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. The Centre undertakes pioneering empirical, theoretical and doctrinal research into complex problems that arise at the interface of law, health, ethics, technology, governance and public policy. End of life is one of the Centre’s three research programs.

Our interdisciplinary researchers have a strong track record of collaboration. We have attracted significant national and international funding, including five Australian Research Council (ARC) grants and one National Health and Medical Research Council (NHMRC) grant in the end-of-life area over the past five years. We have published in leading national and international journals and books.

We aim to translate our research into change that has real impact. Our findings have been cited and approved by courts, law reform bodies and governments and have informed improvements to law, public policy and practice.

The end-of-life research program explores legal, ethical and policy issues in death, dying and decision making including:

- withholding and withdrawing life-sustaining medical treatment;
- provision of futile treatment at the end of life;
- advance care planning;
- palliative care;
- euthanasia; and
- coronial systems and regulation.
Futile treatment at the end of life: Legal, policy, sociological and economic perspectives

**ARC Linkage Project**

Treatment is futile when it either cannot work or cannot achieve an acceptable quality of life for the patient. Futile treatment causes harm to patients, distress to their families and treating health professionals, and wastage of scarce health resources. Despite these adverse outcomes, there is a lack of research on why such treatment is provided and the extent to which it occurs.

This interdisciplinary project considers legal, policy, sociological and economic perspectives of futile treatment at the end of life. These issues are explored through a legal and policy review, in-depth interviews and chart audits at large Queensland public hospitals, and economic modelling. This research will provide a rich understanding of why and how often doctors give treatment they believe to be futile, and will establish an empirical foundation for addressing its causes.

Chief Investigators: Prof Lindy Willmott (QUT), Prof Ben White (QUT), Em/Prof Cynthia Gallois (UQ), Prof Malcolm Parker (UQ), Prof Nicholas Graves (QUT) and Dr Sarah Winch (UQ) (in partnership with the Royal Brisbane and Women’s Hospital).

Enhancing community knowledge and engagement with law at the end of life

**ARC Linkage Project**

Little is currently known about whether individuals know the law, or are able to exercise their legal rights to be involved in the process of making decisions about treatment at the end of life. This research aims to enhance patient and family decision making through a better understanding of legal rights, powers and duties, and to improve the experiences of patients and families at the end of life. This project investigates how and if members of the community understand and act upon these legal rights and explores the barriers to and facilitators of good decision making.

Chief Investigators: Prof Ben White (QUT), Prof Lindy Willmott (QUT), Assoc Prof Cheryl Tilse (UQ) and Prof Jill Wilson (UQ) in partnership with Prof Jeffrey Dunn (Cancer Council Qld), Angela Pearce (Cancer Council NSW) and Dr Deborah Lawson (Cancer Council Vic).

Withholding and withdrawing life-sustaining medical treatment from adults who lack capacity: the role of law in medical practice

**ARC Linkage Project**

When decisions are made to withhold or withdraw life-sustaining treatment from adults who lack capacity, do doctors know and consider the law? More than 40000 adult deaths occur each year across Australia following a decision to withhold or withdraw treatment, yet the role that the law plays in these decisions is unknown. This interdisciplinary empirical project examines the legal knowledge of medical specialists. The project aims to enhance clinical practice through identifying legal education needs and areas for law reform, and to produce better outcomes for patients and their families.

Chief Investigators: Prof Ben White (QUT), Prof Lindy Willmott (QUT), Prof Colleen Cartwright (Southern Cross University), Prof Malcolm Parker (UQ) and Prof Gail Williams (UQ) (in partnership with seven guardianship bodies in Queensland, New South Wales and Victoria).
Our Researchers

Professor Belinda Carpenter

Belinda’s research interests include: autopsy, coroners systems, death investigations, and medico-legal discourses. In 2004 she gained an ARC Linkage grant with the Departments of Health and Justice and Attorney General to investigate the decision making of coroners under the Coroners Act. The findings from this research have been widely published and formed the basis for three more grants in 2008 and 2009, exploring in more detail the issues surrounding a death investigation.

