



# End of Life Research and Education Program





## The Australian Centre for Health Law Research is the country's leading health law research centre and is located at the Queensland University of Technology (QUT), Brisbane, Australia.

End of life decision-making is a key focus for the Centre including research on the law, bioethics, regulation and practice of:

- voluntary assisted dying (VAD)
- withholding or withdrawing life-sustaining treatment
- advance care planning
- palliative care
- organ and tissue donation

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**Our team has been researching in the end of life area for over 20 years. We have written over 300 publications on end of life decision-making and are part of interdisciplinary teams receiving over \$65 million for our end of life research and training programs.**

Our research has been funded by the Australian Research Council, the National Health and Medical Research Council, Commonwealth and State governments, and philanthropic organisations. It has had a significant impact, leading to significant changes in law, policy and practice in Australia and internationally.

## Our Research Projects

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### Optimal regulation of voluntary assisted dying

This 5-year project explores VAD as a new end of life choice in Australia. This international study, which includes research in Canada and Belgium, will propose a new optimal regulatory framework for VAD in Australia.

**Researchers:** Professor Ben White; Professor Lindy Willmott; Dr Eliana Close; Casey Haining; Dr Ruthie Jeanneret; Madeleine Archer

#### International and national collaborators:

Professor Jocelyn Downie (Dalhousie University); Professor Luc Deliens (Vrije Universiteit Brussel (VUB), Ghent University); Professor Kenneth Chambaere (Ghent University); Professor Sharon Friel (Australian National University)

**Funder:** Australian Research Council Future Fellowship (2020-2025)

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### Assessing the operation of voluntary assisted dying laws in Australia

This 3-year project will work with VAD Boards and health departments in 5 states to undertake the first national assessment of how Australia's new VAD laws are operating in practice. The project will recommend changes to law, policy and practice to improve VAD quality and safety for the benefit of patients, families, health professionals and the community.

**Researchers:** Professor Ben White; Professor Lindy Willmott; Dr Rachel Feeney; Katherine Waller

**Partners:** Queensland Health; Queensland Voluntary Assisted Dying Review Board; Department of Health of Western Australia; Western Australian Voluntary Assisted Dying Board; Victorian Voluntary Assisted Dying Review Board; Voluntary Assisted Dying Commission Tasmania; South Australia Department of Health and Wellbeing

**Funder:** Australian Research Council Linkage Project (2025-2028)

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### Voluntary assisted dying and dementia in Australia: An exploratory study

This 3-year project will explore the issue of access to VAD for people living with dementia. It will examine international laws that allow access and the evidence about their use as well as the perspectives of key Australian stakeholders on these models.

**Researchers:** Professor Ben White; Professor Lindy Willmott; Casey Haining; Dr Rachel Feeney; Dr Katrine Del Villar

**Funder:** The Clem Jones Foundation (2024-2027)



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## Healthcare worker survey on voluntary assisted dying in Queensland

This project aims to understand the extent to which healthcare workers' knowledge, perceptions and willingness to participate in VAD have changed since the legislation commenced in Queensland.

**Researchers:** Professor Ben White; Caitlin Lock; Professor Lindy Willmott; Dr Rachel Feeney; Haley McNamara; Imogen Page

**Funder:** Queensland Health (2024-2025)

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## Survey of Queenslanders' views on voluntary assisted dying

This project examines community knowledge on VAD, including the extent to which people are aware VAD is legally available and known sources of information about VAD.

**Researchers:** Professor Ben White; Professor Lindy Willmott; Dr Rachel Feeney

**Funder:** Queensland Health (2024)

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## Review of the Voluntary Assisted Dying Act 2019 (WA): Research report

This project supports the mandatory review of Western Australia's VAD laws. Research with key stakeholders aims to understand how the VAD system is operating in practice. Recommendations for reform based on this research will inform the review panel's findings.

