

Written evidence submitted by Professors Ben White and Lindy Willmott (ADY0330)

Executive Summary

- We are academics whose research focuses on assisted dying. We have been working on end-of-life law, policy and practice for the last 20 years.
- We support law reform to permit access to assisted dying under strict conditions and with robust oversight.
- We provide evidence, based on reliable research and reports of the oversight bodies, about how assisted dying systems are operating in Australia.
- The Australian assisted dying systems are operating safely. There is no evidence of ineligible patients gaining access to assisted dying. Instead, the evidence suggests that some patients who are eligible are not able to access this choice because of the system's complexity and design.
- We endorse Government support for deliberations about assisted dying reform, even when there are different perspectives on assisted dying, and the matter is one for individual parliamentarians to reach their own view. This is because Government support will enhance the quality of debate and consideration of the issues (whether or not a law is ultimately proposed and/or passed).
- Law-making on assisted dying must be evidence-based. This requires evaluating the evidence underpinning factual claims so that the debate is informed by accurate and reliable evidence.

Background and expertise

We are health law academics whose principal area of research expertise is end-of-life law, particularly assisted dying. We have each been researching in the end-of-life area for over 20 years. We have published over 150 publications on end-of-life decision-making and received over \$45 million (Australian dollars) for our end-of-life research and training programs.

Our research on assisted dying includes a body of work on comparative and legal analysis of the various international assisted dying regimes. This includes developing a Model Voluntary Assisted Dying Bill which has been cited widely and also adopted as the basis for law reform in one Australian reform report.

Our current work includes a four-year project 'Optimal Regulation of Voluntary Assisted Dying' which includes research into assisted dying systems in Australia, Canada and Belgium:

<https://research.qut.edu.au/voluntary-assisted-dying-regulation/>. This project will make recommendations about how best to safely regulate assisted dying.

We were also commissioned by the state governments of Victoria, Western Australia and Queensland to design and deliver the legislatively-mandated training for practitioners wishing to provide assisted dying. One of us, Lindy Willmott, is a member of the oversight body for assisted dying in Queensland, the Voluntary Assisted Dying Review Board, while the other, Ben White, is a member of the relevant review tribunal, the Queensland Civil and Administrative Tribunal. (We note, however, that we make this submission only in our capacity as academics.)

In terms of law reform, we have been consulted and participated in various assisted dying law reform exercises in Australia and overseas. We also edited the book *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021). This is a collection of ten case studies from six jurisdictions (the United Kingdom, the United States, Canada, Australia, Belgium and the Netherlands) analysing different aspects of end-of-life law reform.

More background information is available here:

<https://www.qut.edu.au/about/our-people/academic-profiles/bp.white>

<https://www.qut.edu.au/about/our-people/academic-profiles/l.willmott>

Question 2: What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal? The Australian experience

We note the Committee's call for evidence from other countries and provide this in relation to the Australian experience of assisted dying.

Sources of evidence

We base our comments below on two main sources of evidence. The first is the reports of the oversight bodies in the Australian states of Victoria and Western Australia. These are the two systems that have been in operation the longest – Victoria for over three years and Western Australia for more than one year. The other state systems are newer and so the oversight bodies have not yet reported.

The second type of evidence is the research that we have undertaken about the law, policy and practice of assisted dying systems in Australia. This includes articles:

- Analysing the assisted dying models from a legal and regulatory perspective
- Analysing the policies produced by government and non-government bodies about assisted dying
- Reporting on the development and utilisation of the legislatively-mandated assisted dying training
- Reporting on empirical research about how the assisted dying models are operating in practice.

In relation to empirical research, we have conducted over 100 qualitative interviews with patients, families, doctors and regulators in the Australian states of Victoria and Western Australia to understand how these assisted dying models are working in practice. Some of this research has been published, some is under review, and some data are currently being analysed. Because some of this research is not yet in the public domain, it is discussed in general terms. We would be happy to provide more information about specific findings if that would be of assistance, including providing in confidence access to unpublished or under review work.

The published academic research is available here:

https://eprints.qut.edu.au/view/person/White,_Ben.html.

A policy briefing (August 2021)

To inform parliamentary debates in Australia, we produced a policy briefing which summarised the key findings from our research about assisted dying over a period of almost two decades. The briefing may be accessed at the following link: <https://research.qut.edu.au/voluntary-assisted-dying-regulation/other-resources/>. Also available at that website is the research that underpins this policy briefing (see the PDFs extracted into five volumes).