Dr Andrew McGee

Andrew’s research is interdisciplinary, spanning law, health, ethics and philosophy. His main areas of interest are organ donation, dementia, withholding and withdrawing life prolonging measures, euthanasia, palliative care, the ethics of stem cell research, and abortion. Andrew has published in leading international medical law, philosophy, and medical ethics journals including Legal Studies, Bioethics and Cambridge Quarterly of Healthcare Ethics. He has been interviewed by Time magazine and has built collaborative relationships with the world’s leading professors in his field from Harvard University, Oxford University, and the National Institutes of Health. He is currently working on a book with Dr Charles Foster from Oxford University about the use of intuitions in moral reasoning.

Managing family objection to autopsy: a case study of the Queensland coronial system

ARC Linkage Project

Each year in Queensland around 3500 deaths are investigated by the coroner. Despite the coroner’s discretionary power to order an external only autopsy, an internal autopsy is performed in 94 per cent of cases, which is higher than in other jurisdictions. Family objections to the autopsy procedure have, to a small degree, influenced coronial decision making to order less invasive autopsies, yet this has been inconsistently applied. The influence of police, counsellors and pathologists in coronial decision making is also unclear. This research investigates what motivates coronial personnel to take family objections to autopsy into account. It will help establish an integrated and consistent approach to the role of family objection in the Queensland coronial system.

Chief Investigators: Prof Belinda Carpenter (QUT) and Assoc Prof Gordon Tait (QUT) in partnership with Michael Barnes (State Coroner), Charles Naylor (Chief Forensic Pathologist), Ian Thompson (Qld Police Service) and John Drayton (Forensic Scientific Services).

Centre of Research Excellence in End-of-Life Care

NHMRC-funded Centre

The pattern of disease, dying and death has changed dramatically in Australia over the last century. The Centre of Research Excellence in End-of-Life Care brings together four leading research centres in end-of-life care and establishes strategic links with leading investigators in chronic disease, health economics, and legal and ethical issues. The Centre will address the urgent need for evidence-based end-of-life service delivery strategies that are responsive to the complex, unpredictable and often extended patterns of disease progression.

Chief Investigators: Prof Patsy Yates (QUT), Prof Geoffrey Mitchell (UQ), Prof David Currow (Flinders University), Prof Kathy Eagar (University of Wollongong), Prof Helen Edwards (QUT), Prof Glenn Gardner (QUT), Prof Lindy Willmott (QUT), Prof Ann Bonner (QUT), Assoc Prof Robyn Clark (QUT) and Dr Jennifer Tieman (Flinders University). Associate Investigators: Prof Ben White (QUT) and Dr Fiona McDonald (QUT).
Our Researchers

Dr Fiona McDonald
Fiona is an Associate Investigator on the NHMRC-funded Centre of Research Excellence in End-of-Life Care. Her research areas include health governance, health systems law and policy, patient safety, and regulation. Fiona works with Assoc Prof Christy Simpson (Dalhousie University, Canada) examining organisational ethics in hospitals.

Dr Malcolm Smith
Malcolm’s research in the end-of-life context focuses on substitute decision making in relation to adults who lack decision making capacity. He also has research interests in beginning of life issues, consent to medical treatment and medical negligence.

Dr Kelly Purser
Kelly’s research interests include capacity assessment in the context of wills, powers of attorney and advance health directives, elder law, future planning for parents of children with a disability, succession law, trusts and equity.

Dr Kelly Purser

Shih-Ning Then
Shih-Ning’s research interests include withholding and withdrawing treatment from children, guardianship of adults without capacity, and the use of human tissues and tissue transplantation.

Higher Degree Research Students

The research of two of our PhD students in the end-of-life area is profiled here.

Eliana Close
Eliana’s research focuses on the complex legal regime governing futile treatment at the end of life in acute emergencies. In an emergency, doctors must quickly balance a number of competing considerations including patient and family wishes, clinical presentation and scarce resources. Using theoretical, and importantly, empirical methods, Eliana’s research looks at the interaction of the law with all of these factors, and how doctors navigate them in practice.

Bronwyn Betts
Bronwyn’s research will examine how paramedics respond to a situation in which a patient refuses recommended ambulance treatment and/or transport to hospital. Using a combination of three methodological approaches, Bronwyn will examine the frequency and circumstances in which patients refuse ambulance services, the law relating to these decisions, and the process by which paramedics determine if a patient’s decision to refuse is legally valid.

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