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"Another week? Another week! I can't take another week"

Addressing barriers to effective access to legal assisted dying through legislative, regulatory and other means

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Law, The University of Auckland, 2016.

Abstract

Those who oppose a change in the law often shift their arguments to hypothetical victims, some of them glimpsed at the bottom of a slippery slope.¹

Although assisted dying has been legalised by specific statute in 10 jurisdictions in just over two decades, to date none of those statutes has undergone a rigorous, systematic formative evaluation to identify its strengths and weaknesses, in particular any barriers to access for people seeking legal assisted dying. The research literature suggested that such barriers might arise in part as a result of various ‘safeguards’ built into the statutes to protect against any potential for abuse of people vulnerable to being pressured into seeking assisted dying. Applying an interdisciplinary approach, integrating law and medicine with some aspects of psychology and sociology, this research adopted a ‘utilization-focused’ evaluation research paradigm to identify both barriers to access and attempts across jurisdictions to mitigate such barriers, whether by legislative, regulatory or other means. It then analysed the effectiveness of those mitigation strategies and explored other ways in which access barriers might be avoided or mitigated. Significant barriers were identified not only for people seeking legal assisted dying but also for doctors and other health practitioners who wanted to become involved in undertaking assisted dying functions. An analysis of the underlying causes of the diverse barriers identified revealed a pattern of both purposeful and inadvertent gatekeeping by those opposing or equivocal about legal assisted dying. The research explored current developments across jurisdictions proposing to legislate for assisted dying and identified a process of evolution where new assisted dying Bills are innovating rather than transplanting statutory provisions and frameworks. Specific suggestions have been proposed for ‘critical enablers’ within assisted dying statutes to facilitate fair and reasonable access and provide a balance against gatekeeping. A proposal is made for mainstreaming formative evaluation of new statutes as a standard practice in health and social law reform.

¹ Tony Delamothe, Rosamund Snow and Fiona Godlee “Why the Assisted Dying Bill should become law in England and Wales” (2014) 349 BMJ g4349.

Dedication

For my Mum

Title quote

The title quote is from Colin Marriage, 40, newly married, dying from adenocarcinoma of the oesophagus and liver, suffering constant uncontrollable vomiting and unrelievable pain, replying to his doctor when told that he might live for at least another week, despite having refused all life-prolonging treatments and nutrition and hydration in desperation to hasten death (“Good care but a bad death” in Lesley Close and Jo Cartwright (eds) *Assisted Dying: Who Makes the Final Decision?* (Peter Owen, London, 2014)).

Acknowledgements

My greatest debt in undertaking this project is to the people who told me their stories, often emotional and always frank and articulate, about being involved in helping dying people to ease their death. You have my admiration as well as my thanks, I hope I’ve represented your experience faithfully. Big thanks are owed to Jo Manning and Phillipa Malpas for being willing to support a research paradigm that they were not familiar with and give detailed and always thought-provoking comments, and to Katrina Roen for invaluable intellectual and moral support. Special thanks to Rob Jonquiere and Robb Miller for being always available to keep patiently clarifying my questions about what might or wouldn’t work for doctors and others who have to navigate the laws, and to many other people both in New Zealand and elsewhere who gave me their thoughtful and often detailed commentary on suggestions for making law that could work. Thanks to David Wexler for superb networking, Erin Sandberg for providing translation that went beyond the literal, Rob Brennan and Jocelyn Downie for nitpicking at my ideas about what might and couldn’t work in a statute, to Hilary Lapsley for reminding me of the courage of my convictions, Jack Havill for his public support when I was being attacked by the religious righteous, the wonderful Lisa Morice for intelligent proofing, and Mike Wilson for keeping me sane when my computer wouldn’t comply. My gratitude to Prue Taylor and Klaus Bosselman for moral support and practical advice, to the generously helpful staff at the Davis Law Library, and to Phil Carr who first showed me how gentle the euthanasia process is for much-loved animal family members. And above all thanks to my Dad, for teaching me to be meticulous,

and my Mum, for perching in my head and reminding me constantly to think about what will be best for everyone, not just the people who agree with me.

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Table of statutes and Bills

Acts	Abbreviation
New Zealand	
New Zealand Bill of Rights Act 1990.	NZBORA
Contraception, Sterilisation, and Abortion Act 1977.	
Crimes Act 1961.	
Health and Disability Commissioner Act 1994.	
Health Practitioners Competence Assurance Act 2003.	HPCA Act
New Zealand Public Health and Disability Act 2000.	
Australia	
<i>The Rights of the Terminally Ill Act 1995 (NT).</i> ²	
Charter of Human Rights and Responsibilities Act 2006 (Victoria).	
Canada	
Canadian Charter of Rights and Freedoms 1982.	
Europe	
<i>Code pénal Suisse 1937 (Switzerland).</i>	
European Convention on Human Rights 1950.	
<i>Law on Euthanasia of 28 May 2002 (Belgium).</i>	
<i>Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002 (The Netherlands).</i>	
Québec	
<i>Bill 52: An Act respecting end-of-life care 2014.</i>	Bill 52
South Africa	
Constitution of the Republic of South Africa 1996 (South Africa)	
Chapter 2 Bill of Rights.	
Switzerland	
Loi sur la santé (LS) (K 1 03) (Neuchatel) art. 39A.	
Loi sur la santé publique (LSP) (Vaud) AS art. 27d.	
United Kingdom	
Abortion Act 1967 (UK).	

² Assisted dying statutes are in italics.

United States

No. 39. An act relating to patient choice and control at end of life 2013 (Vermont).

Death with Dignity Act (Oregon) 1997.

DWDA

Death with Dignity Act Oregon Revised Statutes 2013.

Death with Dignity Act (RCW 70.245) (Washington).

End of Life Option Act 2015 (California).

Matt Adler Suicide Assessment, Treatment and Management Act 2012 (Washington).

Patient Protection and Affordable Care Act 2010 (P.L. 111-148). PPACA

Bills

Abbreviation

New Zealand

Death with Dignity Bill 1995 (Member's Bill).

DwD (NZ) Bill 1995

Death with Dignity Bill 2003 (Member's Bill).

DwD (NZ) Bill 2003

End of Life Choice Bill 2012 (Member's Bill).

End of Life Choice Bill 2015 (Member's Bill).

EOLC Bill

Australia

Medical Services (Dying with Dignity) 2014 (Exposure Draft Bill 2014 No. 2014) (Parliament of Australia).

Voluntary Assisted Dying Bill 2013 (Bill 61 of 2013) (Tasmania).

Israel

'Physician Assisted Suicide' Bill 2014.

United Kingdom

Assisted Dying Bill 2014 (HL Bill 6).

Lord Falconer's Bill

Assisted Dying for the Terminally Ill Bill [HL].

Lord Joffe's Bill

Assisted Dying (No.2) Bill 2015-16 (HC Bill 7).

Maris's Bill

Assisted Suicide (Scotland) Bill 2013 (SP Bill 40).

Table of cases

New Zealand

Auckland Area Health Board v Attorney General [1993] 1 NZLR 235.
Department of Corrections v All Means All [2014] 3 NZLR 404.
Halligan v Medical Council High Court Wellington CIV-2010-485-222, 2/12/2010.
Lesley Martin v The Queen [2005] NZSCTrans 11 (10 June 2005).
R v Davison HC Dunedin [2011] NZHC 1677.
R v Mott [2012] NZHC 2366.
R v Simpson HC Auckland [2001] NZHC 968.
Seales v Attorney-General [2015] NZHC 1239.

Canada

Carter v Canada (Attorney General) [2015] 1 SCR 331.
Malette v Shulman et al [1990] 72 OR (2d) 417.
R v Morgenthau [1988] 1 SCR 30.
Carter v Canada (Attorney General) 2016 SCC 4.

European Court of Human Rights

Gross v Switzerland [2013] ECHR.
Haas v Switzerland (2011) 53 EHRR 33.
Pretty v United Kingdom (2002) 35 EHRR 1.

South Africa

Stransham-Ford v Minister of Justice And Correctional Services and Others [2015] ZAGPPHC 230; 2015 (4) SA 50 (GP) (4 May 2015).

The Netherlands

Chabot, Nederlandse Jurisprudentsie 1994, no 656.
Heringa v Netherlands Arnhem-Leeuwarden May 13, 2015, ECLI: NL: GHARL: 2015: 3444.
Schoonheim, Nederlandse Jurisprudentsie 1985, no 106.
Sutorius/Brongersma Nederlandse Jurisprudentsie 2003, no 167.

United Kingdom

Airedale National Health Service Trust v Bland [1993] AC 789 (HL).
Gillick v West Norfolk and Wisbech AHA [1986] AC 112 (UK HL).
Greater Glasgow Health Board v Doogan [2014] UK SC 68.
In re T [1992] 4 All ER 649.
R (on the application of Nicklinson and another) v Ministry of Justice [2014] UKSC 38.
R (A, B, X and Y) v East Sussex CC and the Disability Rights Commission (No 2) [2003] EWHC 167.
R (on the application of Nicklinson and another) v Ministry of Justice [2014] UKSC 38.

R (on the application of Purdy) v Director of Public Prosecutions (2009) UKHL 45.

R (Pretty) v Director of Public Prosecutions [2002] 1 AC 800.

Re B (Adult: refusal of medical treatment) [2002] All ER 449.

Montgomery v Lanarkshire Health Authority [2015] 2 WLR 768 (HL).

United States

People v Kevorkian 639 N.W. 2nd 291 (Mich Ct App 2001).

Vacco v Quill 521 US 793, 807–08 (US SC, 1997).

Washington v Glucksberg 521 U.S. 702, 735 (US SC, 1997).

List of abbreviations

Acronym	In full
AD	Assisted dying
CPS	Continuous palliative sedation
FCEC	Federal Control and Evaluation Commission (Belgian commission for reviewing AD reporting)
KNMG	Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (also known as the RDMA, see below)
KNMP	Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie (Royal Netherlands Pharmacists Association)
LEIF	Life End Information Forum (Belgian agency supporting doctors)
NVVE	Nederlandse Vereniging voor een Vrijwillig Euthanasie (Netherlands Voluntary Euthanasia Society)
PTEAG	Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying
RRC	Regional Review Committee ³
RDMA	Royal Dutch Medical Association
RTDs	Right to die societies
SCEN	Support and Consultation on Euthanasia in The Netherlands (Netherlands agency supporting doctors)
VESNZ	Voluntary Euthanasia Society of New Zealand
WFRtDS	World Federation of Right to Die Societies

³ I have used the acronym used most commonly for these committees, see John Griffiths, Heleen Weyers and Maurice Adams *Euthanasia and Law in Europe* (Hart Publishing, Oxford, 2008), although they are now formally named Regional Euthanasia Review Committees.

Preface

A The starting point

This research was inspired by a recognition that I could contribute something of value to the dying with dignity movement by using my accumulated professional knowledge and skills in psychology, health policy, law and evaluation in an area where I saw a need for law reform. I was prompted to undertake it by reading in the *New Zealand Herald* in December 2013 about Evans Mott, who in 2012 helped his seriously ill wife to die, handed himself in to the police, was charged with aiding and abetting a suicide, pleaded guilty, and was ultimately discharged without conviction.⁴ Two years later he was still paying off his legal fees.⁵ Given several contemporary factors - that assisted dying (AD)⁶ had been legalised in nearly a dozen jurisdictions overseas, the 2003 Death With Dignity Bill had been so narrowly defeated in our Parliament,⁷ recent research again showed strong public support for AD, and the then Member of Parliament (MP) Maryan Street had withdrawn her member's Bill from the ballot for purely political reasons - it appeared likely that there would be a new attempt at introducing legislation in New Zealand before long.

Having worked as a professional researcher and evaluator for nearly 20 years, specialising in the evaluation of health sector reform initiatives, I believed that it was essential to learn from the experience of other jurisdictions before introducing a further Bill, so that any legislation proposed here would be informed by evidence from the overseas experience of implementing always controversial AD laws that challenge traditional social mores.

A comprehensive early reading of the research literature on legal AD revealed that there had been no systematic formative evaluation⁸ of the implementation of AD laws anywhere, and also that there were indications of systemic barriers for people seeking AD. While there had been some monitoring of outputs - numbers of applications, declines, actual deaths - none of the jurisdictions had undertaken any significant or rigorous evaluation (as distinct from research) of how well the AD systems were working for any of the key stakeholder groups. Moreover the vast majority of the studies undertaken had used survey

⁴ *R v Mott* [2012] NZHC 2366.

⁵ "Husband to share euthanasia story" *New Zealand Herald* (Auckland, 28 December 2013).

⁶ The term 'assisted dying' (AD) is used throughout this document as a generic term to encompass all forms of legal medical assistance to hasten death; see p xiv below.

⁷ A 1995 Death With Dignity Bill had been soundly defeated, see p 12.

⁸ Defined in the following pages.

methodologies, not qualitative methods, and the researchers often acknowledged gaps in their understanding of the reasons underlying their findings, such as why most people seeking AD were highly educated, why there was a large discrepancy between the numbers seeking AD and those achieving it, or why so few doctors appeared willing to participate. Several authors had explicitly acknowledged a need for more evaluative analysis of AD implementation (see p 30).

