

## International Perspectives on Reforming End-of-Life Law

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### INTRODUCTION

This book has shed light on how and why reform of law that regulates the end of life occurs. Law reform in any area can be challenging, but this is particularly so in relation to such a sensitive and complex field. The book drew together ten case studies from six jurisdictions (the United Kingdom, the United States, Canada, Australia, Belgium and the Netherlands) considering different aspects of end-of-life law reform. Some case studies were framed as practical ‘how to’ guides, providing direct lessons about how to achieve law reform. This perspective is novel because very little has been written articulating a ‘roadmap’ for reform in this area. Downie and Scallion’s analysis of how medical assistance in dying became part of Canadian law federally and the lessons for law reformers is one case study that does this. Another is the Kitzingers’ account of how their research and advocacy led to removal of a supposed requirement to obtain court approval before withdrawing artificial nutrition and hydration from certain patients.

Other case studies took a more conceptual approach to their analysis of law reform. For example, Orentlicher’s analysis of end-of-life law reform in the United States argues that moves to allow assisted dying are consistent with already existing values in the end-of-life field. Taking a different tack, Lewis charts how a law reform proposal for prior judicial approval for assisted dying can simultaneously attract support from both opponents and proponents of law reform, and yet fail to meet key regulatory goals.

Many of the case studies in this book are about law reform in relation to assisted dying. And we note at this point that this chapter will use this generic terminology of

\* The authors acknowledge that within the authorial team there is a diversity of views about what constitutes optimal end-of-life law. This includes differences in opinion about the various assisted dying models in operation internationally (and about assisted dying generally). The authors would like to acknowledge the helpful research assistance of Emily Bartels.

assisted dying (as explained in Chapter 1) unless the context requires otherwise.<sup>1</sup> This focus on assisted dying is not surprising given the current hive of activity on this distinct issue in many parts of the globe. But there are also three case studies outside that field which consider the regulation of withholding and withdrawing life-sustaining treatment: the Kitzingers' examination of the requirement for court approval to withdraw artificial nutrition and hydration in certain cases; Pope's analysis of the passing and subsequent challenges to the Texas Advance Directives Act (resolving medical treatment disputes that arise at the end of life); and Jackson's discussion of how the best interests test for medical decision-making evolved over time. This wider perspective is important because the issues that arise for assisted dying will be relevant for law reform of other areas of end-of-life law and vice versa. Nevertheless, given the focus on assisted dying in this book, much of the discussion below will necessarily focus on reform in the context of that issue.

The purpose of this final chapter is to draw together the themes that emerge from an analysis of these ten case studies. Although it is true, as noted in the opening chapter, that 'all politics is local',<sup>2</sup> there are patterns that emerge about end-of-life law reform that transcend jurisdictional boundaries and the particular case study being considered. This chapter employs the comparative law method<sup>3</sup> to explore these themes, as we can better understand our own individual law reform process by seeing it through different eyes. A global/comparative perspective enables us to realise that what may seem local and parochial is part of a wider movement of law reform internationally. In doing so, we aim to shed light on how and why law reform occurs in the end-of-life field, and by doing so to contribute to reflections about law reform more generally.

### CONCEPTUALISING LAW REFORM

Before considering reform in the context of end-of-life law, it is important to acknowledge two conceptual points about law reform. The first is that, as noted in the book's opening chapter, the term 'reform' implies that the change proposed or occurring is a positive advancement in law.<sup>4</sup> But the case studies, and the wider

<sup>1</sup> As outlined in Chapter 1, assisted dying is referred to using a variety of terms which differ by jurisdiction and ideological outlook (e.g. 'voluntary assisted dying', 'medical aid in dying' and 'euthanasia'). While authors have tended to use local terminology in their chapters, for the purposes of this comparative chapter, we will use the generic term 'assisted dying', as defined in Chapter 1, unless context requires otherwise.

<sup>2</sup> This was a famous saying of the former Speaker of the United States House of Representatives, Tip O'Neill: Andrew Heywood, *Politics*, 2nd ed. (New York, NY: Palgrave Macmillan, 2002), 157.

<sup>3</sup> Mark Van Hoecke, 'Methodology of Comparative Legal Research' (2015) December *Law and Method* 1–35.

<sup>4</sup> William H. Hurlburt, *Law Reform Commissions in the United Kingdom, Australia and Canada* (Edmonton: Juriliber, 1986), ch. 1.

literature on end-of-life law and bioethics, show that legal changes in this area are contested.<sup>5</sup> What one considers to be progress, others consider bad lawmaking. This is particularly evident in relation to assisted dying laws. It will be clear from this chapter and the case studies as a whole, that most, if not all, of the authors regard many of the reforms in this book as positive developments. Indeed, many actively advocated for change in the reform process described. Further, the academic work of many contributing authors also supports the reforms outlined in this book. We acknowledge therefore that law reform as a concept discussed in this book is not a value-neutral one.

The second conceptual point relates to the agent (or agents) *undertaking* law reform. In other words, who initiates law reform, who manages the reform process, and who is responsible for making decisions about matters such as whether or not to reform and if so, what change to law should occur? Traditionally, responsibility for law, and therefore law reform, has been seen as residing with the State, because ultimately law can be changed only by the State acting through parliament or the judiciary. If seen through this top-down lens, law reform is a State-led process in which non-State groups and individuals participate. Victoria's wide and inclusive reform process led by the Government, which ultimately resulted in the passing of its assisted dying laws, provides an excellent case study of this.

However, even accepting such a State-oriented reference point (and some do not),<sup>6</sup> non-State actors such as interest groups, organisations and individuals often play a critical role in law reform. While decisions about whether or not to change the law and what changes to make ultimately rest with the State, others can initiate and lead reform processes. In other words, while law reform can occur top-down, it may also be driven bottom-up.

Some of the case studies in this book provide examples of this. The Kitzingers' case study describes how they, as academics but also family members, initiated and drove a reform process aiming to change the supposed need for mandatory court supervision of some medical decisions in relation to patients with cognitive impairments. Similarly, the case of *Carter v. Canada (Attorney General)* ('Carter')<sup>7</sup> in Canada depended on individual litigants (supported by legal counsel and advocacy organisations) to initiate a challenge to the validity of the law as it then was, ultimately

<sup>5</sup> See for example Emily Jackson and John Keown, *Debating Euthanasia* (Oxford: Hart Publishing, 2011).

<sup>6</sup> Regulation theorists are increasingly arguing that regulation (of which law is a part) is becoming decentred, with non-State actors being pivotal in regulating or guiding behaviour in society: see, for example, Julia Black, 'Decentring Regulation: Understanding the Role of Regulation and Self-Regulation in a "Post-Regulatory" World' (2001) 45 *Current Legal Problems* 103–46 at 103–4; Julia Black, 'Critical Reflections on Regulation' (2002) 27 *Australian Journal of Legal Philosophy* 1–35 at 1–2. This is perhaps truer when talking about regulation other than law (e.g. policy or guidelines) given that law, narrowly construed, generally remains the province of the State.

<sup>7</sup> *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

resulting in a change to that law. Bottom-up reforms cannot occur without the State, at least when they require legal reform. As noted, the State controls formal changes to law. But they do remind us that there can be many agents of change in law reform.

### LAW REFORM CAN OCCUR THROUGH DIFFERENT REGULATORY PATHS

The two main paths for end-of-life law reform, as noted above, are legislative change or judicial change through the courts.<sup>8</sup> In terms of legislative reform, this may occur by passing a new piece of legislation or amending existing legislation. Most commonly, this occurs through parliament as illustrated, for example, in the cases of the Belgian, Victorian, Texan and Québec legislation. In some jurisdictions, new legislation could also come into force via a citizen or voter referendum, as occurred in Oregon in relation to its assisted dying laws and some of the other US states that followed those reforms, such as Washington and Colorado. It is also possible to have a combination of both. Although not one of the case studies in this book, in 2019, the New Zealand Parliament passed assisted dying legislation, which became law only because it was then approved by the public at a referendum during the country's election at the end of 2020.<sup>9</sup>

End-of-life law can also change through judicial decision. One of the case studies which provides an example of this is *Carter*<sup>10</sup> where the Canadian Supreme Court held that the blanket criminal law prohibition on assisting a person to die violated the Canadian Charter of Rights and Freedoms.<sup>11</sup> The Supreme Court's ruling meant that the federal parliament could not prohibit assisted dying when the conditions set out in the decision were met, for example, the person had a grievous and irremediable medical condition. This then prompted the federal parliament to develop a legislative framework for assisted dying.<sup>12</sup>

<sup>8</sup> For a wider discussion of the various paths to law reform for assisted dying, see Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16 *QUT Law Review* 84–112. Another path has been proposed in some US states. Because the practice of medicine is largely self-regulated, some have argued for reform through evolution in the standard of care: Kathryn Tucker, 'Aid in Dying: An End-of-Life Option Governed by Best Practices' (2012) 8 *Journal of Health and Biomedical Law* 9–26.

<sup>9</sup> End of Life Choice Act 2019 (NZ), s. 2; Electoral Commission of New Zealand, '2020 General Election and Referendums: Referendums Results', [https://electionresults.govt.nz/electionresults\\_sults\\_2020/referendums-results.html](https://electionresults.govt.nz/electionresults_sults_2020/referendums-results.html).