**Researchers:** Professor Lindy Willmott; Professor Ben White; Casey Haining

**Funder:** Department of Health of Western Australia (2023-2024)

## International Research Projects

We have a long history of collaboration with international research teams. Our current international research projects include:

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### Exploring the early experiences of the assisted dying service in Aotearoa

This 3-year project led by Dr Jessica Young examines the experiences of stakeholders involved in the assisted dying process in New Zealand.

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### PROPEL: Physician reported preferences for end-of-life decisions

This 4-year project led by Sarah Mroz from Belgium is a mixed-method study across Europe, North America and Australia conducting an international comparison of physicians' own end of life decision preferences and how those preferences impact their clinical practice.



## Collaboration to make a difference

Our interdisciplinary researchers have a strong track record of collaboration. We work closely with other researchers and clinicians as well as collaborating with health departments, statutory bodies, health services, hospitals, aged care facilities and other research centres.

Through this collaboration, we aim to undertake research that can make a real difference to improving end of life care.

## VAD law, policy and practice

We work closely with VAD policymakers, VAD boards and VAD providers in our research. This includes:

- **The VAD Policy and Practice Advisory Group:** Representatives from health departments and

VAD boards from all Australian jurisdictions and New Zealand support the Australian Research Council Future Fellowship project 'Optimal regulation of voluntary assisted dying'

- **Health departments and VAD boards as research partners:** Formal collaboration as research partner organisations in 5 states in the Australian Research Council Linkage project 'Assessing the operation of voluntary assisted dying laws in Australia'
- **Supporting VAD law reviews:** Engaged to deliver a research report to provide an evidence base for the Western Australian review of the VAD Act.





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## Our Education

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### Mandatory voluntary assisted dying practitioner training

These projects developed the mandatory training for VAD practitioners in Victoria, Western Australia and Queensland. This training equips health practitioners with accurate legal knowledge and enhanced clinical skills to support safe and high-quality VAD.

**Researchers:** Professor Lindy Willmott; Professor Ben White; Distinguished Professor Patsy Yates; Emeritus Professor Malcolm Parker; Katherine Waller; Dr Katrine Del Villar; Dr Eliana Close; Casey Haining; Dr Ruthie Jeanneret; Madeleine Archer; Dr Laura Ley Greaves

**Funders:** Victorian Department of Health and Human Services (2018 – 2022); Department of Health of Western Australia (2020 – present); Queensland Health (2021 – present)

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### Voluntary assisted dying education module for healthcare workers

This education module is accessible for all healthcare workers in Queensland and provides an overview of VAD in Queensland, the process to access VAD, and the rights, roles, and obligations of Queensland healthcare workers.

**Researchers:** Professor Lindy Willmott; Professor Ben White; Dr Katrine Del Villar; Katherine Waller; Casey Haining

**Funder:** Queensland Health (2022 – present)

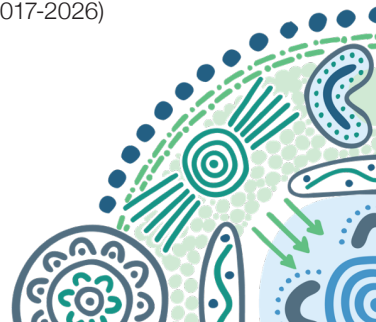
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### End of Life Law for Clinicians

End of Life Law for Clinicians (ELLC) is in its 7th year of delivering training to health professionals across Australia about the laws on end of life decision-making. ELLC's online modules aim to improve clinicians' knowledge and awareness of the law at end of life, and support their delivery of quality end of life and palliative care.

**Researchers:** Professor Ben White; Professor Lindy Willmott; Professor Shih-Ning Then; Distinguished Professor Patsy Yates; Penny Neller; Dr Rachel Feeney; Dr Katrine Del Villar; Dr Eliana Close

**Funder:** Commonwealth Department of Health and Aged Care (National Palliative Care Project) (2017-2026)



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## End of Life Law Toolkit: End of Life Directions for Aged Care

End of Life Directions for Aged Care (ELDAC) is a national specialist palliative care and advance care planning advisory service for health care providers in aged and palliative care led by Distinguished Professor Patsy Yates (QUT). The End of Life Research and Education Program developed ELDAC's End of Life Law Toolkit, which provides practical information about end of life decision-making laws for the aged care sector.

