

# **Australian Centre for Health Law Research**



## **Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying**

Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying is an Australian Research Council Future Fellowship research project led by Professor Ben White in the Australian Centre for Health Law Research, Queensland University of Technology (QUT).

#### What is the aim of the project?

This research project aims to enhance end-of-life care through optimal regulation. It will explore regulation of voluntary assisted dying (VAD) as a new and important aspect of end-of-life decision-making and propose a new optimal regulatory framework for VAD in Australia.

#### Why is this project needed?

- VAD and its regulation is new in Australia.
  Very little is known about how the current regulation of VAD is working in practice and how it can be improved.
- 2. VAD regulation includes a range of regulatory forces, including laws, guidelines and policies, ethical codes and training. Existing research about regulating end-of-life care has focused only on one type of regulation i.e. only law or policy. Exploring end-of-life care in this way fails to see the critical overall perspective of how all regulatory forces are connected and function together to guide decision-making about VAD.
- 3. VAD is governed not only by regulation specifically about VAD, but also by the regulation that guides wider end-of-life care, and health and medical practice generally. This fragmentation and complexity in regulation can lead to inconsistent and suboptimal guidance for doctors, nurses, other health professionals, patients and families.

#### What does the project involve?

This project has two Stages:

Stage I: Determine how current regulatory forces – including laws, guidelines and policies, ethical codes and training – work together to guide decision-making about VAD.

Stage I will catalogue existing regulation of VAD in Australia and identify the complete set of regulatory forces that guide decision-making about VAD. This will involve legal and policy analysis, document analysis and semi-structured interviews with terminally-ill patients and their families, health professionals, and regulators.

This analysis will produce a holistic 'regulatory map' that explains how various regulatory forces influence VAD decision-making, and how they operate in practice.

This research includes learning from two case study countries where VAD is already legal: Canada and Belgium. How these countries regulate VAD will be mapped as outlined in Stage I (above). The strengths and weaknesses of the Canadian and Belgian approaches to VAD will then inform the design of an optimal regulatory framework for Australia.

Stage 2: Design an optimal holistic regulatory framework that strategically aligns regulatory forces guiding decisionmaking about VAD to promote high quality, patient-centred end-of-life care.

Stage 2 will develop an optimal holistic regulatory framework for VAD in Australia. This involves critically analysing current VAD regulation and proposing how existing and new regulatory forces could function together effectively to promote high quality, patientcentred end-of-life care. Designed collaboration with regulators stakeholders, the framework will improve laws, guidelines and policies, ethical codes, medical training and practice.

#### Who is the research team?

Professor Ben White is leading the project and will work with long-standing collaborator, Professor Lindy Willmott. Dr Eliana Close has been appointed as the Postdoctoral Research Fellow and the project will include at least two PhD students. This research is based in the Endof-Life Research Program at QUT's Australian Centre for Health Law Research.

The project is also supported by collaborators at three Host Organisations. The Canadian and Belgian case studies are supported respectively by Dalhousie University (Professor Jocelyn Downie) and Vrije Universiteit Brussel (VUB) (Professor Luc Deliens and Professor Kenneth Chambaere, both also at Ghent University). The Australian National University's School of Regulation and Global Governance (RegNet) with Professor Sharon Friel will support the project's regulatory components.

The project will also involve working collaboratively with regulators and other key stakeholders.

#### How is this research funded?

This research is funded by the Australian Research Council's Future Fellowship Scheme. This provides a four-year research-only Future Fellowship for Professor Ben White, as well as some project support. As part of its commitment to building research capacity in end-of-life regulation, QUT is also providing funding for this project.

### About the Australian Centre for Health Law Research

The <u>Australian Centre for Health Law Research</u> is a specialist research centre which undertakes research into complex problems and emerging challenges in health law, ethics, technology, governance and public policy. The Centre's researchers engage in transdisciplinary research with colleagues in Australia and internationally to produce high quality research that makes a difference.

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Project information and outcomes will be added to the project website: https://research.qut.edu.au/voluntary-assisted-dying-regulation/