Further observations about Australia's assisted dying systems

In addition to the findings summarised in the policy briefing, we make the following further observations based on the two sources of evidence identified above:

- The Victorian and Western Australian oversight bodies' reports show that their assisted dying systems are operating safely. There have not been cases of ineligible patients being wrongly granted access to the assisted dying system. Research participants interviewed have also repeatedly observed how safe the system is.
- Indeed, there appear to be challenges with assisted dying not being sufficiently accessible for terminally-ill eligible patients who want this choice (particularly in Victoria). Although the many

safeguards in these systems are ensuring the system operates safely, there is evidence that people are dying or losing capacity during the rigorous assessment process, and applying for assisted dying is very challenging. While continued focus on safety is essential, work is needed to ensure assisted dying systems can be effectively used by the patients they are designed to help.

- In particular, the requirement for prospective review and approval in Victoria (e.g. via a government permit) has been a cause of delay in accessing assisted dying.
- The Victorian prohibition on being able to raise assisted dying with patients has generally been seen as problematic as it impedes frank conversations about end-of-life choices.
- To date, there are a relatively small pool of doctors (and nurses where permitted) who have trained and are available to provide assisted dying. This can make access to assisted dying difficult, particularly in some areas.
- Some institutions have objected to assisted dying occurring on its premises. This has led to adverse consequences for some terminally-ill patients and their families.
- The thorough and planned implementation processes prior to the law coming into force ensured assisted dying operated safely as soon as the law began.
- The assisted dying care navigators have been pivotal to the effective operation of the assisted dying system.

Question 3: What are the professional and ethical considerations involved in allowing physicians to assist someone to end their life?

We support law reform to permit access to assisted dying under strict conditions and with robust oversight. This book chapter outlines the ethical and empirical reasoning that underpins our reasoning:

- Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson, *Tensions and Traumas in Health Law* (Federation Press, 2017).

A specific law reform issue: prior approval for assisted dying

We take this opportunity to address proposals advanced in the UK that if assisted dying is to be permitted, it should be subject to prior approval by the courts. We consider this will cause significant access issues. The Australian state of Victoria requires prior approval via a permit issued by a public servant before assisted dying is permitted. This has caused delays and access issues in practice, and our empirical study of this aspect of the Victorian system considers the implications of these findings for other jurisdictions considering prior review models:

- Ben White, Lindy Willmott, et al, 'Prospective Approval of Assisted Dying: A Qualitative Study of Doctors' Perspectives in Victoria, Australia' (2021) *BMJ Supportive and Palliative Care* (available early online).

We also note the book chapter on this specific topic in the context of the UK debates by Professor Penney Lewis. It is entitled 'Should Assisted Dying Require the Consent of a High Court Judge?' and is published in Ben White and Lindy Willmott (eds), *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021).

Question 8: What should the Government's role be in relation to the debate?

In this section, we make some observations about our research into law reform and assisted dying, as well as our participation in the six law reform exercises in the Australian states which have legalised assisted dying. This includes comment on the Government's role in this debate and on the need for law reform processes to be evidence-based.

Government resources can support better law reform deliberations

While votes in Australian parliaments have always been conscience votes for individual parliamentarians, some states provided government machinery to support consultation about whether law reform should occur, and if reform was recommended, to support the drafting of a Bill and the provision of accurate information about it. The impact of such Government support for the law reform process in the state of Victoria is discussed here:

- Lindy Willmott and Ben White, 'The Challenging Path to Voluntary Assisted Dying Law Reform in Australia' in Ben White and Lindy Willmott (eds), *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021) pp 84-112

While views may differ about whether assisted dying should be permitted or not, most would accept that careful consideration of the issue, with inclusive consultation is desirable. This points to Government support for a reform process, even when individual parliamentarians are exercising a conscience vote.

For wider consideration of law reform in the end-of-life area, we share the below book chapter. This chapter, a collaborative effort with international end-of-life scholars, examined law making and law reform drawing on ten case studies in six countries:

- White, Ben, Willmott, Lindy, Downie, Jocelyn, Lewis, Penney, Kitinger, Celia, Kitinger, Jenny, et al., 'International Perspectives on Reforming End-of-Life Law' in White, Ben P. & Willmott, Lindy (Eds.) *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021) pp. 250-275.