<sup>10</sup> *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

<sup>11</sup> Canada Act 1982 (UK), c. 11, sch. B, pt. 1, ss. 7, 15 ('Canadian Charter of Rights and Freedoms').

<sup>12</sup> Montana's case, *Baxter v. State*, 224 P 3d 1211 (Mont. 2009), is another example of assisted dying becoming lawful through judicial decision, although of note is that this case did not prompt a legislative response as in Canada. A further example of judicial initiation of reform is in Colombia where a decision of its Constitutional Court (Sentence C-239 (1997), Ref. Expedient D-1490 (Constitutional Court of the Republic of Colombia, 20 May 1997)) eventually prompted further regulation to permit access to assisted dying: see Penney Lewis, 'Legal Change on Assisted Dying', in S. Westwood (ed.), *Regulating the Ending of Life: Death Rights* (London: Routledge, 2021) (in press).

In contrast to cases such as *Carter*,<sup>13</sup> which adjudicate on statutes, changes to the common law through judicial decisions tend to be more incremental. This is illustrated in Jackson's chapter describing the evolution of the best interests test in England and Wales, following codification of factors relevant to a best interests assessment in the Mental Capacity Act 2005 (England and Wales).

Although not law, how actors behave at the end of life is also affected by policy and/or guidelines, which can be alternative paths to reform.<sup>14</sup> One of the case studies described challenges to the practice direction of the Court of Protection in England and Wales which stated that court approval was required for certain decisions to withdraw artificial nutrition and hydration. The culmination of that advocacy was a UK Supreme Court decision, *Re Y*<sup>15</sup> that concluded approval was not required as a matter of course. The abolition of the practice direction through a Court decision, brought about at least in part by advocacy, represents a significant example of law reform.

Another example, although not considered in this book, is the development of prosecutorial guidelines<sup>16</sup> which set out the factors that the Director of Public Prosecutions in England and Wales should take into account when deciding whether a person will be prosecuted for assisting another's suicide. Although they have not changed the law that governs assisted suicide, they have brought greater clarity and transparency to the question of whether a person is likely to face prosecution for assisting a suicide.

As is clear from the above discussion, the paths to law reform overlap. For example, judicial cases have prompted the enactment of legislation (*Carter*<sup>17</sup>), the production of guidelines (*R (Purdy) v. Director of Public Prosecutions*),<sup>18</sup> or the

<sup>13</sup> *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

<sup>14</sup> This can give rise to questions about what counts as law, but scholars are increasingly looking beyond the primary sources of law to include other normative forces in wider regulatory analyses about what shapes behaviour. See, for example, Black, 'Decentering Regulation', 103–4; Black, 'Critical Reflections on Regulation', 1–2.

<sup>15</sup> *An NHS Trust v. Y* [2018] UKSC 46.

<sup>16</sup> Director of Public Prosecutions, 'Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide', Crown Prosecution Service, October 2014, [www.cps.gov.uk/legal-guidance/suicide-policy-prosecutors-respect-cases-encouraging-or-assisting-suicide](http://www.cps.gov.uk/legal-guidance/suicide-policy-prosecutors-respect-cases-encouraging-or-assisting-suicide).

These guidelines were created after the House of Lords ruled that the Director of Public Prosecutions must create offence-specific prosecutorial guidelines for assisted suicide: *R (Purdy) v. Director of Public Prosecutions* [2010] 1 AC 345. Critiques of these guidelines include: Ben White and Jocelyn Downie, 'Prosecutorial Guidelines for Voluntary Euthanasia and Assisted Suicide: Autonomy, Public Confidence and High Quality Decision-Making' (2012) 36 *Melbourne University Law Review* 656–705; Jocelyn Downie and Ben White, 'Prosecutorial Discretion in Assisted Dying in Canada: A Proposal for Charging Guidelines' (2012) 6 *McGill Journal of Law and Health* 113–72. See also Penney Lewis, 'Informal Legal Change on Assisted Suicide: The Policy for Prosecutors' (2011) 31(1) *Legal Studies* 119–34.

<sup>17</sup> *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

<sup>18</sup> *R (Purdy) v. Director of Public Prosecutions* [2010] 1 AC 345.

abolition of a court's practice directions (*Re Y*).<sup>19</sup> In addition, guidelines and policies can shape how both cases and legislation are interpreted and operationalised.<sup>20</sup> The interaction between these sources of law (and 'soft' law of policies and guidelines<sup>21</sup>) suggests that law reform efforts are not focused only on a single legal instrument. This discussion also suggests that law reform is not a finite/discrete exercise with a definite end point. Although the law, once reformed, may stay that way, it also may change again as one reform may be overturned, qualified or explained by other developments that follow (more on this below).

The existence of different paths to law reform invites reflection about the relative strengths and weaknesses of legislation, case law and policy or guidelines in bringing about effective change. For example, there can be limitations in relying solely on case law to reform end-of-life law, particularly in relation to assisted dying. Unless a judicial decision prompts legislative or other regulatory reform, or a substantial body of case law emerges, it may be difficult to craft a comprehensive regulatory system through a handful of court judgements, which inevitably focus on the individual case before the court. If it is accepted that it is appropriate to have a detailed process for oversight and reporting of assisted dying, legislation provides a more appropriate vehicle to do that.<sup>22</sup>

Downie and Scallion, in contrasting the federal Canadian law with the Québec experience, also conclude in favour of reform initiated by the legislature rather than through the courts. They argue that the Québec legislative journey provided an opportunity for significant consultation and reflection in developing the law rather than having reform forced upon a parliament which then has to react, possibly within a tight time frame. When reform is initiated by a parliament, it has greater autonomy in designing its preferred legal framework, rather than having its parameters determined by the courts.<sup>23</sup> However, parliaments may judge that the public will be more accepting of change if they wait until they are required to act by the courts.

<sup>19</sup> *An NHS Trust v. Y* [2018] UKSC 46. Other overlap can be seen in this case, as formal guidance documents from leading medical bodies were explicitly acknowledged by the Supreme Court as part of the relevant regulatory framework considered in its deliberations: at [77], [107].

<sup>20</sup> See, for example, Canadian Association of MAID Assessors and Providers, "The Clinical Interpretation of "Reasonably Foreseeable"", January 2019, <https://camapcanada.ca/wp-content/uploads/2019/01/cpg1-1.pdf>.

<sup>21</sup> 'Soft law' refers to quasi-laws, such as rules, policies or guidelines, which are not enforceable in a legal sense, but influence both the interpretation of primary and delegated legislation and public behaviour. See, for example, Greg Weeks, *Soft Law and Public Authorities: Remedies and Reform* (Oxford: Hart Publishing, 2016), 13–17.

<sup>22</sup> Of course, not everyone accepts that such a process is appropriate: Tucker, 'Aid in Dying', 9–26.

<sup>23</sup> See also Lewis, 'Legal Change on Assisted Dying'.

## LAW REFORM IS MORE LIKELY TO SUCCEED WITH 'GOOD PROCESS'

Many of the case studies highlighted the importance of a good process in securing law reform, particularly those that occurred through legislation. There are a range of features that are generally agreed upon as being part of a 'good process' when making law or public policy. They include: an extended period of time for consideration; engagement with available evidence about current practice and the need for reform; open public and professional dialogue about reform; and clear communication with the community about the nature of the proposed reform.<sup>24</sup>

Some of these are discussed further below in other sections but it is widely agreed that at the heart of a good law reform process is broad and inclusive consultation.<sup>25</sup> As Willmott and White note in relation to the Victorian assisted dying reforms, two key purposes of consultation are optimal design of the law and building support for the law by involving key stakeholders in the process.<sup>26</sup> Consistent with reforms in areas outside of end-of-life law,<sup>27</sup> wide consultation has been significant for successful reform in the case studies considered. As noted already, the extended Victorian assisted dying reform process was rated positively<sup>28</sup> and this was an integral factor which facilitated the eventual passage of the legislation. Consensus-building processes were also regarded as being pivotal in the Texas reforms and in Québec.<sup>29</sup>

<sup>24</sup> These (and other) elements are outlined in the 'Wiltshire Test: Ten Criteria for a Public Policy Business Case': Matthew Lesh, 'Evidence Based Policy Research Project' (2018 Institute of Public Affairs) 5–6; John H. Howard, 'Public Policy Drift: Why Governments Must Replace "Policy on the Run" and "Policy by Fiat" with a "Business Case" Approach to Regain Public Confidence' (2012 Institute of Public Administration Australia) vii–viii. For other discussions of 'good process' in making law or public policy see Michael Hallsworth and Jill Rutter, 'Making Policy Better: Improving Whitehall's Core Business' (2011 Institute for Government) 14; Andrew Wyatt, 'Policy Cycle Models: Are We Throwing the Baby Out with the Bath Water?', in Gemma Carey, Kathy Landvogt and Jo Barraket (eds.), *Creating and Implementing Public Policy: Cross-Sectoral Debates* (New York, NY: Routledge, 2016), 41–57.

<sup>25</sup> See, for example, Peter M. North, 'Law Reform: Processes and Problems' (1985) 101 *Law Quarterly Review* 338–58. See also the extended discussions of the importance of consultation for law reform in a range of settings in Brian Opeskin and David Weisbrot (eds.), *The Promise of Law Reform* (Leichhardt: The Federation Press, 2005).

<sup>26</sup> See also Peter M. North, 'Law Reform: The Consultation Process' (1982) 6 *Trent Law Journal* 19–31.