Accordingly, this research attempts to redress the lack of systematic evaluation of AD systems and processes, adopting a ‘utilization-focused’ evaluation paradigm⁹ – that is, the priority was to produce information that would have most utility for both the various stakeholders involved in delivery of AD services where it has been legalised and those working to introduce new AD laws – focusing in particular on barriers to AD access. Since a thoroughgoing examination of access barriers to AD requires reviewing the interaction of AD statutes with medical practices, this research is interdisciplinary, integrating law and medicine with some aspects of psychology and sociology, and applying a formative evaluation paradigm to understand the problems in implementing AD laws and to identify ways in which they might be resolved.

B Caveats

1 Research focus - out of scope

While this research seeks to identify all factors that are seen as frustrating the intent of AD legislation, it does not intend to explore or examine the ethical arguments for and against AD. That analysis has already been undertaken comprehensively in a plethora of publications over the past 30 years or more, with different authors reaching different conclusions,¹⁰ and the ethical debate is summarised in Chapter 1. Rather, this research intends to focus on the logistics and pragmatics of implementing AD once it has been legalised through democratic processes. Its starting premise is that AD laws reflect a health reform that should therefore be available to those health consumers within the relevant jurisdictions who *prima facie* meet the statutory eligibility criteria, based on the provisions of the respective laws (for example, in the same way as pregnancy termination is available

⁹ Michael Quinn Patton *Utilization-focused evaluation* (2nd ed, Sage, London, 1986).

¹⁰ The debate for and against legalising AD is covered thoroughly in the following texts: Emily Jackson and John Keown *Debating Euthanasia* (Bloomsbury Publishing, London, 2011); Guenther Lewy *Assisted death in Europe and America* (Oxford University Press, Oxford, 2011); Leonard Wayne Sumner *Assisted death: A study in law and ethics* (Oxford University Press 2011).

to eligible women). Specifically, this study seeks to identify factors that are *unintended* barriers to the *safe* implementation of the laws - that is, legally, medically, and psychologically safe - for all of the parties involved in delivering the services (eg doctors, nurses, hospice personnel). Accordingly I discuss aspects of bioethics to the extent that they may create, contribute to or potentially resolve an access barrier or related issue in implementing AD laws. Finally, my research does not encompass AD in relation to minors because such provisions exist in only two jurisdictions to date.¹¹

2 Contemporary dynamics of the legal assisted dying movement

Since I commenced this research in March 2014, there has been a huge increase in attention to AD internationally, and a corresponding acceleration of advocacy, lobbying and research publication, with developments still occurring rapidly. This document includes research data and literature up to 1 March 2016. Further developments may well have occurred in New Zealand and internationally between my writing of this thesis and your reading of it.

C Thesis style and structure

1 Author's voice

Where appropriate, my voice is present in this thesis. This approach reflects my writing philosophy of the past 25 years, which recognises the author's voice as an essential aspect of transparency in qualitative research because of the importance of the research process, in particular where the research has been undertaken by a sole researcher.¹²

2 Terminology

2.1 The terminology of assisted dying

The terminology of AD is confused and contested.¹³ A plethora of terms has been used across jurisdictions, often with the same term used to refer to different concepts. For example, the term 'passive euthanasia' has been used by different authors to mean, variously, the imposition of death on a person without their request, the delivery of a lethal dose to a person at their request with the doctor administering the drugs, or the withdrawal

¹¹ The Netherlands (ages 12-17) and Belgium (no age requirement).

¹² Christine Webb "The use of the first person in academic writing: objectivity, language and gatekeeping" (1992) 17(6) J Adv Nurs 747.

¹³ Kathryn Tucker and Fred Steele "Patient choice at the end of life: Getting the language right" (2007) 28(3) J Leg Med 305.

of life support resulting in a person's death.¹⁴ The term 'voluntary euthanasia', long used to refer to AD, was rejected by advocates in the Oregon and Washington campaigns due primarily to the association of the word 'euthanasia' with the killing of animals and the Jewish holocaust.¹⁵ To confuse the issue further, some authors have distinguished between 'indirect' euthanasia (providing a lethal dose for self-ingestion) and 'direct' euthanasia (injecting a person with a lethal dose).¹⁶ Many commentators have cautioned against this subdivision of euthanasia terms "because there is no meaningful difference scientifically or ethically".¹⁷ The Benelux countries (The Netherlands, Belgium and Luxembourg) continue to use the term 'euthanasia' to refer specifically to the mandated (Belgium) or preferred (The Netherlands and Luxembourg) AD administration method in those countries of doctor-administered lethal injection, but have redefined 'euthanasia' to mean the "deliberate termination of life by someone else, on the explicit request of the person involved".¹⁸

In the US jurisdictions the term 'assisted suicide' has been rejected by advocates of AD and by the psychological associations, on the grounds that the term 'suicide' is deemed as reflecting the precipitous act of a mentally unwell individual, not the well-considered act of a sick person with intolerable suffering;¹⁹ nonetheless it remains used almost universally in Switzerland. As AD via ingestion has become legalised, a multiplicity of terms has been developed to describe the actions of a doctor making a lethal dose available for self-administration, including 'assisted dying', 'assisted suicide', 'physician-assisted suicide', 'physician-assisted dying', 'aid in dying', 'medically assisted dying', 'medically assisted death', and recently 'medical aid in dying'. Nowadays the term preferred in each jurisdiction tends to reflect the method of AD administration commonly used there. For

¹⁴ Lars Johan Materstedt and others "Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force" (2003) 17 Palliat Med 97.

¹⁵ Personal communication, former Director Compassion and Choices Oregon, 20 June 2014. Note that personal phone and email communications to me are referenced throughout this thesis for information items provided by informants who were not interviewed as such for the research but provided responses to specific information requests on behalf of particular organisations (eg medical association and medical school personnel; government and advocacy agencies). To protect informants' anonymity where requested, the name of the organisation is given, with the informant's consent, without necessarily naming the informant's exact position.

¹⁶ Jacquelyn Slomka "The negotiation of death: Clinical decision making at the end of life" (1992) 35 Soc Sci Med 251.

¹⁷ Australian and New Zealand Society of Geriatric Medicine "Position Statement on Euthanasia, Physician-Assisted Suicide and End of Life Care" <www.anzsgm.org>.

¹⁸ Rob Jonquiere "The Dutch experience: Medically assisted dying completes the continuum of end-of-life care" (seminar presented to The University of Auckland School of Medicine, 25 February 2015). Note, to avoid confusion, single quotation marks are used for newly introduced concepts and double quotation marks are used for verbatim quotes, whether from research participants or other sources.

¹⁹ Tucker and Steele, above n 13.

example, the US states mostly use the term ‘aid in dying’ or simply ‘dying with dignity’, reflecting the doctor’s role of prescribing but not administering the medication.

In this document I have used ‘assisted dying’ to encompass all *legal* forms of medical assistance for actively providing or administering a lethal dose, because it is the term used increasingly in the literature for that purpose. Where other terms for AD are used in this document, it is either within quotations or to reflect the common usage in a particular jurisdiction, organisation or profession.

Other terms that are used in this thesis particular to AD are as follows:

- For convenience, the societies that advocate for ‘death with dignity’, which have confusingly similar names, are referred to collectively as the ‘RTD’ (right to die) societies. Where these same organisations provide AD services, they are referred to as ‘AD provider agencies’.
- The term ‘client’ is used, in preference to the term ‘patient’, because ‘patient’ has been challenged as suggesting someone who is a passive participant in medical decision-making,²⁰ which is contrary both to the contemporary ethos of ‘patient autonomy’ or ‘patient-centred care’²¹ and to the philosophies underlying AD.²²
- The term ‘doctor’ is used in preference to ‘physician’, because the former is the term that doctors and the general public use most commonly internationally to refer to that role.

2.2 Evaluation theory and terminology

Because I have used an evaluation paradigm and methodology for this research, it will be helpful for the reader to understand some basic evaluation terms, as follows:

- Evaluation is a distinct discipline that uses research methods (amongst other methods). It is commonly defined as assessing the “value, worth and merit” of an initiative, using a

²⁰ Julia Neuberger “Let’s do away with ‘patients’: Response to “Do we need another word for ‘patient’?” (1999) 318 BMJ 1756.

²¹ The term ‘personal autonomy’ is preferred in this document.

²² The New Zealand Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996 SR 1996/78 <www.hdc.org.nz> uses the term ‘consumer’, but that term sounds clumsy to describe an intimate doctor-client relationship. This Code is referred to henceforth as the ‘New Zealand Code of Rights’.

rigorous methodology, specifically for purposes of decision-making.²³ Where research is “conclusion-oriented”, evaluation is “decision-oriented [and] aimed at action”.²⁴

- ‘Formative’ evaluation is systematic evaluative activity undertaken to assess the effectiveness of the early implementation processes and design features of an initiative. Typically formative evaluation runs over the first 12-24 months of a new initiative, with the goals of, firstly, identifying both what is working well and what is not working in the way intended, and also identifying how the emerging problems (or ‘barriers’) can be addressed. In the health sector, as in other service sectors, formative evaluation of pilot initiatives is now considered standard good practice by governments in both developed and developing countries,²⁵ including New Zealand,²⁶ so that action can be taken early to ensure that the people intended to benefit from the initiative are in fact able to access those benefits, and good policy developed and refined.²⁷ Formative evaluation should not be confused with monitoring, which typically focuses on recording the outputs (and sometimes outcomes) of an initiative, not assessing its processes.
- ‘Barriers’ are those factors that create impediments to an initiative being implemented as intended and/or for the target audiences intended to access or benefit from the initiative²⁸ - in this instance, assisted dying.
- ‘Enablers’ are the factors (sometimes also called ‘success factors’) that facilitate achievement of the intended or other positive outcomes of an initiative.
- ‘Stakeholders’ is used in evaluation to refer to all of those groups or individuals who have a ‘stake’ or investment in a service or initiative. Thus the key stakeholders in AD would include all of the parties who are significantly affected by its legalisation: people potentially or actually seeking AD; their families and other intimates; medical, other health and social services professionals; legislators; advocacy groups; opponents; researchers; litigators.
- The “utilization-focused” approach is a predominant paradigm in evaluation.²⁹ It refers to the value of making evaluative information available as widely and as soon as

²³ Michael Quinn Patton *Qualitative research and evaluation methods: Integrating theory and practice* (4th ed, Sage, Los Angeles, 2015).

²⁴ At 14.

²⁵ OECD “Evaluation of development programmes” <www.oecd.org>.

²⁶ Ministry of Health “Research and evaluation of primary health care initiatives” (2015) <www.moh.govt.nz>.

²⁷ World Health Organisation “Regions for Health Network: Evaluation of health policies and plans” (presentation to Twelfth Annual Conference, Valencia, Spain, 11 November 2004).

²⁸ In contrast, the term ‘safeguards’ is used to refer to those precautions that *are* intended by AD statutes. The issue of how intended safeguards can become unintended barriers to access, and the tensions around that dilemma, is core to this thesis; see Chapter 4.

possible to stakeholders in an evaluation. In professional evaluation, typically this is done by disseminating a summary of the evaluation findings to all of those who participated in the evaluation. Sometimes multiple summaries are compiled for diverse stakeholder groups, to ensure that each type of stakeholder receives only the information that is relevant to them.

3 Layout of the thesis

The focus and content of each chapter are as follows:

Chapter 1 Why was evaluative research needed? overviews the current status of the AD debate and the factors affecting the momentum towards AD laws. As background, recent developments in the legalisation of AD internationally are summarised, including trends in public attitudes propelling legalisation. The three legislative models developed to date are outlined, comparing key statutory provisions. The New Zealand situation is described, including attempts to date at AD legislation, the attitudes of the New Zealand public, health professionals, politicians and the media, and the current campaign to legalise AD. The international literature is canvassed for evidence of access barriers and related problems affecting the implementation of AD laws. The lack of qualitative research and formative evaluation of AD legalisation is discussed briefly to highlight the rationale for the present research, and the purposes of the research are set out.

Chapter 2 Research design and methods details how the research questions were developed, the principles underlying the qualitative evaluation design employed, and the methodological framework. It describes the scope of the evidence review, the rationale for the interview sample and the jurisdictions selected, how participants were recruited, the interviewing approach, cultural and ethical considerations, and the data analysis paradigm.

Chapter 3 Theoretical perspectives on AD access describes the theoretical frameworks, paradigms and perspectives used in both developing the research questions and discussing the findings. Therapeutic jurisprudence is described as a lens suited to examining the effectiveness of AD law reform and a social ecology of health model is developed for understanding the decision-making processes related to both implementing and making law

²⁹ Patton, above n 9.

for AD. Other theories from law, psychology and sociology are discussed relevant to understanding the research findings.

Chapter 4 Assisted dying as a relational decision-making process integrates detailed interview data with a diverse international literature and some supplementary key informant information. It is structured to reflect the decision-making pathway of people seeking AD and the various others involved in the complex, dynamic social ecology of that decision-making, in particular the doctors designated to assess eligibility. It identifies a plethora of access barriers and describes the self-perpetuating pattern in which they operate, together with attempts that have been made variously across jurisdictions to mitigate the barriers. It identifies ways to improve AD statutes and their implementation in practice for fairer access and summarises those suggestions together in categories relevant to a statute framework. Some comments are also made on non-regulatory action that is needed to support the statutes.

Chapter 5 'So what next?' summarises the apparent trends in actual and likely uptake of AD where it is legal, identifies some 'critical enablers' of effective and equitable AD access, discusses what needs to be taken into account to make AD laws that work for those wanting access, and then presents a possible paradigm for AD law-making based on decision-making as a core concept. I also discuss the importance of evaluating AD law reform and draw some implications for potential AD law in New Zealand. Finally I make some comments on useful areas for future research, my research methodology and some issues in undertaking solo research on AD.