### **QUT Law Toolkit Researchers:**

Professor Ben White; Professor Lindy Willmott; Penny Neller

### **Overall Project Consortium:**

QUT (lead: Distinguished Professor Patsy Yates); Flinders University (lead: Professor Jennifer Tieman); University of Technology Sydney (lead: Professor Deborah Parker); Palliative Care Australia; Aged & Community Care Providers Association; Australian Healthcare and Hospitals Association; Catholic Health Australia.

**Funder:** Commonwealth Department of Health and Aged Care (National Palliative Care Project) (2017-2026)



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## End of Life Law in Australia

The End of Life Law in Australia website (<https://end-of-life.qut.edu.au/>) provides information about law at the end of life for all Australian jurisdictions. It is designed to make complex law accessible for patients, families, health and legal practitioners, the media, policymakers and the broader community.

**Researchers:** Professor Ben White; Professor Lindy Willmott; Penny Neller



## Our people

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### Program leads

#### Professor Ben White

Ben is Professor of End-of-Life Law and Regulation and an Australian Research Council Future Fellow.

He has published over 200 book chapters and journal articles on health law, with a particular focus on VAD and end of life decision-making. Ben has been part of interdisciplinary teams awarded over \$65 million in the field of end of life decision-making, including from the Australian Research Council, the National Health and Medical Research Council and Commonwealth and State governments.



#### Professor Lindy Willmott

Lindy is an international expert in end of life law, with particular expertise in VAD. She has been part of interdisciplinary teams awarded more than \$65 million in research funding and has published extensively in the field of health law, with more than 230 publications. Lindy's research has been integral to VAD law reform, policy and practice across Australia. She is a member of Queensland's Voluntary Assisted Dying Review Board.



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### Researchers

#### Professor Shih-Ning Then

Shih-Ning is Deputy Director of the Australian Centre for Health Law Research and collaborates across disciplines in the areas of substituted and supported decision-making for adults, paediatric healthcare, end of life legal issues, and organ and tissue donation. She is part of the End of Life Law for Clinicians (ELLC) team funded by the Commonwealth Department of Health and Aged Care that delivers free online training on end of life law.



#### Professor John Scott

John is Professor and Head of the School of Justice. He is widely published, including 27 books and major research reports and over 100 papers and book chapters. He also has sustained success in attracting nationally competitive grants and industry funding. His research interests include social control, masculinity and violence and the supply and regulation of drugs. His work includes a focus on palliative care in prisons.





### **Associate Professor Andrew McGee**

Andrew is Associate Professor in QUT's School of Law. He holds a PhD in philosophy from the University of Essex and is a qualified lawyer. His research interests include clinical ethics and bioethics; euthanasia, assisted suicide, and withdrawing life-prolonging measures; the definition of death and organ donation, and the nature of moral reasoning.



### **Dr Eliana Close**

Eliana is a Senior Research Fellow with expertise in law and psychology. She is leading a Canadian case study for the Australian Research Council Future Fellowship project, 'Optimal Regulation of Voluntary Assisted Dying'. Eliana is part of the End of Life Law for Clinicians program and contributed to the training for practitioners providing VAD in Victoria, Western Australia, and Queensland. Prior to QUT, Eliana was a Crown Prosecutor in Alberta.



### **Dr Sam Boyle**

Sam is a senior lecturer in QUT's School of Law. He teaches and researches in the areas of medical law and mental health law. Sam's research interests include how the law determines legal capacity; involuntary treatment for mental illness, and consent for medical treatment.



### **Dr Katrine Del Villar**

Katrine is a lecturer in QUT's School of Law. She researches comparative VAD laws, end of life decision making and mental health law. She is an investigator on the Commonwealth government-funded End of Life Law for Clinicians project (ELLC), which provides comprehensive end of life legal training for doctors, nurses and allied health practitioners. She was part of the QUT team which prepared the mandatory VAD training for Western Australia and Queensland practitioners.