<sup>27</sup> See, for example, successful law reform efforts following extensive consultation in areas of Australian succession law and anti-discrimination law in Sarah Moulds, 'Community Engagement in the Age of Modern Law Reform: Perspectives from Adelaide' (2017) 38 *Adelaide Law Review* 441–62; and criminal law in Eurydice Aroney and Penny Crofts, 'How Sex Worker Activism Influenced the Decriminalisation of Sex Work in NSW, Australia' (2019) 8 *International Journal of Crime, Justice and Social Democracy* 50–67.

<sup>28</sup> Lesh, 'Evidence Based Policy Research Project'.

<sup>29</sup> Also of note, in Jersey, is a more recent innovation in participation in law reform processes for assisted dying through the proposed use of citizen juries: Government of Jersey, 'Jersey Assisted Dying Citizens' Jury', [www.gov.je/Caring/AssistedDying/Pages/CitizensJuryOnAssistedDying.aspx](http://www.gov.je/Caring/AssistedDying/Pages/CitizensJuryOnAssistedDying.aspx).

The opposite was noted in relation to the Canadian federal law case study: a failure to consult with experts contributed to the drafting of the legislation being problematic, and a resulting negative response from many.

Hillyard and Dombrink's study of the Oregon assisted dying law reform process also identified the significance of engaging with stakeholders across a range of fields and the value of building a broad coalition of diverse stakeholders in support of the law.<sup>30</sup> But it is not just in the top-down legislative setting that good process is important. The Kitzingers' case study also involved building a coalition of supporters interested in challenging the requirement for court approval. They included health and legal practitioners and academics, as well as families of patients subject to this requirement. Recognising that reform can also be generated from the bottom-up, the principles of wide and inclusive consultation with all key stakeholders apply here as well.

Who to consult and involve in the law reform process is critical. One key group noted in some of the case studies was the medical profession. Doctors are integrally involved in providing end-of-life care, and medical associations and groups also wield considerable lobbying power in policy-making.<sup>31</sup> The technical knowledge and expertise of the medical profession empowers it both to support change or block it. The role and participation of medical organisations in end-of-life law reform has differed depending on their attitude or involvement in different countries, and the social and political roles of its organisations. (Indeed, this diversity in medical opinion on assisted dying exists among doctors as *individuals*, with palliative care specialists – at least in some countries – expressing opposition to reform at a higher rate than other specialties, whose views have tended to be more mixed.<sup>32</sup>)

At one end of the spectrum, the medical profession has traditionally been seen as a major barrier to assisted dying reform, often by framing assisted dying as incompatible with professional medical ethics. For example, this has been the case in the United Kingdom and Australia, where the major medical associations have generally opposed reform.<sup>33</sup> At the other end of the spectrum, assisted dying reform in Québec

<sup>30</sup> Daniel Hillyard and John Dombrink, *Dying Right: The Death with Dignity Movement* (New York, NY: Routledge, 2001).

<sup>31</sup> Jenny M. Lewis, *Health Policy and Politics: Networks, Ideas and Power* (East Hawthorn, Vic: IP Communications, 2005); Jenny M. Lewis, 'Being Around and Knowing the Players: Networks of Influence in Health Policy' (2006) 62 *Social Science and Medicine* 2125–36.

<sup>32</sup> C. Seale, 'Legalisation of Euthanasia or Physician-Assisted Suicide: Survey of Doctors' Attitudes' (2009) 23 *Palliative Medicine* 205–12; Linda Sheahan, 'Exploring the Interface between "Physician-Assisted Death" and Palliative Care: Cross-Sectional Data from Australasian Palliative Care Specialists' (2016) 46 *Internal Medicine Journal* 443–51.

<sup>33</sup> BMA, 'The BMA's Position on Physician-Assisted Dying: The BMA's Policy Position on Voluntary Assisted Dying and How It Has Been Reached', *British Medical Association*, 28 February 2020, [www.bma.org.uk/advice-and-support/ethics/end-of-life/the-bmas-position-on-physician-assisted-dying](http://www.bma.org.uk/advice-and-support/ethics/end-of-life/the-bmas-position-on-physician-assisted-dying); AMA, 'Euthanasia and Physician Assisted Suicide', Position Statement from the Australian Medical Association (2016 AMA), <https://ama.com.au/system/tdf/documents/AMA%20Position%20Statement%20on%20Euthanasia%20and%20Physician%20Assisted%20Suicide%202016.pdf?file=1&type=node&id=45402>. See also Jodhi Rutherford,



emerged from and was driven by the medical regulator, le Collège des Médecins du Québec. In that province, the conceptualisation of assisted dying in certain circumstances as being an act of care located this issue within the medical domain and, therefore, it was seen to be the responsibility of the professional regulator to address it. The importance of some support for reform within the medical profession is also seen in the case study examining the extension of the Belgium assisted dying law to minors. Hillyard and Dombrink also consider that careful engagement with the medical profession about the Oregon assisted dying law led to the neutrality of key medical groups who had traditionally opposed changing the law.<sup>34</sup>

A related theme is the use of experts<sup>35</sup> in law reform. The case studies from Victoria (which took an approach that Western Australia largely followed<sup>36</sup>), Québec, Belgium and the Netherlands all reported the engagement of experts in law reform processes in various ways such as the establishment of expert panels to advise governments or formal hearings with experts to share their knowledge. Expert participation is likely to have dual functions: it helps improve proposed decision-making about what sort of law to enact, but also lends credibility to the reform process and its resulting law. The Ministerial Advisory Panel established in Victoria to develop the legislative framework is a good example of this, particularly given it comprised respected leaders in diverse fields.

Experts can also be pivotal in reform through judicial cases. The *Carter*<sup>37</sup> litigation drew heavily on experts providing social science evidence that assisted dying

'The Role of the Medical Profession in Victorian Assisted Dying Law Reform' (2018) 26 *Journal of Law and Medicine* 246–64. Ball also notes that some consider the American Medical Association as the strongest secular opponent to assisted dying reform in that country: Howard Ball, *At Liberty to Die: The Battle for Death with Dignity in America* (New York, NY: New York University Press, 2012).

<sup>34</sup> Hillyard and Dombrink, *Dying Right*. See also Ball's discussion of the role of medical groups in the historical analysis of law reform in the US: Ball, *At Liberty to Die*.

<sup>35</sup> We note though that while law reform processes have typically engaged doctors and academics as experts, who is considered an 'expert' is contested and changing. For example, patients and their carers or family members have been recognised as experts regarding their own care: Ian Kramer, 'Patients as Experts' (2005) 12 *Nursing Management* 14–15; Kerstin Blomqvist, Eva Theander, Inger Mowide and Veronica Larsson, 'What Happens When You Involve Patients as Experts?: A Participatory Action Research Project at a Renal Failure Unit' (2010) 17 *Nursing Enquiry* 317–23. Family members have also been found to be active participants in assisted dying decision-making: Bernadette Roest, Margo Trappenburg and Carlo Leget, 'The Involvement of Family in the Dutch Practice of Euthanasia and Physician Assisted Suicide: A Systematic Mixed Studies Review' (2019) 20 *BMC Medical Ethics* 1–21; Marianne C. Snijdewind, Donald G. van Tol, Bregje D. Onwuteaka-Philipsen and Dick L. Willems, 'Complexities in Euthanasia or Physician-Assisted Suicide as Perceived by Dutch Physicians and Patients' Relatives' (2014) 48 *Journal of Pain and Symptom Management* 1125–34.

<sup>36</sup> Final Report from the Ministerial Expert Panel on Voluntary Assisted Dying (2019 Government of Western Australia, Department of Health).

<sup>37</sup> *Carter v. Canada (Attorney General)* [2012] BCSC 886, affirmed by *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

systems can be implemented safely (this is discussed further below).<sup>38</sup> Experts can also have an important role to play *after* a relevant law has been passed. The ongoing evaluation of the assisted dying law described in the Netherlands case study is an example of how experts' assessment of a law's operation can determine whether changes in law and practice are required. Another example of expert review following legislative enactment is the work of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. The Expert Panel reported on issues flagged in the federal legislation for further review: access by mature minors, advance requests and access solely for mental illness.<sup>39</sup>

A law reform process can generate credibility in other ways. A key finding from the Victorian case study was the significance of the government, rather than a single member of parliament in their individual capacity, leading the assisted dying reform process. Assisted dying is generally treated as a conscience issue, so each member of a parliament is allowed to vote according to their conscience rather than according to party lines.<sup>40</sup> For example, conscience voting occurred in the Belgian law extension to minors, in Québec, and in Victoria (and indeed in all Australian parliamentary votes on this topic<sup>41</sup>). But even with the choice that a conscience vote provides for individual parliamentarians, it is significant if the carriage of the reform, including advocacy in support of (or at least explaining the justification for) change, has rested with the government rather than an individual. This obviously has implications for the likelihood of success if only because of the differential level of resourcing available for government-led reform. However, the fact that a government is leading reform, rather than an individual parliamentarian, also lends

<sup>38</sup> Jocelyn Downie, 'Social Science and Humanities Evidence in Charter Litigation: Lessons from *Carter v Canada* (Attorney General)' (2018) 22 *The International Journal of Evidence and Proof* 305–13. Downie and Scallion's chapter in this book also notes that this evidence was critical in the subsequent case of *Truchon v. Attorney General of Canada* [2019] QCCS 3792 (CanLII), challenging Canada's federal legislation.