4 Environmental impact

This thesis is printed on 100% recycled paper. The carbon impact of international travel to interviews for the research was offset by donating 500 native trees to the Kaitiaki of Newton Reserve on Waiheke Island.

Chapter 1. Why was evaluative research needed?

Turning Point in Social and Ethical Thought

For the first time, a 2015 poll found that more than half of [US] physicians surveyed favored medical assistance in dying. ... The question [now] is whether more states will authorize the practice and, if so, what safeguards will be put in place to ensure the practice is not misused and remains consistent with prevailing social and ethical thought.³⁰

A Current status of the assisted dying debate

The core arguments – ethical, legal and medical - for and against legalising AD have not changed significantly in the past 20 years,³¹ except perhaps for the degree of emphasis placed on the various factors, for example due to greater societal secularisation and developments in palliative medicine.³² Opponents of legalising AD highlight four main arguments: (i) that it breaches the sanctity of life; (ii) that life is god-given and must not be taken away otherwise than by a ‘natural’ death that is not intentionally hastened; (iii) that populations potentially vulnerable by virtue of age, gender, disability, mental health or a minority status will be at risk of pressure to consider AD if it is legalised; and (iv) the ‘slippery slope’ claims, that legalising AD will lead to abuse in the form of either pressure to choose AD being placed on people who may not wish it and are vulnerable by virtue of age, disability, mental health issues or other vulnerabilities, potentially including poverty and minority ethnicity status, and/or ‘bracket creep’ - relaxation by doctors and others of the legal eligibility requirements or eligibility assessment processes.³³ Added to these claims by AD opponents is an assertion that improved palliative care is now sufficient to address all pain and suffering, an argument refuted consistently in medical and legal evidence.

Proponents’ arguments for legalising AD are based on several claims: the rights of people to determine their end-of-life medical treatment; that AD is a rational, voluntary and

³⁰ Lawrence O Gostin and Anna E Roberts “Physician-Assisted Dying – A Turning Point?” (2016) 315(3) JAMA 249.

³¹ D Harris, B Richard and P Khanna “Assisted dying: the ongoing debate” (2006) 970 Postgrad Med J 479.

³² A comprehensive discussion of the moral and other arguments for and against AD can be found in Sumner, above n 10.

³³ Lorna Bartels and Margaret Otlowski “A right to die? Euthanasia and the law in Australia” (2010) 17 J Law Med 532; contrast José Pereira “Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls” (2011) 18(2) Curr Oncol 38. The reasons given for opposing AD have not changed significantly in the past quarter-century, except perhaps for the degree of emphasis placed on the various factors (e.g. developments in palliative medicine; greater secularisation); compare, for example, the arguments canvassed in D Harris, B Richard & P Khanna “Assisted dying: The ongoing debate” (2006) 82(970) Postgraduate Medical Journal 479, and Leon R Kass and Nelson Lund “Physician-assisted suicide, medical ethics and the future of the medical profession” (1996) 35 Duq L Rev 395, with those presented in the Assemblée Nationale Québec, *Select Committee Dying with Dignity Report*, March 2012. For a comprehensive legal-philosophical analysis of slippery slopes and the potential impacts of their application in legislation, see Eugene Volokh “The Mechanisms of the Slippery Slope” (2003) 116 Harv L Rev 1026.

compassionate response to extreme suffering; the continuing inadequacy of palliative care in extreme cases and in some jurisdictions and/or where the person rejects all forms of continuous sedation as an option;³⁴ a strong evidence base refuting the ‘slippery slope’ claims from the experience to date in jurisdictions with legal AD;³⁵ and good evidence that laws can provide robust protections for potentially vulnerable people, which arguably includes anyone seeking AD.³⁶ Proponents argue further that safe and reasonable medical options should not be denied a population strongly supportive of legal AD because of the objections of:³⁷

... highly vocal, small, values-based minorities, typically the ‘religious right’, whose calls for cautious laws with no potential for future amendment ultimately impedes the access of the (majority) public wishing to have access to those laws.

While research across jurisdictions shows no robust, research-based evidence base to support the ‘slippery slope’ arguments,³⁸ the debate continues, resulting in multiple ‘safeguards’ continuing to be built into AD laws that may translate into major barriers to access. However many commentators, including legal theorists,³⁹ are suggesting that a turning point has been reached, and that the focus now needs to be on how, rather than whether, legal AD will be provided.⁴⁰

B International developments in legalising AD

1 Existing and pending legislation

Legislating to regulate AD has increased significantly in the past two decades. Since 1997, 10 jurisdictions - Belgium, The Netherlands, Luxembourg, Albania, the United States (US)

³⁴ See the extensive discussion in *Seales v Attorney-General* [2015] NZHC 1239 at [32]-[48].

³⁵ Margaret P Battin and others “Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ‘vulnerable’ groups” (2007) 33 J Med Ethics 591; Judith AC Rietjens and others “Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?” (2009) 6 J Bioeth Inq 271.

³⁶ Henk ten Have “Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics” (2015) 12 J Bioeth Inq 395.

³⁷ Frederick Schauer “Slippery slopes” (1985) 99(2) Harv L Rev 361.

³⁸ Battin and others, above n 35; David Benatar “A legal right to die: responding to slippery slope and abuse arguments” (2011) 18(5) Curr Oncol 206; Rietjens and others, above n 35; for a recent review of the slippery slope evidence and the logic of the claims, see Jane Vanderpyl “Evidence for safe and effective legal assisted dying - Challenging the ‘slippery slope’ claims. Submission to the Parliamentary Health Committee on Assisted Dying” (29 January 2016).

³⁹ Gostin and Roberts, above n 30.

⁴⁰ Timothy E Quill, Anthony L Back and Susan D Block “Responding to Patients Requesting Physician-Assisted Dying – Physician Involvement at the Very End of Life” (2016) 315(3) JAMA 245; Michael Swan “Catholics must face facts — euthanasia is here and it’s not going away” *The Catholic Register* (24 December 2015) <www.catholicregister.org>.

states of Oregon, Washington⁴¹ and Vermont, and most recently Colombia, California, and the Canadian province of Québec - have joined Switzerland in legalising AD,⁴² with varying regulatory regimes.⁴³ At the time of writing, the United Kingdom (UK) and Israel have private members' Bills being reviewed through select committee processes, and Canada's new legislation, prompted by the 2015 decision in *Carter v Canada*, is being drafted federally.⁴⁴ Progress on the Israeli Bill has been slowed by strong opposition from religious opponents, though it is supported by the Israeli Health Minister.⁴⁵ Lord Falconer's Assisted Dying Bill 2014 passed a first reading in the House of Lords in July 2014. However a different Bill introduced into the UK House of Commons in 2015 was defeated 330:118 at its first reading, effectively stymieing any further progress on legislating in the UK until the next election in 2020.⁴⁶ A further 24 Bills, variously in Australia, New Zealand, Scotland, 17 of the US states and Washington DC Council, await an appropriate opportunity to be tabled in legislatures, demonstrating an evident trend in the developed world towards legalising AD.⁴⁷

2 Legalisation through the courts

Despite the opinion of some courts that legalising AD should ideally be the preserve of the legislature,⁴⁸ AD has been effectively legalised by the courts in seven jurisdictions – The

⁴¹ The Oregon and Washington statutes were introduced by citizen-initiated referenda.

⁴² Some authors argue that the Benelux statutes do not 'legalise' AD, but rather, like the Swiss Penal Code, provide an exemption from criminal liability for doctors complying with the amendments to the respective criminal codes; see Glenys Williams *"Intention and causation in medical non-killing: the impact of criminal law concepts on euthanasia and assisted suicide"* (Routledge, New York, 2007). However the same argument could be applied to the US statutes, and in effect the Benelux statutes make the practice of AD legal in those countries, as do court decisions in other jurisdictions. The Northern Territory of Australia also introduced assisted dying legislation in 1995, but it was overturned by the Australian Federal government in 1997. In the past two years two Swiss cantons have also introduced cantonal legislation to regulate AD practice.

⁴³ See the summary of key statutory provisions in **Table 1** below.

⁴⁴ *Carter v Canada* (2015) SCC 5 (2 February 2015). The Supreme Court of Canada advised the Canadian federal Parliament (or, in the event of its default, provincial legislatures), in effect, to implement AD legislation within 12 months. The Court recently allowed a four month extension to the February 6 deadline, to allow time for robust federal or territorial/provincial statutes to be developed; "Supreme Court gives federal government 4-month extension to pass assisted dying law" *CBC News* (online ed, Toronto, 15 January 2016). It appeared that federal government considered initially leaving it to the provinces and territories to legislate (see Jocelyn Downie *Draft Provincial/Territorial Legislation to Implement a Regulatory Framework for Medically-Assisted Dying Consistent with Carter v Canada (Attorney General) 2015 SCC 5 and the Final Report of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying*, 14 December 2015).

⁴⁵ "Euthanasia bill passes initial vote, but struggles to become law" *The Jerusalem Post* (Jerusalem, 6 August 2014).

⁴⁶ Assisted Dying (No.2) Bill 2015-16 (HC Bill 7); Hansard (11 September 2015) 599(42) HC 656; "MPs give Assisted Dying Bill a massive 330-118 rejection" *The Times* (online, London, 11 September 2015).

⁴⁷ Personal email communications from the respective presidents of the Tasmanian, New South Wales, Western Australia, Scotland and New Zealand RTDs, May 2015.

⁴⁸ For example, *Carter and Seales*.

Netherlands, Colombia, three other US states, and most recently Canada and South Africa.⁴⁹ In the first two jurisdictions, statutes have been enacted subsequent to the court decisions. In the other four there are movements to legislate, but in the meantime a few doctors in Montana, Hawai'i and New Mexico support one another to provide AD “under the radar”.⁵⁰ No information is available on whether any legal assisted deaths have been provided yet in South Africa.

3 Factors affecting the momentum towards legalising assisted dying

Key factors that have been identified in the literature as affecting the movement towards seeking AD legislation in developed countries tend to centre on debates around human and civil rights, together with health ethics and economics. The momentum for introducing AD laws internationally has been seen as a response to a range of global forces, including: the development of human rights generally worldwide; rapidly increasing populations of elderly people, in particular as the ‘baby boomers’ age; advances in medical technologies that are seen as outstripping our moral ability to regulate their use; the health politics and economics of aging and aged care; increasing religious secularisation affecting the transition in medical practice, and in society, to prioritising personal autonomy over sanctity of life;⁵¹ and the use of social media by dying people to publicise their reasons for having an assisted death and even publish videos of their deaths.⁵²

The movement towards prioritising consumer rights over either sanctity of life or clinician expertise has occurred alongside increasing secularisation in the developed world. People’s right to hasten their death has been supported by regulation. For example, the “right to refuse medical treatment” in the NZ Bill of Rights Act 1990 (s 11), supported by the New

⁴⁹ *Carter v Canada (Attorney General)* 2016 SCC 4 (referred to henceforth as *Carter No 2*) and *Stranham-Ford v Minister of Justice And Correctional Services and Others* [2015] ZAGPPHC 230; 2015 (4) SA 50 (GP) (4 May 2015).

⁵⁰ Personal communication from a family doctor providing AD in New Mexico, 15 June 2015. See also Lindsay Goldwert “Five doctors in Hawaii want to make it legal for physicians to help terminally ill patients end their lives” *NY Daily News* (online, New York, 18 April 2012) <www.nydailynews.com>; NOLO “Death With Dignity in Montana” (online, 30 June 2015) <www.nolo.com>; Scott Sandlin “New Mexico assisted suicide law affirmed” *Albuquerque Journal* (online, Albuquerque, 30 June 2016) <www.abqjournal.com>.

⁵¹ For comprehensive discussions of these changes in relation to AD see Lewy, above n 10, and Jonathan Herring *Medical law and ethics* (Oxford University Press, Oxford, 2014). See also the discussion on the implications of these changes for medical practice and law in *Montgomery v Lanarkshire Health Authority* [2015] 2 WLR 768 (HL) at [75]-[81], noting that “patients are now widely regarded as persons holding rights, rather than as the passive recipients of the care of the medical profession ... [and] widely treated as consumers exercising choices”, at [75].

⁵² See for example “BBC How To Die: Simon Binner Choice Shows The Moment A Father Took His Life At Swiss Suicide Clinic!” (11 February 2016) <www.youtube.com>.

Zealand Code of Rights, effectively permits people to hasten their death by refusing medical interventions, including nutrition and hydration, and the requirement for doctors to respect consumers' attempts to die through these means has been consistently upheld by courts in New Zealand and internationally.⁵³ Some authors have also highlighted the difficulties faced by contemporary governments across the developed world in both financing aged care for an aging population and addressing the frustrations of the very old who feel that they no longer have any quality of life but are being kept alive by the imperatives of medical technologies.⁵⁴ The latter issue has led to the development of the concept of the 'completed life', which is now being addressed in The Netherlands and Switzerland, with both countries developing AD policy to deal with that condition.⁵⁵

Efforts towards legalising AD may also reflect the progressive decriminalisation of 'victimless' activity through and since the second half of the 20th century, for example, in the decriminalising in various jurisdictions of marijuana use, pregnancy termination, homosexuality and prostitution. Important factors lending support to the right to die movement have been the increasing leniency of juries and judges, both in New Zealand and overseas, in relation to a variety of charges reflecting even sometimes violent assistance of another's death where the reasons have been clearly compassionate and the deceased had requested it.⁵⁶ The mass media, and more recently social media, have also played a major role in bringing these issues to public attention. Overt and well advertised support from high profile people has opened the debate further, especially when it has come from people representing institutions that might have been expected to oppose AD, for example the public statements of George Carey, former Archbishop of Canterbury, and Bishop Desmond Tutu during the 2014 campaign surrounding the first reading of Lord Falconer's Bill in the UK.⁵⁷ In New Zealand, Presbyterian Minister Glynn Cardy recently gave a sermon where he

⁵³ For example, *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235; for a full discussion of relevant case law see Lindy Willmott, Ben White and Jocelyn Downie "Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral decision-making in Australia and New Zealand" (2013) 20 JLM 907.