Law-making on assisted dying must be evidence-based

We advocate for evidence-based law-making, and consider this is particularly important in relation to a contested social policy area such as assisted dying. For example, there is a large body of reliable evidence about how assisted dying systems operate internationally. We outline the case for evidence-based law-making in:

- Ben White and Lindy Willmott, 'Evidence-based law making on voluntary assisted dying' (2020) 44(4) *Australian Health Review* 544-546

There is also evidence which is not reliable. For an example of a critical analysis of research which claimed to be reliable evidence for the New Zealand assisted dying referendum – but was in fact not reliable evidence, see:

- Ben White, Lindy Willmott, Jocelyn Downie, Andrew Geddis and Colin Gavaghan, 'Assisted dying and evidence-based law-making: A critical analysis of an article's role in New Zealand's referendum' (2020) 133(1520) *New Zealand Medical Journal* 83-90

In particular, we note the utility of an evidence pyramid (outlined in the two above-mentioned articles) to critically evaluate factual claims about assisted dying.

Concrete testing of eligibility criteria

We also recommend the concrete testing of eligibility criteria to understand properly the boundaries of a proposed assisted dying law. We undertook (with colleagues) an analysis of five assisted dying laws (three Australia models, Oregon and Canada) across nine different medical conditions to determine which models might permit access to assisted dying and for whom.

One key finding was that access to assisted dying under the Australian models like Victoria and Western Australia, and Oregon, which include a proposed time until death is likely to be the same when compared to our Model Bill (which does not have a time frame) regardless of the patient's medical condition. Those two papers also include a range of recommendations about law and regulation that we consider are important for parliaments and law-makers considering assisted dying laws:

- Ben White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663.
- Ben White et al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* 401.

Avoid incoherent law by ad hoc addition of safeguards

A final observation about the law-making process, based on what we have seen in the six Australian law reform processes, is the need to avoid the ad hoc addition of safeguards which are awkwardly tacked on to already sound law. This leads to the assisted dying law being incoherent or inconsistent in important ways.

An example of this in Australia is eligibility for assisted dying depending on a variable time period – 6 or 12 months until expected death – depending on the nature of a patient's illness (the longer period is only available for neurodegenerative conditions). This change in timing was a political compromise in Victoria which has since been uncritically adopted and replicated in all other states in Australia except Queensland. Yet this was only a last-minute addition to the Victorian Bill as a result of political compromise.

Our research has shown that the Victorian assisted dying law fails to meet its own stated policy goals in important respects, sometimes because of these later ad hoc additions during the law-making process:

- Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.

For this reason, we argue that any proposed changes to an assisted dying Bill must be carefully scrutinised in light of the Bill as a whole: [VAD here refers to voluntary assisted dying, the term used in Australia]

'When thinking about the politics of reform, it can be tempting to only consider each safeguard or process individually. Each may have merit and advance a particular policy goal. It may also be difficult politically to argue that a specific safeguard is not needed, particularly if it appears to achieve at least some useful purpose. However, when the safeguards are aggregated, the VAD system as a whole can become very complex and unwieldy, and slowly take the legislation away from its policy goals. This "policy drift by a thousand cuts" – the incremental loss of policy focus through accumulation of individual safeguards without reference to the whole – is a key issue for other states to consider when evaluating their proposed VAD reforms. It is suggested that each part of the law be evaluated both on its own, and also for its impact on the functioning of the overall system. This is needed to enable VAD laws to meet their policy goals, in particular, the two key goals at the core of the design of the VAD Act: safeguarding the vulnerable while respecting the autonomy of eligible persons who wish to access to VAD.'¹

We have also written on this point in 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks':

¹ Ben White, Katrine Del Villar, Eliana Close and Lindy Willmott, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417, 451.

'Taking a holistic view is also an important consideration more generally when designing VAD regulation. While it may be politically attractive to add numerous safeguards to VAD legislation, including in the eligibility criteria, there is a risk of what we have called elsewhere "policy drift by a thousand cuts" if the cumulative effect of these individual safeguards is not properly considered. For example, it is possible that a series of provisions designed to make VAD legislation safe, when aggregated, can in fact make access to VAD cumbersome or even unworkable.'²

Conclusion

Thank you for the opportunity to make a submission to the Committee in relation to its inquiry into assisted dying. We would be pleased to provide any further information to the Committee if that would be of assistance.

Jan 2023

² Ben P White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663, 1699.