<sup>39</sup> 'The State of Knowledge on Medical Assistance in Dying for Mature Minors', Report from the Expert Panel on Medical Assistance in Dying (2018 Council of Canadian Academies); 'The State of Knowledge on Advance Requests for Medical Assistance in Dying', Report from the Expert Panel on Medical Assistance in Dying (2018 Council of Canadian Academies); 'The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition', Report from the Expert Panel on Medical Assistance in Dying (2018 Council of Canadian Academies).

<sup>40</sup> Note, however, that despite a conscience vote being offered, this may not always result in a free vote as informal party pressure can be brought to bear: Lindy Willmott and Ben White, 'Private Thoughts of Public Representatives: Assisted Death, Voluntary Euthanasia and Politicians' (2003) 11 *Journal of Law and Medicine* 77–92; Lindy Willmott, Ben White, Christopher Stackpoole, Kelly Purser and Andrew McGee, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39 *University of New South Wales Law Journal* 1–46 at 13–14; Alison Plumb, 'The Future of Euthanasia Politics in the Australian State Parliaments' (2014) 29 *Australasian Parliamentary Review* 67–86.

<sup>41</sup> Willmott et al., '(Failed) Voluntary Euthanasia Law Reform in Australia', 13.

credibility to the process. This shifts assisted dying from a fringe reform effort to the mainstream and one to be taken seriously.

### LAW REFORM OFTEN REQUIRES COMPROMISE

Law reform, regardless of the topic, often requires compromise.<sup>42</sup> The analogy sometimes given is choosing between half a loaf of bread (an imperfect reform that is the subject of compromise) or starving (insisting on what might be an optimal model which fails to become law). Reform in the end-of-life field is no exception, and indeed there may be a greater imperative for compromise given the strong and vested interests as reflected in the historical difficulties in passing assisted dying legislation. How much to compromise, or indeed whether to compromise at all, is a challenging question and case studies in this book illustrate the sorts of compromises that might be needed to effect change.

In Belgium, for example, to secure agreement to expand the assisted dying laws to include access to minors, more restrictive eligibility criteria and additional safeguards for this cohort were included. Indeed, the issue of access for minors was the subject of compromise in the original 2002 law, and was excluded at that time to secure the necessary political support for law reform. Similarly, the Texas Advance Directives Act only passed because of negotiation and compromise amongst key groups which led to a new agreed model.

Legislative compromise is often the result of the necessity to generate sufficient political support for a law to pass. Both of the examples given above involved the formation of unusual coalitions. In Belgium, the coalition was between both government and non-government parties. For the Texas reforms, the Texas Advance Directives Coalition brought together a diverse group of organisations that might ordinarily be expected to have very different views such as medical and health care associations and disability, right to life and elder rights organisations. The process of reaching consensus required explicit compromise about the precise terms of the law.

One (unsurprising) outcome of compromise is the likelihood of settling on a narrow or conservative legal model. It is easier to gain the necessary political and public support for law reform that is modest and incremental. This was the case in Oregon where an assisted dying model was advanced that permitted only physician-assisted dying (i.e. writing a prescription for medication which the patient themselves must take rather than a physician administering that medication).<sup>43</sup> Similarly, the Victorian Premier, Daniel Andrews, proclaimed the Victorian assisted dying

<sup>42</sup> See, for example, North, 'Law Reform: Processes and Problems', 338–58; Laura Barnett, 'The Process of Law Reform: Conditions for Success' (2011) 39 *Federal Law Review* 161–93.

<sup>43</sup> Hillyard and Dombrink, *Dying Right*.

legislation to be the most conservative model in the world.<sup>44</sup> The proposed requirement for prior judicial approval for assisted dying in the United Kingdom further illustrates the conservative results of compromise. In discussing the ‘consensus’ that appears to have emerged, Lewis observes that even proponents of assisted dying have accepted this arguably impractical requirement in the interests of gathering sufficient political support. A final example may also be the decision of the Canadian government to pass its federal assisted dying law, but identify for further review the issues of access for mature minors, access solely for mental illness and advance requests for assisted dying.

A second outcome of compromise is that it can lead to a failure to achieve desired regulatory goals. Lewis’s analysis of the proposal for prior judicial review before assisted dying can be accessed demonstrates a failure to meet suggested regulatory goals. For example, the time taken for such a process may have the practical effect of precluding access for a person who typically seeks assisted dying, namely a cancer patient with a limited time to live. This disconnect between the law and its regulatory goals can occur because the decision to accept a particular compromise is a tactical, rather than a principled one. A recent analysis of the Victorian assisted dying law has also concluded that in some respects it has failed to align with its own publicly identified regulatory goals.<sup>45</sup> The recent experience in Canada also reflects a failure to achieve the required regulatory outcome. There were discrepancies between the principles that had to guide law reform (here, constitutional rights that the Supreme Court found had been breached by the Canadian criminal law which prohibited all forms of assisted dying) and the actual law passed by the Canadian parliament in response to the *Carter*<sup>46</sup> decision.<sup>47</sup>

#### LAW REFORM IS INCREASINGLY DEPENDENT ON EVIDENCE

One noteworthy trend, which perhaps features more prominently in law reform in the end-of-life area than in other legal contexts, is the use of evidence. Historically, lawmaking has not engaged with evidence in the same way as in other fields.<sup>48</sup>

<sup>44</sup> Premier Daniel Andrews, ‘Voluntary Assisted Dying Model Established Ahead of Vote in Parliament’, Office of the Premier of Victoria, 25 July 2017.

<sup>45</sup> Ben P. White, Katrine Del Villar, Eliana Close and Lindy Willmott, ‘Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?’ (2020) 43 *University of New South Wales Law Journal* 417–51. US states are also considering whether their traditional safeguards are too burdensome and are unduly restricting access: see, for example, H.B. 2419, 2020 Leg., 66th Sess. (Wash. 2020) (studying barriers to the use of the Washington Death with Dignity Act: Death with Dignity Act, Wash Rev Code § 70.245 (2008) (Washington)).

<sup>46</sup> *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

<sup>47</sup> The legislation was found to have breached the Canadian Charter of Rights and Freedoms (the very same rights that were at the heart of *Carter v. Canada (Attorney General)* [2015] 1 SCR 331) in *Truchon v. Attorney General of Canada* [2019] QCCS 3792 (CanLII).

<sup>48</sup> Jeffrey J. Rachlinski, ‘Evidence-Based Law’ (2011) 96 *Cornell Law Review* 901–24.

While evidence-based medicine,<sup>49</sup> evidence-based health policy<sup>50</sup> and evidence-based business<sup>51</sup> have all become established approaches in those fields, evidence-based approaches are yet to fully gain traction in the discipline of law. But this is changing and there are increasing calls for evidence-based lawmaking,<sup>52</sup> including in relation to end-of-life law and particularly assisted dying, which lends itself to fact-based arguments.<sup>53</sup>

This trend towards greater use of evidence in lawmaking is evident in many of the case studies considered in this book. Social science evidence about how assisted dying regimes operated in countries where it is lawful was the subject of extensive consideration by the trial judges in the *Carter* and *Truchon v. Attorney General of Canada* ('*Truchon*') decisions.<sup>54</sup> This research was tendered to the court and some of the experts who produced this research were called to give evidence and subject to cross-examination.<sup>55</sup> The trial judge in *Carter* explicitly based some of her findings on the evidence that it was possible to design a safe and effective assisted dying system.<sup>56</sup> These findings were not disturbed on appeal. This same evidence was also considered and relied upon by the parliamentary committees in the Victorian (and later Western Australian) reform processes. Evidence about the Oregon regime was also regarded as influential in supporting reform in subsequent US states. For example, when deliberating about assisted dying reform in Washington, Ball notes the significance of considering a decade of experience under Oregon's laws.<sup>57</sup> Finally, empirical evidence about the incidence of assisted dying in a country *before* it is lawful has also been influential in law reform. Evidence that assisted dying was already happening in Belgium prior to the 2002

<sup>49</sup> David L. Sackett, William M. C. Rosenberg, J. A. Muir Gray, R. Brian Haynes and W. Scott Richardson, 'Evidence Based Medicine: What It Is and What It Isn't' (1996) 312 *BMJ* 71–2.

<sup>50</sup> Katherine Baicker and Amitabh Chandra, 'Evidence-Based Health Policy' (2017) 377 *New England Journal of Medicine* 2413–15.

<sup>51</sup> Vishwanath V. Baba and Farimah Hakem Zadeh, 'Toward a Theory of Evidence Based Decision Making' (2012) 50 *Management Decision* 832–67.

<sup>52</sup> See, for example, Rachlinski, 'Evidence-Based Law'; Scott Burris, Laura Hitchcock, Jennifer Ibrahim, Matthew Penn and Tara Ramanathan, 'Policy Surveillance: A Vital Public Health Practice Comes of Age' (2016) 41 *Journal of Health Politics, Policy and Law* 1151–73.

<sup>53</sup> Ben P. White and Lindy Willmott, 'Evidence-Based Law-Making on Voluntary Assisted Dying' (2020) 44(4) *Australian Health Review* 544–546.