⁵⁴ For example, see Ezekiel J Emanuel and Margaret P Battin "What are the Potential Cost Savings from Legalizing Physician-Assisted Suicide?" (1998) 339 New Engl J Med 167.

⁵⁵ "Dignitas – to live with dignity, to die with dignity" Brochure of Dignitas (Forch, Switzerland) <www.dignitas.ch>; KNMG "The role of the physician in the voluntary termination of life. Position paper" (KNMG, Amsterdam, June 2011) 23.

⁵⁶ Bartels and Otłowski, above n 33; Diane E Hoffman "Physicians who break the law" (2009) 53 St Louis U L J 1049.

⁵⁷ "Assisted dying: Ex-Archbishop of Canterbury Lord Carey backs bill" *BBC News Online* (online ed, London, 12 July 2014); Clare Dyer "Assisted dying bill passes second reading in Lords, as support and opposition seem equally divided" (2014) 349 BMJ g4739.

presented strong theological arguments for why assisted dying should not be denied people with extreme suffering,⁵⁸ in Australia a pro-assisted dying Christian organisation has been established,⁵⁹ in Europe respected Christian and other theologians are supporting legal AD,⁶⁰ and in Switzerland a Catholic nun recently became a member of the AD provider agency EXIT Suisse Romande, giving vocal support to assisted dying as an act of Christian compassion.⁶¹

The cumulative impact of these forces is a momentum that the right to die with dignity movement has recognised as a wide societal debate whose time has come.

4 Public attitudes towards legalising AD

Surveys over 20 years have revealed strong and increasing public support for AD across developed nations. Research in 2012, reviewing 110 studies across 24 countries, found consistent majority public support for AD, including among people in caregiver roles.⁶² The authors concluded that “attitudes remained consistent across groups regardless of illness or disability, and there were no apparent differences between countries, whether assisted dying was permitted by law or not”.⁶³ The authors drew attention to a core debate over whether eligibility for AD should be based on illness or suffering, noting that:⁶⁴

... unbearable suffering relating to psycho-emotional factors such as hopelessness, feeling a burden, loss of interest or pleasure and loneliness were at least as significant as pain and other physical symptoms in motivating people to consider assisted dying. While intractable pain was considered by some to be a reason to ask for help to die, for others, pain was perceived as controllable.

In addition, the authors noted the consistent discrepancy between the supportive views of the general public and the more oppositional, or at least reluctant, position of doctors, commenting that “the dichotomy between the views of doctors and the general public needs to be urgently explored”.⁶⁵ The research on doctors’ views of legalising AD shows that doctors have become much less oppositional over the past 20 years, with up to half

⁵⁸ Glynn Cardy “Physician Assisted Dying” (Sermon, The Community of St Luke, Auckland, 28 June 2015).

⁵⁹ Christians for Voluntary Euthanasia <www.christiansforve.org.au>.

⁶⁰ Rosie Harper “Hans Kung’s Theses on Dignified Dying” (2015) 56(2) *Modern Believing* 124; Jonathan Romain “A Jewish View of Assisted Dying” (2015) 56(2) *Modern Believing* 106.

⁶¹ “Je veux soutenir Exit et ceux qui font le choix de mourir” *Le Matin* (online ed, Paris, 29 June 2014).

⁶² Maggie Hendry and others “Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying” (2013) 27 *Palliat Med* 13.

⁶³ At 23.

⁶⁴ At 23.

⁶⁵ At 24.

supporting it in principle,⁶⁶ but consistently only smaller percentages being willing to engage actively.⁶⁷ That is, across jurisdictions a majority of doctors remain opposed to legalising AD, especially palliative care doctors, and that opposition is reflected in the formal policies of most medical associations.⁶⁸

Public attitudes are also reflected in the attitudes of the courts in recent years, which have become increasingly less willing to convict or impose severe sanctions on private individuals who have assisted family members to die where their primary motive is shown to be compassion. In 2010, in response to a legal challenge asking for clarification of the circumstances under which people helping someone to die might be prosecuted,⁶⁹ the UK Director of Public Prosecutions published comprehensive guidelines, at the direction of the courts, clarifying when a prosecution is or is not likely to occur in that jurisdiction. It recently relaxed those guidelines further, making it less likely that medical professionals or family members might be prosecuted where it is evident that the assisting parties have nothing to gain personally.⁷⁰

C The New Zealand situation

1 New Zealand law relevant to AD

1.1 Health law and regulations

While there is no reference to either euthanasia or AD as such in New Zealand's laws, various statutory provisions make assisting a person to take their own life unlawful. The New Zealand Crimes Act 1961 makes it a criminal offence, variously to: kill a human being, "directly or indirectly, by any means whatsoever" (s 158, s 160, ss 167-168) where that amounts to culpable homicide; "accelerate" or "hasten" the death of another person (s 164); "incite, counsel or procure" a suicide, or "aid or abet" a suicide (s 179); or take part in a "suicide pact" (s 180). No person may consent to being killed and such consent provides no defence to the person carrying out the killing (s 63). These provisions collectively ensure that anyone, including a doctor, providing support to another person to take their own life,

⁶⁶ "Most U.S. Doctors Now Support Aid in Dying: Survey" *NBC News* (online ed, New York, 16 December 2014).

⁶⁷ For a summary of trends in doctors' attitudes to legal AD, see Rod Duncan MacLeod, Donna M Wilson and Phillipa J Malpas "Assisted or Hastened Death: The Healthcare Practitioner's Dilemma" (2012) 4 *Glob J Health Sci* 87 at 89.

⁶⁸ *Ibid.* Doctors' opposition is discussed in detail in Chapter 4.

⁶⁹ *R (on the application of Purdy) v Director of Public Prosecutions* (2009) UKHL 45.

⁷⁰ The Director of Public Prosecutions "Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide" (February 2010, updated October 2014) <www.cps.gov.uk>.

even where the assister's motives are solely compassionate, may be charged with an offence. The New Zealand Bill of Rights Act 1990 (BORA; s 8) states as a right that "No one shall be deprived of life except on such grounds as are established by law and are consistent with the principle of fundamental justice". Contrasting with these provisions are those in the New Zealand Code of Rights and NZBORA (s 11) that recognise a person's right to hasten their own death, which potentially challenges the criminalisation of counselling, procuring, aiding or abetting such actions for a loved one, as canvassed in *Purdy* and *Seales*.

1.2 Case law in New Zealand

Because AD is not legal in New Zealand, there is no case law on AD provision. Since the focus of the present research is not on so-called 'mercy-killing', it is mentioned only briefly here. There have been no instances of health practitioners being charged in their professional capacity with an offence related to assisting a death and the courts have consistently upheld the doctrines of double effect and lawful excuse.⁷¹ Only two health practitioners have been charged for assisting a person to die, each in a family context. Dr Chris Simpson was convicted of manslaughter in relation to the killing of his terminally ill mother, and received a custodial sentence of three years.⁷² Nurse Lesley Martin received an 18 month custodial sentence in 2004 for the attempted murder of her mother in 1999.⁷³ Other cases of mercy-killing have been treated with increasing leniency by the New Zealand courts,⁷⁴ as by those overseas.⁷⁵

Until 2015 there had been no strategic legal challenges to the provisions of the Crimes Act 1961 like those brought in the US.⁷⁶ However in May 2015, terminally ill lawyer Lecretia

⁷¹ The doctrine of double effect, long established in UK law, recognises that a doctor is not culpable of an offence if s/he administers treatment to a dying person that may have the effect of hastening the person's death, provided that the intent of the treatment was to alleviate the symptoms and not to hasten the death, even where the doctor knows that it may also have the latter 'double' effect; see *Seales*, above n 34 at [105].

⁷² *R v Simpson* HC Auckland T010609 [2001] NZHC 968.

⁷³ *Lesley Martin v The Queen* [2005] NZSCTrans 11 (10 June 2005); "Defiant Martin chooses prison" *New Zealand Herald* (1 May 2004).

⁷⁴ A useful summary reviewing increasing leniency across New Zealand cases is provided in Sarah Elizabeth Mathieson "Live and Let Die: The Legalisation of Euthanasia in New Zealand" (Bachelor of Laws dissertation, University of Otago, October 2013).

⁷⁵ Bartels and Otlowski, above n 33; Emily Jackson *Medical Law: Text, Cases, and Materials* (3rd ed, Oxford University Press, Oxford, 2013) 876-878.

⁷⁶ For example, *Vacco v Quill*, 521 US 793, 807-08 (US SC, 1997) and *Washington v Glucksberg*, 521 U.S. 702, 735 (US SC, 1997), where the plaintiffs - doctors and terminally ill consumers - were supported by the RTD Compassion and Choices (or its predecessor agencies) to seek declarations that the relevant criminal

Seales initiated an action in the High Court,⁷⁷ seeking a declaratory judgment that the assistance of her doctor to hasten her death would not be an offence under the Crimes Act 1961, on the grounds either that (1) the sections creating the offence of assisting ‘suicide’ did not envisage and were not intended to apply to situations of AD, and/or that (2) those sections (s 160(1)(a) and s 179(b)) are contrary to Sections 8 and 9 of the NZBORA that protect, respectively, the rights to life and not to be subjected to cruel, degrading or disproportionately severe treatment.⁷⁸ The latter argument relied significantly on the 2015 rulings in *Carter* and the South African case of *Stranham-Ford v South Africa*.⁷⁹ Although neither of Ms Seales’ claims was upheld by the court, Collins J’s judgment included several statements that were supportive of the key arguments for legalising AD (discussed further in Chapter 5). He also held that it was the constitutional role of Parliament, not the courts, to change the law.

2 New Zealanders’ attitudes towards AD

2.1 The general public

The attitudes of the New Zealand public have been canvassed in recent years through media opinion polls, surveys undertaken by the Voluntary Euthanasia Society (VESNZ),⁸⁰ and some academic research, often coinciding with the presentation of a Bill to Parliament. They have all found majority public support for legalising AD. Percentages of the public supporting legal AD in polls have increased from around 60-70 percent in the early 2000s,⁸¹ to more than 70 percent in the current decade, with polls generally showing no statistically significant variation across age, gender, ethnicity, political persuasion (based on voting behaviour in the previous national election), or any demographic other than religiosity. For example, the most recent poll found 74 percent support for legalising AD and only 20 percent unsupportive;⁸² half of those surveyed also believed that someone other than a doctor should be legally able to support a person with an incurable disease who wanted to end their life. An academic survey of New Zealanders’ attitudes towards AD found that 65-82 percent of respondents supported AD, with the level of support increasing with more

provisions were in contravention of the Due Process Clause of the 14th amendment of the US Constitution, which protects against arbitrary denial of the right to life and liberty.

⁷⁷ *Seales*, above n 34.

⁷⁸ Rebecca Macfie “The Rights Choice” *New Zealand Listener* (Auckland, 4 April 2015).

⁷⁹ *Seales* at [70].

⁸⁰ VESNZ now brands itself the ‘End of Life Choice Society’; this document uses its legal name.

⁸¹ For example, “Assisted suicide doctors get support” *The Dominion Post* (Wellington, 3 February 2003); “Precedent set, say experts” *Waikato Post* (Hamilton, 30 August 2002).

⁸² Research New Zealand “Should euthanasia be legalised in New Zealand?” (press release, 14 April 2015).

serious types and degrees of suffering, and only 46 percent thought that mental illness should preclude access to AD.⁸³

Other indicators of support are evident in the public's response to media coverage of the issue. Where family members of people suffering from terminal illnesses have been necessarily prosecuted for assisting loved ones to die, at their request, reporting of court cases has typically generated an overwhelmingly benevolent public response. The decision in 2015 by lawyer Lecretia Seales to take an action to the High Court received not only sympathetic coverage in literally hundreds of media items,⁸⁴ but also hugely compassionate public support to her Facebook page, including comments from politicians past and present.⁸⁵

2.2 Doctors and nurses

New Zealand studies of doctors' end-of-life decision-making and practices have shown steadily increasing support for AD in instances of extreme suffering. A 2002 study found that 1.5 percent of doctors had "provided some form of physician assisted death",⁸⁶ and nine percent had "taken actions partly or explicitly with the intention of hastening death". More recent research has demonstrated a major increase in doctors' support for AD, to between a third and nearly half of doctors surveyed in 2015.⁸⁷ A *NZ Doctor* survey in July 2015 found that nearly 12 percent of doctors polled had "intervened to help a terminally ill and suffering" patient to die, and 45 percent believed that there should be a legal role for doctors in AD and that the relevant law needed to be changed.⁸⁸ The most recent study found that nearly 10 percent of doctors and three percent of nurses had wittingly provided a lethal dose of medication to hasten a death, many of them on multiple occasions.⁸⁹

⁸³ Nicola Rae, Malcolm H Johnson and Phillipa J Malpas "New Zealanders' Attitudes toward Physician-Assisted Dying" (2015) 18 *J Palliat Med* 259.

