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Evidence-based law-making on voluntary assisted dying

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Abstract: Voluntary assisted dying is a major social policy issue with significant implications for the health system, health and medical professionals, and the wider community. Voluntary assisted dying is now lawful in Victoria in limited circumstances and other States are likely to follow Victoria and legalise the practice. In the same way that we expect the making of health policy and the provision of health care to be evidence-based, so too should we should expect evidence-based *law-making* from our parliamentarians on this important topic.

1. What is known about the topic?

The importance of evidence when making health policy and providing evidence-based medical care is well accepted. Australian states are actively considering laws about voluntary assisted dying.

2. What does this paper add?

This paper argues that evidence-based law-making by parliamentarians is needed as they deliberate proposed voluntary assisted dying laws. There has been limited recognition of the value of evidence-based approaches in the discipline of law.

3. What are the implications for practitioners?

A failure by parliaments to adequately consider evidence can lead to sub-optimal law-making. When this occurs about important health issues such as voluntary

assisted dying, this leads to problematic regulatory frameworks for patients, health professionals and health systems.

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Evidence-based law-making on voluntary assisted dying

Voluntary assisted dying (VAD) is a major social policy issue with significant implications for the health system, health and medical professionals, and the wider community. VAD is now lawful in Victoria in limited circumstances and other States are likely to follow Victoria and legalise the practice.¹ The Western Australian parliament is currently debating a VAD Bill tabled in August and Queensland and South Australia are holding parliamentary inquiries. A Bill is also expected to be presented to the Tasmanian parliament within the next year. In the same way that we expect the making of health policy² and the provision of health care³ to be evidence-based, so too should we should expect evidence-based *law-making* from our parliamentarians.

There are diverse views on VAD across the community. While public opinion broadly favours reform,⁴ individuals, advocacy groups and organisations on both sides of the debate continue to advance conflicting viewpoints. Of interest is the recent activity by health and medical organisations releasing a spectrum of position statements. While the Australian Medical Association⁵ is against changes to the law, the Royal Australasian College of Physicians⁶ and the Royal Australian College of General Practitioners⁷ have both chosen not to oppose reform. Significantly, the recent Palliative Care Australia Position Statement ‘neither advocates for, nor argues against’ legalisation of VAD.⁸ All four organisations specifically endorse that the decision about whether VAD laws should be passed is an issue for government and society. In contrast to the medical organisations, the Australian Nursing and Midwifery Federation supports law reform for a limited cohort of persons.⁹

This breadth of community and organisational interest in VAD is illustrated by the thousands of submissions the Victorian, Western Australian, Queensland and South Australian parliamentary committees collectively received. Parliamentarians in Victoria and Western Australia have also reported being heavily lobbied when they were actively debating their laws. How then should parliaments weigh the diverse and often conflicting arguments about whether VAD laws should be passed?

Sometimes viewpoints will differ because of different positions about the ethics of VAD. These are matters on which people can reasonably disagree. For some, VAD is ethically wrong because it involves the intentional ending of life. Others consider VAD is ethically permissible as an appropriate response to a competent request to relieve suffering. Law-making on complex social policy inevitably and appropriately involves weighing competing ethical considerations.¹⁰

However, some differences in views about VAD are based on claims about facts: whether or not something is happening in practice. Examples are whether vulnerable cohorts are more likely to seek VAD or whether VAD adversely affects palliative care. These are factual claims, and the extent to which they are true or not depends on evidence. There is not scope here to engage in these debates; although we note that two Australian parliamentary committees to date have undertaken evaluations of available evidence about VAD.^{11,12} Rather, the point here is to distinguish views about the *ethics* of VAD from views based on *facts* about VAD. We do acknowledge there can be overlap: for example, claims about facts are not necessarily value-free. Nevertheless, we contend this distinction remains important because claims about facts are capable of being evaluated against evidence.

The use of evidence in health and medicine is vexed and there are debates about a range of issues including the effects of values and research design, and challenges of translating evidence into practice.^{2,13} Nevertheless, the important role of evidence in making health policy and in providing evidence-based medical treatment to patients is well accepted. Evidence-based approaches are increasingly gaining traction in other fields such as business.¹⁰ We should also expect law-makers to make their decisions based on reliable evidence. Unfortunately, law's utilisation of evidence has lagged behind other disciplines.¹⁰ There is also relatively little literature on the concept of evidence-based law-making. Although some may conceptualise law as a subset of health policy, even if this is true, there are very distinctive facets of law-making that warrant careful and separate consideration of the role of evidence in parliamentary debate. For example, the legislative process, by definition, occurs in the public domain and there is an opportunity for scrutiny of such decision-making that is often not present in health policy-making.

One challenge for evidence-based law-making is that established models from medicine for evaluating evidence in different settings^{14,15} are not readily applicable to law-making. (This is also a known problem in health policy.¹³) To assist with the process of assessing evidence, Downie proposed an approach specifically designed for the context of law-making about VAD (see Fig 1). This model incorporates the traditional notion of ascending reliability up a pyramid but is adapted to reflect those types of evidence likely to be used in these debates. For example, randomised control trials are omitted. In addition, Downie's model includes external testing of that evidence not only through the usual peer review but also by common law and policy processes such as evaluation by a court or parliamentary committee.