<sup>54</sup> *Carter v. Canada (Attorney General)* [2015] 1 SCR 331; *Truchon v. Attorney General of Canada* [2019] QCCS 3792 (CanLII); Downie, 'Social Science and Humanities Evidence in Charter Litigation', 305–13.

<sup>55</sup> See, for example, the complete list of experts called by the plaintiffs, the Attorney General (Canada) and the Attorney General (British Columbia): *Carter v. Canada (Attorney General)* [2012] BCSC 886 at [160]. Note also that this is a further example of experts being used as an important part of the reform process, as noted above.

<sup>56</sup> *Carter v. Canada (Attorney General)* [2012] BCSC 886, affirmed by *Carter v. Canada (Attorney General)* [2015] 1 SCR 331 at [3], [8].

<sup>57</sup> Ball, *At Liberty to Die*.

law<sup>58</sup> was a key factor for reform, with some arguing that regulation of this practice was needed.

One key outcome of the use of evidence in law reform debates is what has been referred to as a 'shrinking battlefield'.<sup>59</sup> Because there is evidence that assisted dying regimes can operate safely and effectively, arguments against reform which make claims about risks to the vulnerable should now be hard to sustain. This reduced ground to marshal arguments against assisted dying has shaped the nature of assisted dying debates and made reform more likely. This evidence can also change the views of some who, after engaging with the evidence, reduce their opposition to assisted dying reform, or indeed may be willing to support it.

It is not just in relation to assisted dying that evidence has been influential in bringing about reform. The Kitzingers' case study about withdrawing artificial nutrition and hydration reports on the systematic research undertaken by them and others to document the economic and personal costs of applying for court approval to withdraw treatment. This evidence was translated into easy to digest forms to assist with its wide dissemination to policy-makers and key stakeholders, ultimately supporting the case for change. This evidence was also placed before the UK Supreme Court in *Re Y*,<sup>60</sup> and informed professional guidance issued by the British Medical Association and the Royal College of Physicians. On the other hand, a perceived *lack* of evidence about the operation of the Texas Advance Directives Act (e.g. it is unknown the number and demographic characteristics of patients who have had the dispute resolution process invoked) was identified as contributing to the persistent challenges that have been mounted against it.

## AN ENVIRONMENT CONDUCTIVE TO LAW REFORM

Many of the case studies of successful reform also include discussions of failed attempts to change the law about assisted dying. Many of those reform efforts have been long-standing. In Australia, after earlier success with the Northern Territory legislation, there were approximately forty Bills aiming to change the law in Australia before the Victorian, and now Western Australian and Tasmanian, law changed.<sup>61</sup>

<sup>58</sup> Luc Deliens, Freddy Mortier, Johan Bilsen, Marc Cosyns, Robert Vander Stichele, Johan Vanoverloop and Koen Ingels, 'End-of-Life Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey' (2000) 356 *The Lancet* 1806–11.

<sup>59</sup> Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42 *Australian Health Review* 616–20.

<sup>60</sup> *An NHS Trust v. Y* [2018] UKSC 46.

<sup>61</sup> Willmott et al., '(Failed) Voluntary Euthanasia Law Reform in Australia', 1–46; White and Willmott, 'Future of Assisted Dying Reform in Australia', 616–20. For a comprehensive analysis of the arguments raised by politicians in debates on these Bills, see Andrew McGee, Kelly Purser, Christopher Stackpoole, Ben White, Lindy Willmott and Juliet Davis, 'Informing the Euthanasia Debate: Perceptions of Australian Politicians' (2018) 41 *University of New South Wales Law Journal* 1368–417.

Lewis notes ten failed attempts at reform in the UK Parliament to date, and almost twenty years elapsed after the *Rodriguez v. British Columbia (Attorney General)*<sup>62</sup> case before the Canadian law was again challenged in *Carter*.<sup>63</sup> In Belgium, there had been ongoing discussion, even since the debates at the time the initial law passed in 2002, about whether assisted dying should extend to minors.

So, what factors contribute to an environment conducive to law reform? It has already been observed that a good process that includes engagement with experts and key stakeholders is more likely to lead to reform. But there can be other wider factors that may contribute to a favourable reform ‘environment’ such as the emergence of influential individuals or groups, legal changes outside the end-of-life law field, shifts in community sentiment and when the political parties represented in parliaments favour reform.

An important component in a reform environment is the leadership of one or more individuals in advancing the debate. There is a long history of the advocacy of individuals or a small group in bringing about social change and law reform more generally and that also appears to be true in the end-of-life field. The Victorian assisted dying case study names a number of key individuals whose leadership roles in politics, public advocacy and policy-making were influential in the assisted dying law passing.<sup>64</sup> In a different way, Gloria Taylor and Kay Carter’s family as plaintiffs in the Canadian Charter of Rights and Freedoms challenges were pivotal to the law changing there. The same could be said for Jean Truchon and Nicole Gladu in the subsequent litigation in Québec. The Kitzingers themselves could also be included in this category as academic advocates and family members arguing for change. In some instances, the participation of a key group rather than an individual has been decisive in law reform efforts. The Québec assisted dying reform provides a good illustration of a key group, here its medical regulator, playing an important role in framing the eventual debate about reforming the law.

Another example, this time from the United States, was twenty-nine-year-old Brittany Maynard who moved to Oregon to access assisted dying for a brain cancer and whose advocacy is widely regarded as critical for the passage of assisted dying legislation in California. A key feature of Maynard’s advocacy from a law reform perspective was the successful harnessing of the media.<sup>65</sup> In the weeks before her death, Maynard and her husband, Dan Diaz, partnered with the advocacy group

<sup>62</sup> *Rodriguez v. British Columbia (Attorney General)* [1993] 3 SCR 519.

<sup>63</sup> *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

<sup>64</sup> These key figures included: former Chief Minister of the Northern Territory, Marshall Perron; Premier of Victoria, Daniel Andrews; former Minister for Health, Jill Hennessy MP; media personality, Andrew Denton; neurosurgeon and former federal President of the Australian Medical Association, Professor Brian Owler; and retired urologist and activist, Dr Rodney Syme.

<sup>65</sup> Kimberly Lauffer and Sean Baker, ‘U.S. Media Coverage of Brittany Maynard’s Choice to Die: How Ideology and Framing Converged’ (2019) 12 *Atlantic Journal of Communication* 1–14.

Compassion and Choices, to publicise her story.<sup>66</sup> The video interview they created immediately garnered considerable public and media attention globally.<sup>67</sup> She recorded a second video which was tendered as evidence to the California legislature ahead of the Senate committee vote on the State's assisted dying law.<sup>68</sup> These examples of individual or organisational advocacy are linked to the conceptual point made at the outset of this chapter that reform can occur both from the top-down and from the bottom-up. However, regardless of where a reform process sits within this spectrum, it is clear that key individuals and organisations can have decisive roles as instigators and/or drivers of reform.

An environment for law reform may also develop because of a change in a different, although related, legal context. For example, the *Carter*<sup>69</sup> challenge was made possible because of changes in Charter jurisprudence. These occurred in non-assisted dying contexts, but were capable of being applied to the blanket criminal law prohibition against assisted dying. That new legal environment was pivotal to the success of the *Carter*<sup>70</sup> challenge.

Other changes may be more incremental, so that the window for reform is not flung open at once but slowly pushed further and further ajar. The gradual accumulation of empirical evidence that assisted dying regimes can operate safely (mentioned above) is one such example. Perhaps another is the gradual shift of community sentiment in support of reform, as occurred in Oregon. Clark examined the right to die movement in the United States and why the use of citizen-initiated ballot measures had been an effective vehicle of law reform (she considers the initial failure to pass laws in Washington and California, followed by success in Oregon<sup>71</sup>).

<sup>66</sup> 'Brittany Maynard', Compassion and Choices, 2020, <https://compassionandchoices.org/stories/brittany-maynard>. See also Barbara Coombs Lee and David Grube, 'Medical Aid in Dying: The Cornerstone of Patient-Centered Care' (2017) 41 *Generations: Journal of the American Society on Aging* 39–41.

<sup>67</sup> At the time of her death, Maynard's video was reported to have over nine million views on YouTube: BBC, 'Right-to-Die Advocate Brittany Maynard Ends Life', *BBC News*, 3 November 2014, [www.bbc.com/news/world-us-canada-29876277](http://www.bbc.com/news/world-us-canada-29876277). An exclusive story of Maynard's death on the *People* magazine website had the largest audience any Time Inc. brand publication had ever had for a single story, according to internal figures: Michael Sebastian, 'Brittany Maynard Story Leads to Record Digital Traffic for People', *Ad Age*, 6 November 2014, <https://adage.com/article/media/brittany-maynard-story-sets-digital-traffic-record-people/295738>.

<sup>68</sup> Eliana Dockerman, 'Watch Brittany Maynard's Video in Support of Right-to-Die Legislation', *Time*, 25 March 2015, <https://time.com/3759208/brittany-maynard-right-to-die-video-california/>.

