenile justice, law enforcement, and family support services. However, in most cases, these systems fail to incorporate data on family AOD use when assessing the needs of affected children and young people. This groundbreaking project seeks to address this gap by identifying critical moments and pathways where timely support can significantly improve the likelihood of positive outcomes for children, young people, and their families.

APPROACH

Misuse of AOD in families is a significant risk for various harms to children and young people, including neglect, emotional and physical abuse, and exposure to intimate partner violence. Building on an initial scoping review with our industry partners, this research takes a broad approach to examine outcomes such as family care, child removal, education, social and developmental wellbeing, and housing. The focus is on identifying which services help or strain parents influencing their ability to provide safe, nurturing, and responsive care, which is vital for children's safety and development. This study also looks at how factors like parents' wellbeing, income, socio-economic status, location, and personal aspects such as gender, culture, and language shape access to and engagement with key services.

OUTCOMES

The findings from this research have the potential to enhance the physical, social, and overall wellbeing of children, young people, and their families in Australia and globally. Our team is conducting a comparative analysis to highlight the Australian experience, and identify key differences and strengths of systems within and beyond Australia. At the policy level, increasing international attention on the importance of support services for children will encourage the development of effective national and international policies aimed at reducing harm from family AOD misuse. By leveraging the expertise of young people with lived experience, researchers, service providers, and policymakers there is a significant opportunity to influence changes in service provision, communication, policy analysis, policymaking, treatment, and prevention.

"By listening to the voices of young people, we can gauge their needs in a modern service context and work with them to develop innovative solutions."

Uniting VIC TAS



TOGETHER AT THE END OF LIFE: CONNECTION, PLANNING AND SOCIAL SUPPORT



Project title:	Healthy End of Life Planning (HELP) App
Investigators:	Dr Andrea Grindrod, Dr Sumina Shrestha, Dr Sora Lee, Niki Read, Holly Smith, Dr Ali Lakhani, Prof. James Boyd, Dr Magan Abdi, Assoc. Prof. Kerrie Noonan
Timeline:	June 2018 to December 2025
Location:	National
Partners:	Palliative Care Australia, South Australian Department of Health and Wellbeing, Sydney North Health Network, Palliative care peak bodies, Plus 30+: Primary Health Networks, health consortia, hospices, aged care, community and disability services

CONTEXT

Caring for someone at the end of life can be a lonely experience with far-reaching impacts on the carers health and wellbeing. Research by La Trobe’s HELP team reveals that carers are reluctant to accept help from friends and family, typically turning down support due to concern about being a burden, viewing death as a private matter, or perceiving the need for assistance as a sign of weakness. By challenging some of social norms around offering and accepting help, the HELP App encourages community support during difficult times. With an ageing population and the rising prevalence of chronic diseases, Australia is facing a 50% increase in demand for palliative care over the next decade, with a projected doubling of need by 2050. Addressing the urgent need for better support for those caring for people with chronic and life-limiting illness is critical.

APPROACH

The HELP App takes a public health approach to palliative care, reimagining it as a shared responsibility and privilege. It empowers individuals and communities to work together in creating pathways for end-of-life care, be it at home, in hospital or any other setting. The research involved multiple industry partners across Australia, both within and outside the healthcare sector, to facilitate social prescribing referrals for patients, caregivers, and families, helping them tap into their social networks for support through the HELP App. The app connects formal care services with informal, community-based networks enabling ‘coordinators’- usually family members, caregivers, or those receiving end-of-life care – to mobilise their social connections, making it easier to ask for and offer relevant and necessary supports.

OUTCOMES

The data emerging from the HELP App is offering promising signs of a positive behavioural shift within the community. When caregivers are empowered to tap into and make the most of their informal care networks, the evidence demonstrates that cultivating a culture of shared responsibility and open communication results in improved outcomes. This research highlights that, with the right tools and conversations, we can break down societal barriers and build supportive environments where caregivers can work together with family and friends to navigate the complexities of end-of-life care, rather than doing so alone. This approach not only benefits those receiving care but also enables the wider network to better understand and be prepared for future end-of-life care experiences.

“The app aligns directly with our strategies to value the engagement of patients and their carers.”

Employee of palliative care service

BREAKING THE SILENCE: A GROUNDBREAKING LOOK AT CONVERSION PRACTICES IN AUSTRALIA



CARE
ECONOMICS,
SOCIAL AND
POLICY



Project title:	Improving spiritual health care for LGBTQA+ Australians
Investigators:	Dr Timothy Jones, Prof. Jennifer Power, Dr Joel Anderson, Prof. Tiffany Jones
Timeline:	June 2019 to June 2025
Location:	National
Partners:	The Brave Network, Australian LGBTIQ+ Multicultural Council, Macquarie University



CONTEXT

This pioneering study on the harms of conversion practices in Australia was driven by survivors who sought to create an evidence base to support their advocacy for law reform and social change. The prevalence of conversion practices in Australia is much higher than anticipated, with 8% of the LGBTQA+ community having undergone formal conversion practices, and 45% experiencing informal practices ‘frequently’ or ‘often’. These conversion practices are linked to serious health impacts, including complex post-traumatic stress disorder, spiritual conflict, self-harm, and suicide, while training and resources to support survivors have historically been scarce.



APPROACH

The research aims to raise awareness of conversion practices in order to support legal reforms to end them, as well as enhance survivor recovery, and improve safety in pastoral care. The research took form in the shape of a major national survey and over fifty life history interviews with survivors of conversion practices. It constitutes the most significant dataset on queer and trans experiences of conversion practices in this country. Findings from the research have informed the creation of training programs for mental health professionals and led to the development of *A Guide to Improving Safety in Pastoral Care with LGBTQA+ People* (2023), which helps those in religious ministries provide safer care for LGBTQA+ individuals.



OUTCOMES

The high levels reported by participants are evidence of the persistence of, and harms associated with, conversion practices. This research has led to a swathe of law reform processes in all Australian jurisdictions, with legislation passed in Queensland, New South Wales, South Australia, and the Australian Capital Territory similar to the “Change or Suppression (Conversion) Practices Prohibition Act 2021” in Victoria. The community education resources, and professional training developed from this research have led to the team working with the Victorian Equal Opportunity and Human Rights Commission to extend their education and training materials.

“La Trobe University’s contribution has not only been foundational for our world-leading legislation, in providing evidence of the practices and the harm they cause, but also vital in underpinning the civil response scheme at the Victorian Equal Opportunity and Human Rights Commission (VEOHRC).”

Victorian Equal Opportunity and Human Rights Commissioner



The Care Economy Research Institute acknowledges that our researchers are located on the unceded lands of many traditional custodians. We recognise their ongoing connection to the land and value their unique contribution to research and learning and to Australian society.

We pay our respects to their Elders, past and present, and thank them for their ongoing care of the land, skies and waterways of this beautiful country.



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