### **Dr Rachel Feeney**

Rachel is a Postdoctoral Research Fellow. She previously worked as a speech pathologist and has a PhD on speech pathology and epidemiology. She has extensive experience in quantitative and qualitative research methods. Rachel's research has focused on end of life decision-making, including law, policy and clinical practice. She has a particular interest in VAD and the specific legal issues relevant to allied health professionals working in end of life care.



## Casey Haining

Casey has qualifications in biomedicine, population health and law. She holds research fellow appointments at QUT and the University of Melbourne. She has conducted and analysed over 100 Australian interviews on VAD. She was the appointed research fellow for carrying out the statutory review for the WA VAD legislation and was engaged as a legal writer for the mandatory training in Queensland. Her PhD thesis considers VAD and dementia.



## Madeleine Archer

Madeleine's research examines assisted dying regulation in Belgium, and the influence that regulation has on health professionals' behaviour and decision-making in relation to assisted dying. It aims to identify how assisted dying regulation might be improved in Belgium, and has broader significance for understanding assisted dying regulation in other jurisdictions, including Australia. She also works on the projects delivering the mandatory training for VAD in WA and Queensland.



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## Project Managers

### Penny Neller

Penny is the National Palliative Care Projects Manager. She manages two projects funded by the Commonwealth Department of Health and Aged Care:



- End of Life Law for Clinicians, a national training program for health professionals to improve their knowledge relating to end of life decision-making
- End of Life Law Toolkit in End of Life Directions for Aged Care, a resource for health professionals to support delivery of quality end of life and aged care.

### Katherine Waller

Kat manages the development and delivery of legal training for healthcare professionals in the area of VAD. She is the Project Manager for the VAD Training Projects in Western Australia and Queensland as well as for the Australian Research Council Linkage project 'Assessing the operation of voluntary assisted dying laws in Australia'. Kat also undertakes comparative research in the area of VAD.



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## PhD Students

### Dr Laura Ley Greaves

Laura's research explores a longitudinal study of doctors' experiences following the commencement of VAD in Queensland, and whether these change over time. Laura's background is as a medical doctor, where she practised in the UK and Australia. She also has an interest in end of life ethics and is a clinical advisor on the projects delivering mandatory training for VAD.



### Dr Aurélie Copin

Aurélie's PhD is entitled 'Conscientious objection to voluntary assisted dying – ethics, law and practice.' This research will examine the limits that may exist to contentious objection, the ethical acceptability of the construction of contentious objection in current legislative frameworks and the impacts of contentious objection on clinical practice. Aurélie is also a practicing intensive care registrar.



### David Cusack

David's PhD is a critical analysis of institutional conscience in the delivery of VAD services. This research examines the ethical and legal legitimacy of claims of a right to institutional conscientious objection to legally permitted VAD services in Australia.

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## Research Assistants

Ms Katie Cain

Dr Alison Fraser

Ms Katie Quinn

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## Adjuncts

- Professor Kenneth Chambaere (Ghent, Belgium)
- Professor Luc Deliens (VUB and Ghent, Belgium)
- Professor James Downar (Ottawa, Canada)
- Professor Jocelyn Downie (Dalhousie, Canada)
- Professor Ian Freckelton AO KC (University of Melbourne, Monash University, Australia)
- Professor Dale Gardiner (Nottingham University Hospitals NHS Trust, UK)
- Professor Margaret Hall (Simon Fraser, Canada)
- Professor Dominique Martin (Deakin University, Australia)
- Emeritus Professor Malcolm Parker (University of Queensland, Australia)
- Professor Thaddeus Pope (Hamline, USA)
- Associate Professor Bernadette Richards (University of Queensland, Australia)
- Professor Julian Savulescu (National University of Singapore, Singapore)
- Dr Jessica Young (Victoria University, New Zealand)



## Contact

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*The Indigenous artwork in this brochure was designed by Isaac Simon and Kit Kreative for the End of Life Law for Clinicians training program.*