Using this approach, the Dutch¹⁶ and Belgian¹⁷ research about rates of VAD over time would be regarded as reliable evidence. These are population-level studies and through publication in top international medical journals have been subject to rigorous peer review. Other significant evidence includes annual reports published by health departments about patients' and doctors' participation in VAD each year. The best examples are reports of data mandated to be collected under the *Oregon Death with Dignity Act 1994* (and this approach is replicated in other parts of the United States). Although not in peer-reviewed journals, these reports provide insight into how VAD systems as a whole function by collecting all reported cases of VAD over an extended period; now 21 years in the case of Oregon.¹⁸

At the other end of the spectrum are anecdotes in media reports about a particular case or cases of VAD. These are at the bottom of the pyramid and have not been externally tested and so are not reliable evidence. The positions against and for VAD reform of the Australian Medical Association and the Australian Nursing and Midwifery Federation respectively are also worth considering. We regard them as statements based on values, rather than purporting to be factual claims about VAD of the type discussed above. However, to the extent they may be advanced by others as a form of evidence, we consider them to be 'opinion', which is also at the bottom of the pyramid.

Parliamentarians, and indeed the wider discipline of law, must follow the evidence-based approach increasingly expected in other fields. We should be clear though that we are not suggesting law-making become just a technical exercise of implementing evidence; some limits on using evidence were noted above. Further, we acknowledge that it is appropriate for values to play a role in what is ultimately a political exercise,¹⁰ although those values should be disclosed by parliamentarians. Nevertheless, we call

for evidence-based law-making and consider this especially important for complex social issues such as VAD where proponents of various positions make broad and often conflicting factual claims. Decisions about our laws must reflect the state of available evidence so these claims must be rigorously evaluated. Accordingly, we call on parliaments to engage in evidence-based law-making that includes careful deliberation informed by reliable evidence.

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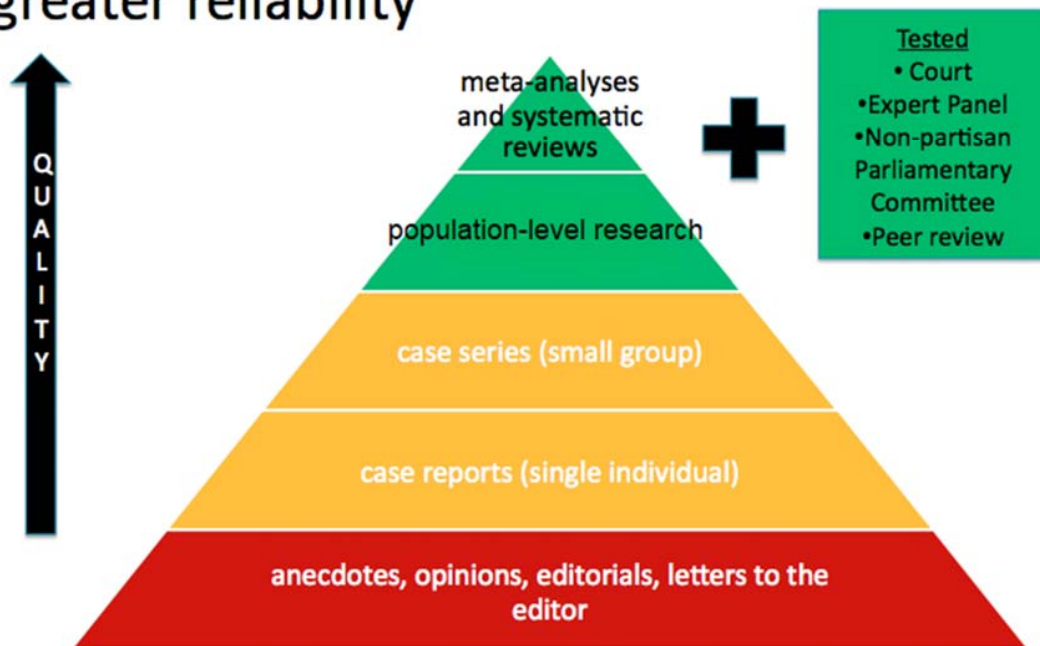
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Figures

Figure 1: Downie J. Reliability of Evidence [Internet]. End-of-Life Law and Policy in Canada. Available at: http://eol.law.dal.ca/?page_id=966.

Higher up pyramid + tested =
greater reliability



Conflicts of interest

This research did not receive any specific funding. However, we disclose that Ben White and Lindy Willmott have been engaged by the Victorian Government to design and provide the legislatively mandated training for doctors involved in VAD. Lindy Willmott is also a member of the board of Palliative Care Australia, but this article only represents her views. Ben White is an Associate Editor for Australian Health Review.

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