<sup>69</sup> *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

<sup>70</sup> *Ibid.*

<sup>71</sup> Nina Clark, *The Politics of Physician Assisted Suicide* (New York, NY: Routledge, 1997). See also Thaddeus M. Pope, 'Legal History of Medical Aid in Dying: Physician Assisted Death in U.S. Courts and Legislatures' (2018) 48 *New Mexico Law Review* 267–301. Early assisted dying reform in Washington, California and Oregon involved a citizen-initiated ballot process in which a petition signed by registered voters could lead to a public vote on proposed legislation if sufficient support was achieved. In California, a 1988 attempt failed to achieve sufficient support to place legislation authorising both self-administration and practitioner administration assisted dying on the ballot. Further attempts restricted to legislation permitting



She concludes that a failure of the traditional policy machinery of government to engage substantively with the issue combined with a sense that ‘time had come’ for assisted dying meant that these initiatives were a logical outlet for this desire for change.<sup>72</sup>

A final, and perhaps obvious, example is the political environment in which end-of-life reform is considered. For example, the composition of a parliament will have a significant impact on the likelihood of a law being passed and the content of any such law. Particularly critical here is the political philosophy of the governing party or parties. Historically, socially progressive parties are more likely to undertake and support reform than conservative or religiously aligned parties.<sup>73</sup> Of course, reform may be required of governments, regardless of their political philosophy, to comply with constitutionally entrenched human rights, as occurred in Canada. But generally speaking, changes are more likely to occur with progressive governments, as recently occurred in Victoria. This was also the case in the Netherlands where the assisted dying legislation was enacted while the coalition government was comprised of liberals and social democrats and did not include the Christian Democratic Party.<sup>74</sup>

The foregoing discussion reveals some themes that transcend individual case studies. However, the factors that will ultimately lead to reform in any one jurisdiction at any particular time are idiosyncratic. The impact of particular individuals, the position and involvement of key groups and the composition of parliaments will vary in each jurisdiction. To this extent, as mentioned earlier, all politics is local. The triggers for change and how the window for reform arises will vary significantly from place to place. That said, being attentive to external factors which can make an

self-administration in Washington, in 1991, and California, in 1992, failed at the ballot stage. Oregon enacted its assisted dying legislation successfully using the ballot process in 1994 after remodelling its campaign and inclusions based on the previous failed attempts. Washington also passed legislation modelled on the Oregon Act through a successful ballot initiative in 2008. Colorado passed nearly identical legislation through a ballot initiative in 2016.

<sup>72</sup> Clark, *The Politics of Physician Assisted Suicide*. It is significant to note that those early pre-1994 ballot initiatives were for both self-administration and practitioner administration assisted dying. All subsequent bills in the United States have been limited to legislation permitting only self-administration: Pope, ‘Legal History of Medical Aid in Dying’, 267–301.

<sup>73</sup> Although not always. For example, the Northern Territory assisted dying legislation was passed when a conservative government was in power: Willmott et al., ‘(Failed) Voluntary Euthanasia Law Reform in Australia’, 13.

<sup>74</sup> John Griffiths, Heleen Weyers and Maurice Adams, *Euthanasia and Law in Europe: With Special Reference to the Netherlands and Belgium* (Portland, OR: Hart Publishing, 2008), 29–50; Heleen Weyers, ‘Euthanasia: The Process of Legal Change in the Netherlands: The Making of the “Requirements of Careful Practice”’, in A. Klijn, F. Mortier, M. Trappenburg and M. Otłowski (eds.), *Regulating Physician-Negotiated Death* (The Hague: Elsevier, 2001), 11–27; Francis Pakes, ‘Under Siege: The Global Fate of Euthanasia and Assisted-Suicide Legislation’ (2005) 13 *European Journal of Crime and Justice* 119–35; Francis Pakes, ‘Tolerance and Pragmatism in the Netherlands: Euthanasia, Coffeeshops and Prostitution in the “Purple Years”, 1994–2002’ (2003) 5 *International Journal of Police Science and Management* 217–28.

environment ripe for reform may be strategic for those seeking to bring about change, or they may even wish to take steps to try and create such an environment.

The other global observation about environment is that reform generally only occurs after persistent agitation for change. Reform on any topic rarely happens quickly and this seems particularly so in the end-of-life field. All of the case studies described, in various ways, were the result of a long process which finally culminated in reform.

### CRITICAL EVALUATION OF LAW REFORM AND PROPOSED LAW REFORM IS IMPORTANT

The case studies show that critical evaluation of proposed laws and indeed laws which have been enacted is important. The reason for evaluating proposed reforms is self-evident. The utility of a law and its likelihood of achieving proposed policy goals are important to consider when deciding whether or not the law, as proposed, should pass. Lewis's evaluation of prior judicial approval for assisted dying is a good example of this. As mentioned above, the quality of a law and its alignment with regulatory goals can sometimes be a casualty of compromise.<sup>75</sup> Given the difficulty of passing a law, and the difficulty of changing even a flawed law, careful evaluation of proposals is critical. We consider this should occur both in relation to the proposed law's stated policy goals<sup>76</sup> but also in relation to the proposal's alignment with wider values or ethical principles.<sup>77</sup>

But it is not just evaluation *prior* to a law coming into force that is important. The Netherlands has made a key contribution to assisted dying law reform internationally through the ongoing and rigorous government-funded evaluation of the operation of its law, providing a crucial evidence base for other jurisdictions to assess.<sup>78</sup> These reviews are undertaken by independent academics and their outcomes are publicly available. This transparency has not only supported law reform in other jurisdictions, but has also facilitated frank discussions about the efficacy of the Dutch law within

<sup>75</sup> White et al., 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?', 417–51.

<sup>76</sup> *Ibid.*

<sup>77</sup> For an example of an articulation of the values that should guide assisted dying reform, see Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model for Reform', in K. A. Petersen and I. R. Freckelton (eds.), *Tensions and Traumas in Health Law* (Sydney, NSW: The Federation Press, 2017), 479–510. For an example of this approach in relation to unilateral medical decisions about withholding and withdrawing potentially life-sustaining treatment, see Jocelyn Downie, Lindy Willmott and Ben White, 'Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment' (2014) 26 *New Zealand Universities Law Review* 24–59; Jocelyn Downie, Lindy Willmott and Ben White, 'Next Up: A Proposal for Values-Based Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment' (2017) 54 *Alberta Law Review* 803–29.

<sup>78</sup> Bregje Onwuteaka-Philipsen, Lindy Willmott and Ben P White, 'Regulating Voluntary Assisted Dying in Australia: Some Insights from the Netherlands' (2019) 211 *Medical Journal of Australia* 438–39.e1.

that jurisdiction. The Dutch case study in this book reports on the most recent (third) evaluation and its implications for the existing law. It reviews the law and its operation against the law's identified policy goals, providing opportunities for reflection on possible changes to the law and its application in practice. The evaluation also includes a study of public opinion to determine the degree and nature of support for the law. Given the debates about the operation of all assisted dying laws, including whether they should be narrowed or widened, that will continue after their enactment, a systematic method of evaluation should be encouraged. As already noted, the failure to do this in relation to the Texas Advance Directives Act has made it vulnerable to challenge for failing to operate fairly and effectively.

### LAW REFORM EFFORTS ARE ONGOING

It is apparent from the book as a whole and this chapter in particular that law reform at the end of life is an ongoing exercise. This is especially evident in relation to law regulating assisted dying. Even if such a law is passed, there are likely to be calls from all sides for ongoing consideration of that law. For some individuals or groups, the law will not go far enough and they may advocate widening the law or considering categories of cases not currently covered. Other groups or individuals may continue their efforts to either narrow the law or repeal it entirely.

There have been sustained efforts to repeal or amend many of the end-of-life laws discussed in this book (and beyond). The enactment of a law might serve as a catalyst for efforts to change or repeal the law by judicial, legislative and/or policy means.<sup>79</sup> The Texas Advance Directives Act case study is an excellent case in point. The law passed after significant compromise, but since then there have been attempts (some successful) to narrow the scope of its application (e.g. to exclude artificial nutrition and hydration) as well as attempts to overturn the entire law on the ground that it is unconstitutional. The Belgian law extending assisted dying to minors was also the subject of an unsuccessful constitutional challenge,<sup>80</sup> as was the Oregon assisted dying law (challenged in numerous cases<sup>81</sup>). Another example is the Northern Territory assisted dying law, which was also unsuccessfully challenged on constitutional grounds,<sup>82</sup> but was ultimately overturned by the federal Australian government after only a brief period of operation.

This book has included two of the very few major changes internationally to the scope of assisted dying laws. The first is the Belgian extension of their law to include

<sup>79</sup> Ball, *At Liberty to Die*. One of Ball's key contributions to law reform literature is to document the battles that continue after assisted dying laws are passed.

<sup>80</sup> Judgement 153/2015, Constitutional Court of Belgium (29 October 2015) (English translation).

<sup>81</sup> See, for example, Ball, *At Liberty to Die*. Assisted dying laws in California, New Jersey, Oregon, and Vermont were subjected to judicial challenges. Assisted dying laws in Montana and Washington, DC were subject to legislative challenges.

<sup>82</sup> *Wake and Gondarra v. Northern Territory and Asche* (1996) 5 NTLR 170.

access for minors in limited circumstances. Although controversial internationally at the time of passing, this case study has shown that this change was the product of debate and consideration over an extended period of time, that the law was subject to parliamentary and other scrutiny, and in practice has represented a very modest change of law with only four minors having used the law since its passing in 2014. The second is the *Truchon*<sup>83</sup> case, which struck down the Québec requirement that a patient be ‘at the end of life’ and the federal requirement that ‘natural death has become reasonably foreseeable’ on the grounds that they violated the Canadian Charter of Rights and Freedoms. In this instance, it could be argued that rather than extending the scope of law in Canada, this case simply reflects the position that was required by Canada’s constitutional law.