⁸⁴ For example, Macfie, above n 78. For a collation of more than 150 press articles across New Zealand see <<http://lecretia.org/media/>>.

⁸⁵ Lecretia's Choice <www.facebook.com>.

⁸⁶ Kay Mitchell and R Glynn Owens "National survey of medical decisions at end of life made by New Zealand general practitioners" (2003) 327 *BMJ* 202 at 203.

⁸⁷ Phillipa J Malpas, Kay Mitchell and Heidi Koschwanez "End-of-life medical decision making in general practice in New Zealand—13 years on" (2015) 128(1418) *NZMJ* 27; Phillipa Malpas, Michael Wilson and Pam Oliver "Attitudes of New Zealand doctors and nurses towards legalising assisted dying. Submission to the Parliamentary Health Committee on Assisted Dying" (29 January 2016); Cliff Taylor "GPs admit to helping patients die, amid calls for law change" *NZ Doctor* (online ed, Wellington, 8 July 2015).

⁸⁸ Taylor, above n 87.

⁸⁹ Malpas, Wilson and Oliver, above n 87.

2.3 Politicians' views

The views of New Zealand politicians were comprehensively voiced in the parliamentary debates around two Death with Dignity Bills, respectively in 1995 and 2003, but have not been systematically canvassed since that time. However a number of MPs have made public comments since the issue hit headlines prior to New Zealand's national election in late 2014. Prime Minister John Key commented publicly then that he was supportive in principle of "euthanasia" for a terminally ill person, but that he had concerns about some of the provisions of the End of Life Choice Bill then in the New Zealand Parliament Members' Bills Ballot.⁹⁰ Auckland Central MP Nikki Kaye stated in 2015 that she was "sympathetic to a possible change in the law to enable people who may be suffering intolerably to end their life [but that] previous bids before parliament on this issue ... have not been in a form that I could have voted for".⁹¹ MP Kevin Hague, the current Green Party spokesperson on health, commented in 2015 that the issue has historically been avoided by politicians on the grounds that it is not a popular political platform,⁹² and it is noteworthy that, at the time of writing this, none of the political parties in New Zealand yet has a formal policy on AD or euthanasia (as distinct from end-of-life health care in general). The Green Party is developing such policy currently. However in October 2015 MP and ACT Party leader David Seymour sponsored a new End of Life Choice Bill into the Members' Bills Ballot (discussed further below).⁹³

2.4 Policies and positions of medical bodies

Most of New Zealand's professional medical bodies have consistently either voiced opposition to AD or declined to take a formal stand on the matter. This response mirrors the typically oppositional stance of medical professional bodies worldwide.⁹⁴ The NZMA has consistently opposed AD, stating that "euthanasia is unethical and cannot be condoned by the NZMA as a professional body",⁹⁵ even if legislation were introduced. The position of the profession's regulator, the New Zealand Medical Council, is that AD constitutes

⁹⁰ "Euthanasia legitimate up to a point, says Key" *New Zealand Herald* (Auckland, 5 July 2014).

⁹¹ Personal email from MP Nikki Kaye, 2 March 2015.

⁹² Jo Moir "Politicians shy away from 'risky' euthanasia issue" *Stuff* (online ed, Wellington, 23 March 2015).

⁹³ End of Life Choice Bill, 14 October 2015 <www.parliament.nz>; "David Seymour introduces End of Life Choice Bill" *3 News* (Wellington, 14 October 2015).

⁹⁴ Bosshard and others "A role for doctors in assisted dying? An analysis of legal regulations and medical professional positions in six European countries" (2008) 34 *J Med Ethics* 28.

⁹⁵ Taylor, above n 87.

euthanasia and is therefore illegal.⁹⁶ The various palliative care bodies all oppose AD, though some appear to acknowledge the potential for legalisation in New Zealand. The Australian and New Zealand Society of Palliative Medicine (ANZSPM) formally “opposes the legalisation of both euthanasia and assisted suicide”.⁹⁷ The Palliative Care Council of New Zealand’s policy states that it believes that “euthanasia and physician-assisted suicide do not have a place in New Zealand society” but also acknowledges that “there are divergent views held by wider society about the ethics of euthanasia and physician-assisted suicide [and that] it is not always possible to completely relieve suffering”.⁹⁸ Hospice New Zealand does “not support a change in the law to legalise assisted dying”, but recognises “the right of everyone to take an individual position ... [and that] the question of whether there should be a change in the law is one for society to consider and for the parliament to decide”.⁹⁹

Other professional medical bodies have yet to clarify their positions, though some acknowledge movement in public attitudes. The Australian and New Zealand Society for Geriatric Medicine (ANZSGM) position statement considers it “likely that further legislation will be introduced” and that “the aim of [a formal] position should be to advocate for and optimise care for older people in line with scientific and evidence-based principles”.¹⁰⁰ The New Zealand Society for Oncology has no formal position on the issue, nor does the Australian & New Zealand Association of Neurologists (ANZAN).¹⁰¹ Due to polarised member views, the New Zealand Nurses Organisation (NZNO) declined earlier to take a formal stance,¹⁰² and still has no formal position.¹⁰³ Recently a number of senior doctors representing large government-funded health providers have stated their support for legal AD.¹⁰⁴ The Royal Australasian College of Physicians (RACP) and other colleges for

⁹⁶ Ian St George (ed) *Cole’s Medical Practice in New Zealand* (12th ed, Medical Council of New Zealand, Wellington, 2013) Chapter 11.

⁹⁷ Australian and New Zealand Society of Palliative Medicine “Position Statement: The Practice of Euthanasia and Assisted Suicide” (31 October 2013) <www.anzspm.org.au/c/anzspm>.

⁹⁸ “The Palliative Care Council of New Zealand’s Position on Euthanasia” (June 2013) <www.health.govt.nz>.

⁹⁹ “Statement on hospice care and assisted dying” (Hospice New Zealand, March 2012).

¹⁰⁰ Australian and New Zealand Society for Geriatric Medicine, above n 17.

¹⁰¹ Personal email communications from the presidents of those associations, March 2015.

¹⁰² “You can’t gatecrash heaven” *Sunday Star Times* (Auckland, 20 July 2003).

¹⁰³ Personal email communication from NZNO Research Manager, 25 March 2015.

¹⁰⁴ See Taylor, above n 87.

New Zealand medical specialisations are currently collaborating on a joint position statement, expected to be announced some time in 2016.¹⁰⁵

3 Attempts at AD legislation in New Zealand

3.1 Previous Bills

Bills have been debated twice by the New Zealand Parliament. The first Death with Dignity Bill, introduced by then National MP Michael Laws in 1995, was soundly defeated (61:29 votes). The sponsor's speeches, and those of others supporting the Bill,¹⁰⁶ identified the intent of the legislation as (1) reflecting 'patient autonomy' as the prevailing principle in medical decision-making, (2) compassion and the avoidance of intolerable pain and indignity and/or (3) the desirable and necessary regulation of a practice that was widely acknowledged as occurring already, to protect both people and doctors. Opponents typically identified the key reasons for opposing such a law as 'slippery slope' arguments, moral reasons (the imperative against killing, the Hippocratic oath) and/or a belief that palliative medicine could satisfactorily address all pain and indignity at the end of life. In 2003 a modified Death with Dignity Bill with more stringent eligibility measures was introduced by then New Zealand First Deputy Leader, Peter Brown MP. His speeches again emphasised the intent of the legislation as being focused on 'patient autonomy', compassion and regulating for safe medical practice, but also on evidence of strong public support.¹⁰⁷ Opposing speakers again focused on the 'slippery slope', moral arguments and their views that developments in palliative care made such legislation unnecessary. The Bill was defeated only narrowly, by 60 votes to 58 (with one abstention and one failure to vote or register a proxy).

In 2012 the End of Life Choice (EOLC) Bill 2012 was submitted to the Members' Bills Ballot by then New Zealand Labour Party List MP Maryan Street but withdrawn prior to the national election in 2014. The intent of that Bill was clearly stated in its introductory General Policy Statement as being to:¹⁰⁸

... promote compassion and the preservation of human dignity. It also reinforces the notion that someone who is a vigorous, self-determining person throughout their life

¹⁰⁵ Personal email communication from the RACP President, 24 September 2015.

¹⁰⁶ Hansard (2-3 August 1995) 550 NZPD.

¹⁰⁷ Hansard (30 July 2003) 610 NZPD 7482.

¹⁰⁸ End of Life Choice Bill 2012 at 1-3.

should be entitled to be self-determining at the end of their life, without criminal proceedings being visited on any professionals or loved ones who might assist them.

As none of these Bills reached a select committee, AD Bills have never been canvassed robustly with the New Zealand public and interest groups until now. The likely effectiveness of the provisions of the previous Bills in light of my research findings will be discussed in Chapter 5.¹⁰⁹

3.2 The new campaign

Subsequent to the Labour Party's decision following the 2014 national election that legalising AD was not amongst its immediate priorities, a new campaign emerged. Key components have included Lecretia Seales' High Court challenge (*Seales*), a petition launched by VESNZ that resulted in a Parliamentary Health Committee Inquiry,¹¹⁰ and the submission of a new End of Life Choice Bill (discussed in detail in Chapter 5). In addition, there has been increasing and generally supportive media coverage in publications with large audiences and supportive comments from many high profile New Zealanders.¹¹¹ Irrespective of the outcome of the Health Committee Inquiry, anticipated for the middle of 2016, it appears unlikely that the issue will disappear from the New Zealand stage any time soon.

D Legislative models for AD

The primary aims of all AD statutes are, in summary, to make AD available under certain conditions, decriminalise actions by health professionals¹¹² assisting a person to end their own life at their own volition where the motives of the assister are benign, and provide robust safeguards to ensure that no person is coerced into taking their life or helping someone to do so. Three main legislative models for AD have been identified which, though similar in their due care requirements, are differentiated by the relative

¹⁰⁹ 'Effective' legislation is defined for the purposes of this thesis as encompassing both 'effectiveness' and 'efficacy' as defined by Helen Xanthaki, that is, "the measure by which the performance data of the legislation match its objective" (efficacy, relating to the outcomes availed by the legislation) and "the extent to which the legislation manages to introduce adequate mechanisms capable of producing the desired regulatory results" (effectiveness, relating to implementation processes and systems in the legislation); Helen Xanthaki *Drafting Legislation: Art and Technology of Rules for Regulation* (Hart Publishing, Oxford, 2014) 5-6. This differentiation is discussed further in Chapters 3-5.

¹¹⁰ New Zealand Parliament "Make a Submission: Petition of Hon Maryan Street and 8,974 others" <www.parliament.nz>.

¹¹¹ Eg "Inquiry should have more emphasis on assisted death – MP" *Manawatu Standard* (online ed, Palmerston North, 18 January 2016); see Lecretia's Choice <<http://lecretia.org/media/>>.

¹¹² And potentially other assisters in Switzerland.

permissiveness or restrictiveness of their scope. The ‘Oregon’ model, common across the US states, is the most restrictive, permitting AD only to people who are terminally ill and after a specified minimum wait between requests. The Benelux countries and Québec base eligibility on the person’s suffering, rather than primarily on their illness, and allow for urgent requests to be processed more quickly. The Swiss law is highly permissive in terms of who may in principle receive AD, requiring only that the assister have benign motives, with eligibility criteria determined by each individual AD provider agency; however the regulations imposed by those agencies and more recently by some cantonal laws (see **Table 1**) ensure rigorous assessment processes. **Table 1** (following pages) provides an overview and comparison of the key legal AD eligibility and due care requirements and provision systems across jurisdictions.¹¹³ It expands on a 2015 summary published by Penney Lewis.¹¹⁴ The material in **Table 1** includes the statutes in the six jurisdictions with legislation included in the interview sample for this research (see p 36). *The relevant features and provisions of each statute are discussed comprehensively in Chapters 4 and 5.*

In essence, the three legislative models differ primarily in terms of the eligibility conditions and the wait period required for requests, with some unique variations in the due care requirements as statutes have built on earlier ones. However all three models, including the protocols developed by the various Swiss AD provider agencies and the recent cantonal laws in Vaud and Neuchatel (see **Table of statutes and Bills**), focus on providing robust safeguards against AD being too readily available without protections for potentially vulnerable people.

¹¹³ Albania and Colombia are not included in this analysis because information was unobtainable in any language that I can read.

¹¹⁴ Penney Lewis “Assisted dying: What does the law in different countries say?” *BBC News* (online ed, London, 6 October 2015).