The Dutch system of official and regular evaluations of their assisted dying law reflects government recognition that review of the law and its operation should be ongoing. As noted above, that evaluation includes whether the existing law is working as intended, as well as the views of the general public about the current scope of the law and whether it should be extended to other groups of people who do not currently have access to assisted dying.

One lesson for those interested in law reform – particularly in a field that is as important and emotionally charged as end-of-life law – is that it is an open-ended process, rather than a one-off event. Even if a law is enacted, we should expect ongoing discussion about its operation, its scope and whether it should be retained, amended or repealed. Reform is a journey and not a destination, and those active in the field need to adopt a long-term approach and be prepared for these ongoing debates. The Dutch approach also counsels a willingness to evaluate end-of-life law and to be open to reforms that such evaluation may signal.

### DESIGN OF LAW IS CHALLENGING

Before turning to the future of law reform in this area, a final point to note is the challenge of designing law to govern end-of-life decision-making. We have mentioned that sometimes the design of a law can be complicated by a decision to compromise. This can result in inconsistency within the law, a failure to align with regulatory objectives and suboptimal lawmaking generally.

But even where compromise does not occur, designing law to govern the complex interface between law and medicine in the setting of end-of-life decision-making is difficult, at both a policy and a practical level.<sup>84</sup> One example in the assisted dying context is whether to adopt a model that permits or requires administration of the

<sup>83</sup> *Truchon v. Attorney General of Canada* [2019] QCCS 3792 (CanLII).

<sup>84</sup> Ben White, Lindy Willmott and Eliana Close, ‘Victoria’s Voluntary Assisted Dying Law: Clinical Implementation as the Next Challenge’ (2019) 210 *Medical Journal of Australia* 207–9.e1.

assisted dying medication by a doctor (or health professional), one that requires the person to take that medication themselves, or one that permits both, in some or all circumstances. These are matters about which people and policy-makers can have different views, depending on the values or principles they prioritise as most important.

Even if higher-level principles can be agreed upon, expressing them in concrete legislative form can be challenging. Long-standing regulatory challenges when designing law include the problems of rule indeterminacy and interpretation.<sup>85</sup> Orentlicher commented that the US model of assisted dying reflects a preference for ‘bright-line’ policy choices, which is manifested, for example, in the inclusion of a six-month anticipated time period until death in their laws. This can be contrasted with the more open-ended and subjective approaches to assessing time to death that have been used in Canada, such as natural death being reasonably foreseeable (federal) or a patient being at the end of life (Québec). Putting aside recent changes to the Canadian law, the point here is that both bright-line and more subjective approaches bring challenges. The US model is arguably arbitrary in selecting a specified time frame,<sup>86</sup> whereas the Canadian and Québec approaches proved difficult to interpret and apply consistently. There is not scope here to critique these various approaches, but it is sufficient to observe the inherent challenges in drafting a law which is certain but does not unjustly exclude access to assisted dying for some people.

Another challenge is that it cannot always be predicted how a law will work in practice. The consensus that supported the Texas reforms was based in part on assumptions that did not eventuate, namely that hospital transfers would be readily available for patients. The Canadian federal law failed to anticipate situations such as people voluntarily stopping eating and/or drinking to become eligible for assisted dying, or ceasing pain medication to maintain decision-making capacity in order to provide informed consent immediately prior to receiving assistance in dying. There are also examples of these unforeseen consequences outside the case studies. One from the Victorian law is the much-discussed prohibition on health professionals

<sup>85</sup> Karen Yeung, ‘Regulating Assisted Dying’ (2012) 23 *King’s Law Journal* 163–79.

<sup>86</sup> In the Australian context, charges of arbitrariness in terms of criteria about expected time until death have been made in Willmott and White, ‘Assisted Dying in Australia’, 503–4 and White et al., ‘Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?’, 417–51. Prognostication about time until death is notoriously difficult: Joanne Lynn, Frank E. Harrel Jr., Felicia Cohn, Mary Beth Harrell, Neal Dawson and Albert W. Wu, ‘Defining the “Terminally Ill”: Insights from SUPPORT’ (1996) 35 *Duquesne Law Review* 311–36; Eric Chevlen, ‘The Limits of Prognostication’ (1996) 35 *Duquesne Law Review* 337–54; James Downar, Russell Goldman, Ruxandra Pinto, Marina Englesakis and Neill K. J. Adhikari, ‘The “Surprise Question” for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-Analysis’ (2017) 189 *Canadian Medical Association Journal* E484–93; Paul Glare, Christian Sinclair, Michael Downing, Patrick Stone, Marco Maltoni and Antonio Vignano, ‘Predicting Survival in Patients with Advanced Disease’ (2008) 44 *European Journal of Cancer* 1146–56 at 1147.

raising the topic of assisted dying with their patients.<sup>87</sup> Although designed to ensure the patient's decision was voluntary and not a result of influence from health professionals, in practice it has led to confusion about what health professionals can and cannot say (as well as the wider question of whether this prohibition is consistent with the assisted dying law's policy goals.)<sup>88</sup> As has been suggested above, for example in contrasting the Québec legislation with the federal Canadian law reform, a good consultation process may assist with addressing some of these challenges. However, it is not always possible to foresee the various possible issues that can arise with a law once implemented.

### LIMITS OF A CASE STUDY APPROACH: WHAT IS MISSING?

This chapter has undertaken a comparative law analysis of ten case studies of reform in six countries. The breadth of this analysis has helped provide new insights about law reform that would otherwise not emerge. Although ten case studies is regarded as a large sample in comparative law terms, such an approach necessarily has some limitations. One is that not all cases of end-of-life law reform can be examined.<sup>89</sup> Another is that the majority of the case studies focus on assisted dying. While this reflects important recent trends in assisted dying reform internationally, this has implications for the applicability of the analysis to end-of-life law reform more broadly.

The case studies also generally consider reforms or proposed reforms that are relatively recent, including new developments rather than original law reforms in jurisdictions that legalised assisted dying some time ago, such as Belgium and the Netherlands. There is literature considering reform from earlier eras,<sup>90</sup> and that has informed the present analysis. But that experience is now dated and occurred in a different environment, for example, before there was a body of reliable social

<sup>87</sup> *Voluntary Assisted Dying Act 2017* (Vic), s. 8. See also: Lindy Willmott, Ben White, Danielle Ko, James Downar and Luc Deliens, 'Restricting Conversations about Voluntary Assisted Dying: Implications for Clinical Practice' (2020) 10 *BMJ Supportive and Palliative Care* 105–110; Carolyn Johnston and James Cameron, 'Discussing Voluntary Assisted Dying' (2018) 26 *Journal of Law and Medicine* 454–63; Bryanna Moore, Courtney Hempton and Evie Kendal, 'Victoria's Voluntary Assisted Dying Act: Navigating the Section 8 Gag Clause' (2020) 212 *Medical Journal of Australia* 67–8.e1; White et al., 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?', 417–51.

<sup>88</sup> Willmott et al., 'Restricting Conversations about Voluntary Assisted Dying', 105–10; Johnston and Cameron, 'Discussing Voluntary Assisted Dying', 454–63; Moore, Hempton and Kendal, 'Victoria's Voluntary Assisted Dying Act', 67–8.e1; White et al., 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?', 417–51.

<sup>89</sup> For example, a case study about reform of the law governing palliative care was not selected by any of the contributing authors for inclusion in this book. Further, the need to select a feasible number of case studies also meant that not all significant cases of end-of-life law reform could be included.

<sup>90</sup> See, for example, Ball, *At Liberty to Die*; Clark, *The Politics of Physician Assisted Suicide*; Hillyard and Dombink, *Dying Right*; Pope, 'Legal History of Medical Aid in Dying', 267–301.

science evidence about how assisted dying regimes can function in practice. Accordingly, the case studies in this collection represent a deliberate choice to provide an analysis of modern efforts to undertake end-of-life law reform.

A final limitation is that the case studies in this book predominantly consider instances when reform did occur. This prevents an effective comparison between case studies of successful reform and those where reform was unsuccessful, although some insight into this comes from jurisdictions where the law changed after a history of many failed attempts. This focus on cases of successful reform may also prioritise particular perspectives because, by definition, reform that is successful means that barriers and opponents to change were not sufficient to prevent the law from changing. As a result, the focus of these case studies was more often on the reasons why the law changed – that is, the facilitators of reform and the individuals or groups who were influential in fostering change – rather than on the reasons why reform was challenging. This is perhaps particularly so for those case studies examining why reform had happened after many failed attempts; the ‘how to guides’ necessarily focus more on the facilitators of reform than the barriers to it.

One implication of this is that the case studies include only modest discussion of opposition from certain groups. For example, some literature about assisted dying law reform identifies churches, particularly the Catholic Church, and other religious organisations as having long-standing opposition to assisted dying.<sup>91</sup> Yet these groups received limited consideration in the preceding chapters.<sup>92</sup> The opposition of medical associations and bodies in some jurisdictions to assisted dying reform was also given modest attention. As noted, the limited engagement in this book with these potentially opposing groups may be due to the book’s focus on successful cases of law reform. But it may also reflect the declining influence on the formation of

<sup>91</sup> Taylor E. Purvis, ‘Debating Death: Religion, Politics, and the Oregon Death with Dignity Act’ (2012) 85 *Yale Journal of Biology and Medicine* 271–84; Ball, *At Liberty to Die*; Steven Kettell, ‘How, When, and Why Do Religious Actors Use Public Reason? The Case of Assisted Dying in Britain’ (2019) 12 *Politics and Religion* 385–408; Eli D. Stutsman, ‘Political Strategy and Legal Change’, in Timothy E. Quill and Margaret P. Battin (eds.), *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (Baltimore: Johns Hopkins University Press, 2004), 259.