Table 1. Summary of key statutory provisions across jurisdictions	
Features of the legislation	Statute sections and terminology
How did the law change in the various jurisdictions?	
<ul style="list-style-type: none"> • In The Netherlands, euthanasia and assisted suicide were legalised initially through the use of the defence of necessity in prosecutions of (mainly) doctors providing AD. • In Belgium, Luxembourg, Québec, Vermont and California the legislature changed the law. • In Switzerland the penal code exempts acts of compassion from criminal liability for assisting a ‘suicide’. • In Oregon and Washington, legislation was enacted because a (small) majority voted in favour of a citizen-initiated referendum. Accordingly these Bills were not debated in the Oregon legislature and did not go through a select committee process, but were adopted as written. • In Colombia, Montana, New Mexico, Hawai’i, South Africa and Canada¹¹⁵ the courts took the lead in changing the law, on the basis of human rights claims. 	<ul style="list-style-type: none"> • Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002 (The Netherlands) (effective 1 April 2002). • Law on Euthanasia of 28 May 2002 (Belgium) (effective 28 May 2002). • Bill 52: An Act respecting end-of-life care 2014 (Québec) (effective 10 December 2015). • Code pénal Suisse 1937 (Switzerland), article 115 (effective 1942). • Death with Dignity Act Oregon 1997 (effective 27 October 1997). • Death with Dignity Act (RCW 70.245) (Washington) (effective 5 March 2009).

¹¹⁵ Note that at the time of writing Canada had not finalised its statute(s), but Canada is referred to in this summary because some of the proposed statutory provisions are discussed later.

Table 1. Summary of key statutory provisions across jurisdictions	
Features of the legislation	Statute sections and terminology
What are the eligibility conditions?	
<ul style="list-style-type: none"> • In The Netherlands, the person's suffering must be enduring and unbearable, with no prospect of improvement. The suffering need not be related to a terminal illness and is not limited to physical suffering. It can include, for example, the prospect of loss of personal dignity, increasing personal deterioration, a fear of suffocation or the notion that one's life is 'completed'. • The Belgian law is similar. The person's suffering must be constant as well as unbearable, resulting from a serious and incurable disorder. Additional checks are imposed if the person is not terminally ill. • In Québec the person must have a 'serious and incurable illness', be in an 'advanced state of irreversible decline' and 'at end of life', and have 'constant and unbearable' suffering. Whether 'illness' includes a psychiatric illness is not defined in the statute. • In Switzerland, the person must demonstrate an incurable illness or multiple irreversible medical conditions related to old age, together with a well-considered wish to die. • The US statutes require that the person be terminally ill with a prognosis of less than six months. There is no requirement relating to the person's experience of suffering. • In Canada, people will qualify if they have a "grievous and irremediable medical condition (including an illness, disease or disability) that is causing enduring suffering that is intolerable to the individual". 	<ul style="list-style-type: none"> • <i>Netherlands</i>: Article 2(1)(b) and (d): "the patient's suffering was lasting and unbearable", and "there was no other reasonable solution for the situation he was in". • <i>Belgium</i>: Section 3, §1: "patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated". • <i>Québec</i>: Section 26(3)-(6): "be at the end of life; "suffer from a serious and incurable illness; be in an advanced state of irreversible decline in capability; and experience constant and unbearable physical or psychological suffering". • <i>Switzerland</i>: For example, EXIT eligibility guidelines; www.exit-geneve.ch/conditions.htm • <i>Oregon</i>: Sections 127.800 §1.01 and 127.805 §2.01, "suffering from a terminal disease [that will] produce death within six months" • <i>Washington</i>: Section 70.245.010, an "incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months". • See the draft Canadian legislation, p 5.¹¹⁶

¹¹⁶ Downie, above n 44.

Table 1. Summary of key statutory provisions across jurisdictions	
Features of the legislation	Statute sections and terminology
Which requests by persons will qualify?	
<ul style="list-style-type: none"> All of the regimes require the person to be mentally competent, well-informed, and to make at least two voluntary requests free of coercion (which is not defined in the statutes). One request must be in writing, on a prescribed form, and signed by the person. Some jurisdictions require one or more witnesses to the signing, either a doctor or prescribed others. In the US states, the person's second request must be at least 15 days after their previous request. In Belgium and Québec the timing of requests depends on the progression of the person's illness. In The Netherlands no time frame is specified in the statute, but is left to the judgment of the assessing doctor, as it is in Switzerland (see discussion p 177 ff). 	<ul style="list-style-type: none"> <i>Netherlands</i>: Article 2(1)(a), the doctor must “hold the conviction” of a “voluntary and well-considered” request, which is taken to imply repeated requests. <i>Belgium</i>: Section 3 §1, “request is voluntary, well-considered and repeated and [free from] external pressure”. <i>Québec</i>: Sections 26-28, the person must make repeated “informed” requests, “freely and without any external pressure”. <i>Oregon</i>: Section 127.805 §2.01, the person must be “capable, acting voluntarily, and is not being coerced”; and s 127.840 §3.06, the person must “reiterate the oral request ... no less than fifteen (15) days after making the initial oral request”. <i>Washington</i>: Section 70.245.010(1), the written request must be “signed and dated by the patient and witnessed by at least two individuals who, in the presence of the patient, attest that to the best of their knowledge and belief the patient is competent, acting voluntarily, and is not being coerced to sign the request. <i>Belgium</i>: Section 3 §2(2), requests “spread out over a reasonable period [depending on] the progress of the patient's condition”. <i>Québec</i>: Sections 28, requests must be made over “reasonably spaced intervals given progress of the patient's condition”.

Table 1. Summary of key statutory provisions across jurisdictions	
Features of the legislation	Statute sections and terminology
How old must the person be?	
<ul style="list-style-type: none"> • Only The Netherlands and Belgium permit euthanasia for people under the age of 18. • In The Netherlands, a competent person between the ages of 16 and 18 may request euthanasia or assisted suicide. The parent or guardian does not have a veto, but must be consulted. Competent minors aged between 12 and 16 may also qualify, but only if their parent or guardian consents. • In Belgium, a competent person under the age of 18 may request euthanasia with parental consent. Additional scrutiny of the child's competence is required, and suffering based on a psychiatric disorder is excluded. 	<ul style="list-style-type: none"> • <i>Netherlands</i>: Articles 2(2) and 2(3) respectively permit AD for a “minor patient ... between sixteen and eighteen years [and a] minor patient aged between twelve and sixteen years [who is] deemed to have a reasonable understanding of his interests”. • <i>Belgium</i>: Section 3 permits euthanasia (sic) to an “emancipated minor [who is] legally competent and conscious at the time of the request”.

Table 1. Summary of key statutory provisions across jurisdictions	
Features of the legislation	Statute sections and terminology
What procedural safeguards are imposed?	
<ul style="list-style-type: none"> In the Benelux countries, a second “consultant” doctor must see the person to confirm their request is valid and their suffering unbearable. Networks of participating doctors in The Netherlands (SCEN) and Belgium (LEIF)¹¹⁷ are trained to undertake these consultations. People must be assessed by a mental health professional if either assessing doctor cannot confirm the person’s mental competence. The requirements in Québec reflect the Benelux model. In the US states, a second doctor must see the person to confirm they are terminally ill and their request is valid, and refer the person for an assessment by a mental health professional if either the attending or consulting doctor suspects the person may be suffering from a psychological disorder causing impaired judgment. In Switzerland four NGOs have been established that provide AD services, each developing its own procedural guidelines that reflect those of the other jurisdictions. Specific laws have been passed in two Swiss cantons (Vaud and Neuchatel) that set out procedural requirements. 	<ul style="list-style-type: none"> <i>Netherlands</i>: Article 2(1)(e), the doctor must consult “at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care”. <i>Belgium</i>: Section 3 §2(3), the “physician consulted ... must be certain of the patient’s constant and unbearable physical or mental suffering that cannot be alleviated”. <i>Québec</i>: Section 28(3) “physician consulted must be independent ... [and] must consult the patient’s record, examine the patient and provide the opinion in writing”. <i>Oregon</i>: Section 127.820 §3.02, the “consulting physician [must confirm] the attending physician's diagnosis that the patient is suffering from a terminal disease, and verify that the patient is capable, is acting voluntarily, and has made an informed decision”. <i>Washington</i>: Section 70.245.050, has identical wording to the Oregon statute except for using the term “competent”, not “capable”. For example, EXIT eligibility guidelines; www.exit-geneve.ch/conditions.htm Loi sur la santé publique (LSP) (Vaud) AS art. 27d Loi sur la santé (LS) (K 1 03) (Neuchatel) art. 39A

¹¹⁷ Support and Consultation on Euthanasia in The Netherlands (SCEN) and Life End Information Forum (LEIF).

Table 1. Summary of key statutory provisions across jurisdictions	
Features of the legislation	Statute sections and terminology
What procedural enablers are provided for people requesting AD?	
<ul style="list-style-type: none"> • In Québec the person's first request must be recorded on their medical record (s 31). Where the person is not physically capable of signing, the required form may be signed by a proxy with witnesses (s 26). Some interested parties are excluded from being proxies to protect against coercion (s 27). • The US statutes allow for the person's wishes to be communicated through "persons familiar with the patient's manner of communicating if those persons are available" (Oregon, s 127.800 §1.01(3); Washington, s 70.245.101). They also require the assessing doctors to advise the person requesting AD that they are not required to discuss their decisions with family or others (Oregon s 127.835 §3.05; Washington s 70.245.080). 	
What protections are available for participating health practitioners?	
<ul style="list-style-type: none"> • Doctors are given explicit immunity from criminal prosecution in all regimes (except Québec, see discussion p 128-129) provided that they comply with the legal requirements either in good faith (US and Switzerland) and/or without negligence (Switzerland, The Netherlands and Belgium) • The US statutes provide doctors wishing to participate in AD with protection from reprimand, contractual prohibition or loss of privileges or similar from their employer or professional body. • All of the regimes provide for conscientious objection to participation by doctors, except The Netherlands, where the authors of the statute deemed such an option self-evident. Only the Québec law provides explicitly for conscientious refusal by other "health professionals" (s 44). 	<ul style="list-style-type: none"> • <i>Netherlands</i>: Preamble to the Act, doctors have "exemption from criminal liability for the physician who with due observance of the requirements of due care to be laid down by law". • <i>Belgium</i>: Section 3 §1, "the physician who performs euthanasia commits no criminal offence when he/she ensures that" the provisions of s 3 and other "conditions and procedures" of the Act are met. • <i>Switzerland</i>: People will not be prosecuted for assisting a 'suicide' where they do not have "selfish motives". • <i>Oregon</i>: Section 127.885 §4.01(1), doctors (and others) are protected from "civil or criminal liability or professional disciplinary action for participating in good faith compliance". • <i>Washington</i>: Section 70.245.190, has identical wording to the Oregon statute.

Table 1. Summary of key statutory provisions across jurisdictions	
Features of the legislation	Statute sections and terminology
What accountabilities are there for doctors in the statutes?	
<ul style="list-style-type: none"> • In all jurisdictions, doctors must report to an authority, providing key details on the death (eg date, time, drugs used, people present), including information on any issues that arose, as follows: • In the Benelux countries, doctors must report to an independent review committee which reviews all death reports and carries out investigations if there are anomalies apparent. Doctors can be penalised for not carrying out the due care requirements adequately. • Participating doctors in Québec must report to the relevant chapter of their professional association. • In the US states, the attending doctor involved in providing the prescription completes a report for the health authority if they are aware of the death and it is in fact an assisted versus ‘natural’ death. • In Switzerland, the provider agency contacts the local police and completes a prescribed certificate. 	<ul style="list-style-type: none"> • <i>Netherlands</i>: article 8, the “committee assesses on the basis of the report referred to in Article 7 second paragraph of the Burial and Cremation Act whether the physician who has terminated a life on request or assisted in a suicide has acted in accordance with the requirements of due care”. • <i>Belgium</i>: Section 5, the doctor is “required to fill in a registration form drawn up by the Federal Control and Evaluation Commission established by section 6 of this Act and deliver this document to the Commission within four working days”. • <i>Québec</i>: Section 33, the doctors must “give notice to the council of physicians, dentists and pharmacists of which the physician is a member”. • <i>Oregon</i>: Section 127.855 §3.09(7), requires a “note by the attending physician indicating that all requirements under ORS 127.800 to 127.897 have been met and indicating the steps taken to carry out the request, including a notation of the medication prescribed”. • <i>Washington</i>: Section 70.245.120 (7), has identical wording to the Oregon statute. • See “La Suisse et La Bonne Mort” p 19 http://www.ub.edu/fildt/revista/pdf/RByD21_PubAct1_Sobel_PPT.pdf

Table 1. Summary of key statutory provisions across jurisdictions	
Features of the legislation	Statute sections and terminology
What is the involvement of the medical professional bodies?	
<ul style="list-style-type: none"> Only the Québec law provides specifically for the participation of any medical professional body or health practitioner statutory body in determining procedural requirements. This was achieved through a collaboration with the Collège des Médecins in drafting the law. In The Netherlands and Québec the medical associations and the Collège des Médecins (Québec) have been integrally involved in initial and ongoing developing practice guidelines and standards. No medical professional body in any of the other regimes is actively involved in regulating AD practices and all but three remain formally opposed to AD. The Oregon, Californian and Canadian medical associations leave it to the individual doctor to determine their participation on a conscience basis. The Swiss association is currently reviewing its position. 	<ul style="list-style-type: none"> Section 32: “The council of physicians, dentists and pharmacists established for an institution must, <i>in accordance with the clinical standards established by the professional orders concerned</i>, adopt clinical protocols applicable to terminal palliative sedation and medical aid in dying.” See discussion p 121. See discussion p 223.

Table 1. Summary of key statutory provisions across jurisdictions	
Features of the legislation	Statute sections and terminology
Who provides AD delivery services?	
<ul style="list-style-type: none"> • In the Benelux countries AD is provided by a broad range of family doctors, oncologists and general medicine doctors, mainly in people's homes and end-of-life health care facilities, supported by a trained SCEN doctor as the consulting doctor in most instances. The RTDs in each country provide trained volunteer supporters where needed to assist people seeking AD. • In Oregon and Washington, the vast majority of assisted deaths are provided by the RTDs in each state (Compassion and Choices Oregon and End of Life Washington respectively) who provide volunteer doctors to prescribe medications and trained volunteers providing other support people. • In Switzerland AD is provided by five NGO agencies. EXIT Suisse Romande and EXIT Deutsche Schweiz provide AD for Swiss citizens only, also using trained volunteers and volunteer doctors. Dignitas, EX International and Lifecircle provide AD primarily to people from other countries. 	<ul style="list-style-type: none"> • No specific regulation. The RTDs Nederlandse Vereniging voor een Vrijwillig Euthanasie (NVVE) and Recht Op Waardig Sterven (RWS) each have written internal policy and protocols for volunteer activity. SCEN also has comprehensive policy and protocols. • Compassion and Choices Oregon and End of Life Washington (previously called Compassion and Choices Washington) each has written internal policy and protocols for volunteer activity. • Each Swiss provider agency has comprehensive written internal policy and procedures.

E Access barriers and related issues in implementing AD laws

1 The evidence to date

Prior to this project, no systematic research had been undertaken that focused specifically on the barriers to accessing legal AD,¹¹⁸ though some Netherlands and Belgian research has examined rates of and reasons for AD being declined.¹¹⁹ In the jurisdictions with AD laws, the outcomes (versus processes) of implementation have been closely monitored, and at least three comprehensive reviews have been published that examine the outcomes across jurisdictions.¹²⁰ Generally, the experience in each jurisdiction has shown that opponents' fears around the legislation, typically 'slippery slope' arguments, have not been borne out in reality.¹²¹

However there have been 'teething' issues in each jurisdiction, and the experience internationally shows that there continue to be a number of ways in which the primary intent of the legislation - that is, to assist people experiencing major suffering to ease that suffering through proactive medical intervention to hasten their death - has been frustrated by a range of factors, some foreseen and others unforeseen.

This section overviews evidence of those barriers, which will be described comprehensively in later chapters. The apparent barriers vary somewhat across jurisdictions depending on the particular requirements of each statute. While the factors described in the introductory overview below are set out as individual points, they are linked in a complex constellation that can create an ultimately overwhelming obstacle course for frail, ill people. Moreover, it is apparent that there are major barriers for doctors and other health practitioners who wish to participate in legal AD.

¹¹⁸ In a comprehensive review of end-of-life practices generally in the US, a 2000 paper identified several legal barriers for patients to accessing a hastened death, due to "myths" common amongst doctors, but made only passing reference to AD which was then only newly legal in one state; see Alan Meisel, Lois Snyder and Timothy Quill "Seven Legal Barriers to End-of-Life Care: Myths, Realities, and Grains of Truth" (2000) 284(19) JAMA 2495.

¹¹⁹ For example, Kenneth Chambaere and others "Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium" (2015) 372 N Engl J Med 1179; Steven K Dobscha and others "Oregon physicians' responses to requests for assisted suicide: a qualitative study" (2004) 7 J Palliative Med 451; Ilinka Haverkate and others "Refused and granted requests for euthanasia and assisted suicide in the Netherlands: interview study with structured questionnaire" (2000) 321 BMJ 865.

¹²⁰ Griffiths, Weyers and Adams, above n 3; Jackson, above n 75; Lewy, above n 10.

¹²¹ Battin and others, above n 35; Katrina Hedberg and others "The 10-Year Experience of Oregon's Death with Dignity Act: 1998-2007" (2009) 20 J Clin Ethics 124.

2 Access barriers and related issues

The access barriers apparent in the literature available prior to undertaking the interviews for this research are summarised here. Later material is presented in the discussion chapters.

Varying rates of granting AD

- Significant variations across jurisdictions in the percentage of requests that result in doctors writing a prescription suggest that people seeking AD encounter barriers. For example the approval rate was only 15 percent in Oregon in 2011, as compared with nearly 50 percent in The Netherlands in 2010,¹²² even though the Oregon law had been in force longer than the Dutch one.
- Approval of requests is significantly more likely if the consumer is in a hospice programme at the time of request.¹²³

Interpretation of terms and other aspects of the laws

- Doctors experience difficulties in deciding and agreeing on what constitutes ‘terminal’ illness, especially as medical interventions that extend life are constantly being introduced, resulting in people being declined.¹²⁴
- Similar difficulties have arisen in determining what constitutes sufficient evidence of ‘unbearable’ suffering,¹²⁵ and some doctors have struggled with how to validly evaluate the person’s subjective perspective.¹²⁶ Adams and Nys have highlighted how the Belgian law, in attempting to clarify the eligibility criteria, has so complicated the Belgian statute that even the courts have struggled to interpret the requirements.¹²⁷

Variable medical capacity, capability or willingness to process requests

- Worldwide, doctors are significantly less supportive of AD than the general population, suggesting potential doctor unavailability.¹²⁸

¹²² Lewy, above n 10.

¹²³ Linda Ganzini and others “Experiences of Oregon Nurses and Social Workers with Hospice Patients Who Requested Assistance with Suicide” (2002a) 347 New Engl J Med 582.

¹²⁴ Birgit Aabom and others “Defining cancer patients as being in the terminal phase: who receives a formal diagnosis, and what are the effects?” (2005) 23 J Clin Oncol 7411; Katrina Hedberg and Susan Tolle “Putting Oregon’s Death with Dignity Act in Perspective: Characteristics of Decedents Who Did Not Participate” (2009) 20 J Clin Ethics 133; see generally Lewy, above n 10.

¹²⁵ H Pasman and others “Concept of unbearable suffering in context of ungranted requests for euthanasia: qualitative interviews with patients and physicians” (2009) 339 BMJ b4362; Judith AC Rietjens and others “Judgement of suffering in the case of a euthanasia request in The Netherlands” (2009) 35 J Med Ethics 502.

¹²⁶ Hilde M Buiting and others “Dutch criteria of due care for physician-assisted dying in medical practice: a physician perspective” (2008) 34 J Med Ethics e12.

¹²⁷ Maurice Adams and Herman Nys “Euthanasia in the low countries. Comparative reflections on the Belgian and Dutch euthanasia acts” in Paul Schotsmans and Tom Meulenbergs (eds) *Euthanasia and Palliative Care in the Low Countries* (Peeters, Paris, 2005) 5.

¹²⁸ For a comprehensive summary of research across jurisdictions internationally see Clive Seale “Legalisation of euthanasia or physician-assisted suicide: survey of doctors’ attitudes” (2009) 23 Palliat Med 205 at 205.

- Significant proportions of eligible medical practitioners (up to 75 percent in many places) have been unwilling to act on or even accept a request for legal AD,¹²⁹ resulting in frustrated applications, especially in rural contexts.¹³⁰ By 2010 only one percent of eligible Oregon doctors had written legal AD prescriptions.¹³¹
- There is a lack of accredited education and/or practice guidelines across most jurisdictions for doctors on how to apply the legislation safely and effectively,¹³² so many decline participation due to fears of prosecution, stigma and/or professional reprimand.¹³³

Assessing mental competence

- Doctors' inability to accurately distinguish the symptoms of end of life and 'demoralization syndrome' from clinical depression can result in people's requests being denied, rather than being referred for a mental competence assessment.¹³⁴
- Frail, ill people may make requests that appear vague, inarticulate or not sufficiently credible to physicians due to the impacts of palliative drugs,¹³⁵ resulting in being declined for lacking mental competence.
- In the absence of authorised guidelines for mental competency assessments, professionals rely on generic mental competency assessment guidelines, or simply apply their own notions of what constitutes an appropriate approach.¹³⁶

¹²⁹ Linda Ganzini and others "Attitudes of Oregon Psychiatrists Toward Physician-Assisted Suicide" (1996) 153 Am J Psychiat 1469.

¹³⁰ Ganzini and others, above n 123.

¹³¹ Kenneth Stevens "Cornering the market on physician-assisted suicide" *The Oregonian* (Portland, 10 March 2010).

¹³² Griffiths, Weyers and Adams, above n 3; Berniek AM Hesselink and others "Education on end-of-life care in the medical curriculum: students' opinions and knowledge" (2010) 13 J Palliat Med 381.

¹³³ Delamothe, Snow and Godlee, above n 1; Bert Gordijn and Rien Janssens "Euthanasia and Palliative Care in the Netherlands: An Analysis of the Latest Developments" (2004) 12 Health Care Anal 195; Linda Sheahan "Report on the interface between palliative care and legalized physician assisted suicide and voluntary euthanasia" (The Winston Churchill Memorial Trust of Australia, 30 May 2013).

¹³⁴ Johanna H Groenewoud and others "Psychiatric consultation with regard to requests for euthanasia or physician-assisted suicide" (2004) 26(4) Gen Hosp Psychiatry 323; Cristina Monforte-Royo and others "The wish to hasten death: a review of clinical studies" (2011) 20 Psychooncology 795.

¹³⁵ Buiting and others, above n 126; Linda Ganzini, Elizabeth R Goy and Steven K Dobscha "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey" (2008) 337 BMJ a1682.

¹³⁶ Cathy de Campos "'Doctor, can you help me?' Responding to and assessing requests for death with dignity" (paper presented to a Conference on Aid in Dying, Washington State Psychological Association and Group Health, Seattle, 30 January 2010).

Passive provider opposition to AD

- Under the US laws doctors are not required to state reasons for declining, leaving declined people in limbo as to their next options.¹³⁷ None of the statutes clarifies further options if a request is declined.
- Several studies have shown that doctors' or nurses' religiosity can be a potential barrier to access.¹³⁸
- The conscientious objection provisions (or lack of them) in existing statutes allow both doctors and organisations to decline participation in AD, resulting in some end-of-life care providers contractually prohibiting their entire staff from any participation whatsoever in AD.¹³⁹
- Frail and suffering people can be easily deterred from making a request by even well-intended health practitioners who oppose AD.¹⁴⁰

Lack of specified time frames to support AD requests

- None of the existing statutes includes a requirement that declining doctors refer requests on, or a specified time frame for doing so.
- Without a specified minimum period for processing requests, delays can result in people dying while their request is in process or even resorting to self-starvation or active suicide to hasten their death.¹⁴¹

Relationship between the health professions and the law

- Several commentators have explored issues for health practitioners in implementing laws around end-of-life care, highlighting a paucity of practical guidance for health professionals in implementing health law reforms generally¹⁴² and doctors' difficulties in

¹³⁷ Elizabeth Trice Loggers and others "Implementing a Death with Dignity Program at a Comprehensive Cancer Center" (2013) 368 New Engl J Med 1417; Sheahan, above n 133.

¹³⁸ For a summary of studies, see Kasper Raus and others "Continuous sedation until death: the everyday moral reasoning of physicians, nurses and family caregivers in the UK, The Netherlands and Belgium" (2014) 15(1) BMC Med Ethics 14.

¹³⁹ Sheahan, above n 133.

¹⁴⁰ Claudia Gamondi and others "Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: a qualitative study" (2013) BMJ Support Palliat Care bmjspcare-2013; Gordijn and Janssens, above n 133; Sheahan, above n 133.

¹⁴¹ Ganzini and others 2002a, above n 123; Marijke C Jansen-van der Weide, Bregje D Onwuteaka-Philipsen and Gerrit van der Wal "Requests for euthanasia and physician-assisted suicide and the availability and application of palliative options" (2006) 4(4) Palliat Support Care 399.

¹⁴² MB Kapp "Decisional capacity in theory and practice: legal process versus 'bumbling through'" (2002) 6 Aging Ment Health 413.

interpreting the legal requirements of permissive laws in particular.¹⁴³ These authors argue for greater involvement of health professionals in the drafting of health laws.

- The role of nurses is ignored in all of the statutes, even though they are affected in multiple ways by AD requests, leaving many nurses reluctant to participate even where they wish to.¹⁴⁴

Cultural and socioeconomic factors

- People requesting AD are disproportionately white, relatively highly educated and in middle to high income brackets (as indicated by their health insurance status),¹⁴⁵ but there has been almost no research to determine why.
- There are major differences between doctors in the French- versus Dutch-speaking regions of Belgium in their compliance with the requirements of the legislation and in their apparent substitution of continuous deep sedation to people explicitly requesting AD.¹⁴⁶

Other barriers to access

- Drug availability and costs can be prohibitive for some people.¹⁴⁷
- Some US doctors have reported being deterred from participating in AD due to ‘paperwork’ and prescription requirements.¹⁴⁸
- People attempting to access AD through an advance directive have run into barriers for a range of reasons even where it is legal.¹⁴⁹
- Many pharmacists are unwilling to dispense the drugs.¹⁵⁰

It was anticipated that there might well be other barriers, as yet unidentified in the literature, for example, around the reasons underlying doctors’ reluctance to participate, the impact of

¹⁴³ Diane E Hoffmann “Physicians Who Break the Law” (2009) 53 St Louis U L J 1049; Sandra H Johnson “Regulating physician behavior: Taking doctors’ ‘bad law’ claims seriously” (2009) 53 St Louis U L J 973.

¹⁴⁴ Nele De Bal, Chris Gastmans and Bernadette Dierckx de Casterlè “Nurses’ involvement in the care of patients requesting euthanasia: a review of the literature” (2008) 45 Int J Nurs Stud 626; Frances Trowell “Exploring the nursing implications of physician-assisted suicide in the UK” (2009) 105 Nurs Times 31.