<sup>92</sup> For example, Raus, Deliens and Chambaere note the opposition of churches, particularly the Belgian Catholic Church, to the extension of assisted dying to minors. Van der Heide, Legemaate, Delden and Onwuteaka-Philipsen note that the absence of the Christian Democratic political party from the coalition government was a key factor in the passage of assisted dying legislation in the Netherlands. Willmott and White note that leaders of religious and faith-based organisations actively provided evidence to the Parliamentary Inquiry that preceded assisted dying legislation in Victoria. Lewis notes that groups calling for prospective judicial approval of assisted dying legislation in Canada and the United Kingdom include those opposed to reform on religious grounds. Orentlicher also notes that the Catholic Church has been vocal in ethical debate surrounding assisted dying and the withdrawal of life-sustaining treatment. Pope acknowledges that the Texas Advance Directives Act was enacted in part due to the support of a broad coalition of stakeholders, including the Christian group, Texas Right to Life, while the loss of this consensus resulted in attempts to dismantle the legislation.

public policy of these and other groups who oppose assisted dying reform.<sup>93</sup> This is an empirical question not resolved in this book but is one which warrants future research.

### FUTURE OF END-OF-LIFE LAW REFORM

Reforming end-of-life law is a challenging exercise. In the opening chapter, we identified five features that made reform in this area even more difficult than law reform generally. Law reform at the end of life involves issues of obvious gravity and significance that concern every individual in society; it requires deliberation on complex ethical issues and engages sincerely held values about which reasonable people can differ; there is a large and complex body of empirical evidence to grapple with and interpret; it requires legal mastery to draft new end-of-life laws or coherently amend existing complex laws; and finally, aligning oneself with a particular position on assisted dying can be politically dangerous.

These ten case studies across six jurisdictions provide global lessons about how law reform can occur, despite these challenges. One clear theme that emerged is that law reform in this field is hard. However, a review of the current landscape reveals an environment that is increasingly more conducive to reform. Internationally, at least in relation to assisted dying, there is a growing momentum for change.<sup>94</sup> First, there has been a slow but steady trend towards enacting assisted dying laws internationally, which itself can create an environment for further reform.<sup>95</sup> This has been supported by the body of social science evidence and its use in debates, creating a 'shrinking battlefield' which can limit opponents' arguments that previously had traction.<sup>96</sup> This evidence can also change the minds of individuals and organisations who may have opposed assisted dying.

Societal attitudes and values that support reform also appear to be evolving. Patient autonomy, including in relation to end-of-life choices, is increasingly becoming an important social norm that is driving changes to the law. Orentlicher has argued that these values already underpinned existing laws about withholding and withdrawing life-sustaining treatment in the United States, and are now being reflected in the passage of limited assisted dying laws in a growing number of states. While individual rights have historically been a feature of the US legal system, this trend is emerging more generally in the Western countries included in this book. For example, in the Netherlands and Belgium, where arguably the assisted dying law initially developed primarily as a compassionate

<sup>93</sup> See, for example, the discussion of the declining influence of the Catholic Church on public policy in Purvis, 'Debating Death', 271–84; Kettell, 'How, When, and Why Do Religious Actors Use Public Reason?', 385–408.

<sup>94</sup> White and Willmott, 'Future of Assisted Dying Reform in Australia', 616–20.

<sup>95</sup> *Ibid.*

<sup>96</sup> *Ibid.*



response to suffering, there appears to be growing recognition of patient autonomy as an important justification for their laws.<sup>97</sup> We also see greater recognition of patient views, albeit in a more modest way, in Jackson's analysis of how the best interests test has evolved in England and Wales.

As a result, we anticipate that assisted dying law reform, and other end-of-life law reform, is likely to continue. The rate of change to date has been slow but these factors are likely to align to bring about ongoing change in the law, and perhaps at a faster rate than in the past. The future reform attempts that will be successful are likely to be those that have some or all of the features outlined earlier in this chapter.

The subtitle of this book, 'Politics, Persuasion and Persistence', captures the essence of many of the issues considered in this chapter. Reform is most likely to succeed if careful attention is paid to the politics of reform. This, of course, encompasses the political or parliamentary process, which is often a critical component in reform. But the politics of reform also should involve a robust law reform process that includes broad and inclusive consultation involving experts, key stakeholders and the wider community.

Persuasion is linked to the politics of reform but also refers to the types of arguments that should be mounted. A key component is the importance of evidence. Persuading lawmakers about the importance of reliable evidence and explaining what it means in a particular context has been significant in effecting legal change, and will continue to be so. Persuasion should also focus on arguments at a principled level. Proposing reforms that are internally sound, consistent and align with the identified regulatory goals is important and essential to effective advocacy.

Finally, persistence is an essential part of law reform. All of the case studies of reform resulted from long-standing efforts over an extended period of time. Sometimes this required waiting for the right reform environment to emerge, and at other times it was possible to advocate to create that environment. In all cases, however, there were no overnight successes.

We conclude by briefly noting the implications that this review has for law reform generally. When thinking about reform in the end-of-life field, we have naturally drawn on wider law reform debates and scholarship. As noted in the opening chapter, we acknowledge that this book sits within a long-standing tradition of discussion about how and why law reform occurs. The factors that support reform

<sup>97</sup> Pauline S. C. Kouwenhoven, Ghislaine J. M. W. van Thiel, Agnes van der Heide, Judith A. C. Rietjens and Johannes J. M. van Delden, 'Developments in Euthanasia Practice in the Netherlands: Balancing Professional Responsibility and the Patient's Autonomy' (2019) 25 *European Journal of General Practice* 44–8; H. A. M. J. ten Have, 'Euthanasia: Moral Paradoxes' (2001) 15 *Palliative Medicine* 505–11; Joachim Cohen, Isabelle Marcoux, Johan Bilsen, Patrick Deboosere, Gerrit van der Wal and Luc Deliens, 'Trends in Acceptance of Euthanasia Among the General Public in 12 European Countries (1981–1999)' (2006) 16 *European Journal of Public Health* 663–9.

to occur in other socially progressive settings such as same-sex marriage,<sup>98</sup> abortion,<sup>99</sup> non-therapeutic sterilisation<sup>100</sup> or access to IVF<sup>101</sup> are also relevant here.

Indeed, many of the contributors to this book have been involved in law reform processes on a range of topics and in a range of roles, including as a parliamentarian, law reform commissioners, experts before courts and parliaments, litigants in public interest cases and members of pro bono legal teams advancing those cases. In the same way that this book benefitted from insights from the wider law reform field, we hope too that reform in the end-of-life area may help shed light on and advance thinking about law reform generally. End-of-life law reform may therefore be seen as a case study of how change can occur. The authors hope that the findings of this book may be useful for law reformers striving in other controversial fields to change the law.

<sup>98</sup> See, for example, Celia Kitzinger and Susan Wilkinson, 'Social Advocacy for Equal Marriage: The Politics of "Rights" and the Psychology of "Mental Health"' (2004) 4 *Analyses of Social Issues and Public Policy* 173–94; Rosemary Auchmuty, 'Same-Sex Marriage Revived: Feminist Critique and Legal Strategy' (2004) 14 *Feminism and Psychology* 101–26; Jamie Gardiner, 'Same-Sex Marriage: A Worldwide Trend?' (2010) 28 *Law in Context* 92–107.

<sup>99</sup> See, for example, Jenny Morgan, 'Abortion Law Reform: The Importance of Democratic Change' (2012) 35 *University of New South Wales Law Journal* 142–74; Mary Ziegler, 'The Framing of a Right to Choose: *Roe v. Wade* and the Changing Debate on Abortion Law' (2009) 27 *Law and History Review* 281–330; Joanna N. Erdman, 'The Politics of Global Abortion Rights' (2016) 22 *The Brown Journal of World Affairs* 39–57; Emily Jackson, 'Abortion', in *Regulating Reproduction Law, Technology and Autonomy* (Oxford: Hart Publishing, 2001), ch. 3, 71–111.

<sup>100</sup> See, for example, Penney Lewis, 'Legal Change on Contraceptive Sterilisation' (2011) 32 *Journal of Legal History* 295–317; Emily Jackson, 'Birth Control', in *Regulating Reproduction Law, Technology and Autonomy* (Oxford: Hart Publishing, 2001), ch. 2, 11–69.

<sup>101</sup> Emily Jackson, 'Reproductive Technologies', in *Regulating Reproduction Law, Technology and Autonomy* (Oxford: Hart Publishing, 2001), ch. 5, 161–259; Anna Smajdor, 'The Changing Face of IVF Regulation' (2008) 3 *Expert Review of Obstetrics and Gynecology* 433–6; Kirsty Horsey, 'Revisiting the Regulation of Human Fertilisation and Embryology', in Kirsty Horsey (ed.), *Revisiting the Regulation of Human Fertilisation and Embryology* (New York, NY: Routledge, 2015), 1–11.