¹⁴⁵ Hedberg and Tolle, above n 124; see generally Sumner, above n 10.

¹⁴⁶ Tinne Smets *The euthanasia practice in Belgium: Behavior and attitudes regarding reporting and adherence to legal safeguards* (VUB Press, Brussels, 2010).

¹⁴⁷ BioEdge “Embargo on lethal drug stops executions and assisted suicides in US” (23 May 2014) <www.bioedge.org>.

¹⁴⁸ Sheahan, above n 133; Smets, above n 146.

¹⁴⁹ Cees MPM Hertogh “The role of advance euthanasia directives as an aid to communication and shared decision-making in dementia” (2009) 35 J Med Ethics 100.

¹⁵⁰ Colin Meek “Pharmacy involvement where assisted suicide and euthanasia are permitted” (2006) 277(7427) Pharm J 614.

the conscientious objection options within the statutes, or other aspects of the legislative frameworks.

3 Lack of formative evaluation or qualitative research on AD implementation

The barriers listed above reflect problems where the laws and regulations are silent on implementation or provide insufficient guidance for people wanting AD or for doctors. Despite studies identifying these problems, none of the formal reporting on AD implementation by the relevant health authorities in each jurisdiction (as distinct from academic research and investigation by the AD provider agencies) explores the underlying reasons any further. Several authors have highlighted a notable absence of qualitative research to explore the factors underlying access barriers.¹⁵¹ Moreover, there is very little literature on how refusals and the aftermath of those for people who seek AD are managed. No statute or Bill to date has included any requirement or suggestion for formative evaluation. While the Québec statute, passed in June 2014, establishes a statutory commission to undertake (inter alia) ‘evaluation’ of the implementation of the legislation (sections 38-47), it does not provide for formative evaluation and leaves it to the commission to determine what evaluation may be useful and at what point. The legislation in The Netherlands and Belgium was accompanied by some dedicated government funding for monitoring research, but until late 2014 that research comprised almost exclusively quantitative surveys of doctors’ activity or health authorities’ monitoring of AD uptake and provision of assisted deaths. As a result, no systematic formative evaluation of the effectiveness and appropriateness of either the implementation processes or the legislative frameworks has been undertaken to date.

F Purposes, focus and scope of the research

1 Focus and scope

The overarching purpose of this research was to examine the role of the law in creating or mitigating access barriers to legal AD. The focus has been to undertake a comprehensive evaluation of the implementation of the laws in selected jurisdictions, focusing on the pragmatics of implementation (that is, not on the ethical arguments for and against AD) to identify *unintended* barriers to access and related issues and also ways in which those barriers can be mitigated.

¹⁵¹ Jackson, above n 75; Lewy, above n 10; Smets above n 146.

2 Purposes of the research

The key objectives of the research were to:

- Identify and describe the range of factors encountered in implementing AD legislation in selected international jurisdictions that have resulted, directly or indirectly, in frustrating the intended access of people to the assistance sought;¹⁵²
- Identify and describe the links between the access barriers encountered and the ways in which the statutes are framed and phrased;
- Identify and describe the responses - both formal (legislative, regulatory and other) and informal - that have been used variously to address access barriers, and
- Identify and describe the extent to which those mitigation measures are perceived by a range of key stakeholders as having been effective in removing or reducing the barriers, and which barriers remain;
- Explore (i) the potential for the barriers identified internationally to occur in New Zealand, were the End of Life Choice Bill 2015 to be enacted in its current phrasing and framework, and (ii) opportunities for developing legislation and other effective practice that might avoid or mitigate those barriers;
- Disseminate lessons from the research to the international legal, health and social communities interested in facilitating effective AD legislation.

¹⁵² The ‘intended’ access is meant here as access by those people who might reasonably meet the eligibility conditions in the statute relevant to their jurisdiction.

Chapter 2. Research design and approach

A Scoping the research

The research questions and methods were scoped through key informant interviews and discussions with an advisory group. Interviews were undertaken with 10 selected key informants to assist with determining the research questions, relevant theoretical frameworks and the shape of the research sample. The key informants were selected to represent, collectively, the three legislative models and the range of roles relevant to implementation of legal AD (see below). Interviews were guided by a rough framework of questions that canvassed informants' ideas about the most valuable focus for the research and identified key stakeholders in AD legislation.

An advisory group was established to provide expert input into each phase of the research, including identifying potential participants. In addition to the research supervisors (from the University of Auckland Faculties of Law and Medical and Health Sciences, with expertise respectively in health law and AD ethics and research), the advisory group comprised: one European and one US academic specialising in AD law; a Netherlands doctor closely involved in AD for 30 years; a District Health Board Clinical Director and former general practitioner (GP); and a senior Māori health evaluator/researcher, in case the interview sample might include people representing indigenous cultures.

B Research questions

The key research questions, developed through the scoping phase, were:

1. What are the main barriers to people's ability to successfully access assistance to die in (selected) jurisdictions with AD legislation?
2. What factors or related issues - aspects of the legislation and other factors - underlie or contribute to the presenting barriers?
3. How have those barriers - formal and informal - variously been addressed in the selected jurisdictions, and how effective have those mitigation measures been?
4. Are there any barriers - presenting or underlying - that remain significant and unresolved?
5. What are the lessons for the development of legislation in New Zealand and internationally?

C Design principles and methodological framework

1 Design principles

Because this research was essentially qualitative and evaluative, the principles guiding design and methodology reflect acknowledged best practice in qualitative evaluation.¹⁵³ The qualitative research paradigm is an interpretive approach to making sense of how people understand (usually) social phenomena. In contrast with quantitative research, which employs hypothetico-deductive analysis, qualitative research does not begin with an hypothesis. Rather, this approach develops a series of open questions around a phenomenon, seeking diverse input in response to those questions and examining the data inductively.¹⁵⁴ It investigates the phenomenon in its natural setting, asking key players to describe and interpret their experiences and understandings of that thing. *The following points overview how best practice qualitative research and evaluation principles have been applied in this research.*¹⁵⁵

Mixed-method data collection – Information was sought through in-depth interviews, a comprehensive review of documentary evidence from a wide range of sources, and personal communications with additional key informants across several sectors to clarify items of information.

Triangulation¹⁵⁶ – Triangulation involves drawing on multiple data sources that represent a diversity of viewpoints on the research questions to ensure that all relevant viewpoints are canvassed. Data sources were triangulated for this research through: exploring AD across disciplines - law, medicine, psychology and sociology; using mixed methods; and interviewing multiple stakeholder types, across several jurisdictions representing the three diverse ‘models’ of providing legal AD services.

Developmental research¹⁵⁷ **and iterative process**¹⁵⁸ – Developmental research involves ongoing development of the research focus and scope, questions and participants, as appropriate, as data patterns emerge. Questions were added to the interview set and literature sought on additional topics as those emerged as important. Due to the

¹⁵³ See Patton, above n 23, Chapter 3.

¹⁵⁴ See Norman K Denzin and Yvonna S Lincoln *The SAGE handbook of qualitative research* (4th ed, Sage, Los Angeles, 2011); Patton, above n 23, Chapter 8.

¹⁵⁵ Each of these principles is discussed in detail in Patton (above n 23), who is widely acknowledged as the leader in formative evaluation theory and practice.

¹⁵⁶ Patton, above n 23, 661.

¹⁵⁷ Michael Quinn Patton *Developmental Evaluation: Applying Complexity Concepts to Enhance Innovation and Use* (Guilford Press, New York, 2011).

¹⁵⁸ Patton, above n 23, at 484.

contemporary dynamics of developments in legalising AD, this occurred constantly throughout the data collection and writing up of the research. Iterative process involves each component of the research method being informed by and building on information obtained from previous components, so that the research focus is constantly in development, based on accumulated findings. Initial interviews were undertaken over a six month period with 81 participants, moving across jurisdictions and comparing participants' experience of implementing different AD models, adding participants as they were identified, and accessing further literature in each jurisdiction. Each participant was given an opportunity to review the notes of their interview and add to those, and several were interviewed again subsequently to clarify points and/or to update on legislative and implementation developments in their respective jurisdictions. A further 11 participants were interviewed during 2015 to obtain information on new developments in AD legislation internationally.

Appreciative inquiry¹⁵⁹ – Appreciative inquiry examines not only the nature and features of the presenting issue but focuses on ways in which it is being addressed or might be further mitigated. As ideas and experiences of effective problem-mitigation were revealed through the interviews, these were discussed with subsequent participants.

Cultural relevance – Each of the jurisdictions included in the research has one or more distinct national or state/provincial cultures. The research focused on understanding the relationships between those cultures and the AD experience in that place.

Utilisation focus¹⁶⁰ – Evaluation prioritises making research findings available for use. I have made my research findings available for development of new AD legislation, in New Zealand and overseas, to research participants who wanted information about AD implementation in other jurisdictions and others who could use my data to inform their research, and to inform submissions to the Parliamentary Health Committee on Assisted Dying.

2 Methodological framework - grounded theory

Because there had been so little evaluative research undertaken previously to identify and understand the barriers to accessing legal AD, an integration of grounded theory with thematic analysis (described below) was the most appropriate research framework.

¹⁵⁹ Charles Elliott *Locating the Energy for Change: An Introduction to Appreciative Inquiry* (International Institute for Sustainable Development, Winnipeg, 1999).

¹⁶⁰ Patton, above n 23, at 18.

Grounded theory has been described as “a qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action, or interaction grounded in the views of participants in a study”¹⁶¹ – that is, rather than an existing theoretical framework driving data collection, theory is developed systematically *from* the findings. The grounded theory approach was developed by Glaser and Strauss in the late 1960s,¹⁶² in reaction to the prevailing dominance at the time of hypothetico-deductive method, which purported then to be the only valid method for developing social science theory. Grounded theory integrates deductive and inductive thinking to develop theory from the data, rather than using data collection merely to test predetermined theory. Theory is generated by examining research data for emergent themes and then exploring how those themes can be linked, through multidimensional modelling, to explain aspects of the phenomena under study. The researcher may also weave in existing theories or perspectives to help explain the phenomena observed.¹⁶³ This approach has become a “pillar” of qualitative research methodology over the past 40 years.¹⁶⁴

D Data collection

Information was obtained through literature, legal documents and stakeholder interviews.

1 Evidence review

Documented information was obtained from a broad range of sources, including statutes, regulations and other legal documents for various jurisdictions,¹⁶⁵ the academic and gray literature, internet materials, including government materials, newsletters and websites of the RTDs and other organisations,¹⁶⁶ newspaper and magazine articles, blogs, other media postings and broadcasts, Facebook, and materials provided by the research participants. Information was sought relevant to jurisdictions with AD laws and those with Bills before the legislature or in the process of development.

¹⁶¹ J Cresswell *Research design: Quantitative, qualitative and mixed methods design* (London, Sage, 2013) 229.

¹⁶² B Glaser and A Strauss *The discovery of Grounded Theory: Strategies for qualitative research* (Aldine Publishing, Chicago, 1967).

¹⁶³ Helene Starks and Susan Brown Trinidad “Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory” (2007) 17(10) Qual Health Res 1372.

¹⁶⁴ Cresswell, above n 161, at 229.

¹⁶⁵ Including jurisdictions additional to those where interviews were undertaken.

¹⁶⁶ Including the World Federation of Right to Die Societies (WFRtDS).

2 Stakeholder interviews

2.1 Sample attributes and composition

The aim was to interview at least eight people from each of the selected jurisdictions, including at least 3-4 people directly involved in providing AD services and where possible at least one who had been involved in developing the legislation. The jurisdictions were selected to include all three legislative models and represent both well-established AD implementation and more recent or developing laws.¹⁶⁷

- Six jurisdictions with AD legislation - Oregon and Washington states (US), Québec (Canada), The Netherlands, Belgium, and Switzerland;¹⁶⁸
- Two jurisdictions - the UK and Scotland - with Bills being debated or redrafted at the time of commencing the research.

Sampling was purposive,¹⁶⁹ to ensure that participants were included from all relevant stakeholder groups. Key AD implementation roles were identified by the key informants, as follows:

- Doctors with significant experience of managing AD requests;
- Other health professionals with significant experience of responding to AD requests (eg hospice managers, nurses, social workers);
- Other AD support roles (eg psychologists, psychiatrists, medical insurance liaison personnel);
- AD provider agencies – management, legal, medical, policy and administrative personnel, and support volunteers;
- Researchers, academics and ethicists monitoring the implementation of AD and/or teaching in medical or law schools or centres for end-of-life research;
- Government health officials responsible for monitoring AD;
- Lawyers involved in legal aspects of AD;
- Politicians and others involved in drafting or sponsoring legislation;
- Medical professional associations and colleges.

¹⁶⁷ Constraints on the number of jurisdictions included were location, language barriers (eg Albania and Colombia) and that the research was self-funded.

¹⁶⁸ Switzerland is included here, because it has a clause in its penal code that avails legal AD, and Vaud canton had passed cantonal legislation regulating AD in 2013.

¹⁶⁹ Patton, above n 23, at 265.

A ‘snowball’ approach was adopted,¹⁷⁰ with participants recommending others with valuable perspectives for interview, and a majority of those were invited to take part.¹⁷¹ As the research focus expanded over time, stakeholders in other roles were interviewed, including academics and ethicists in medical schools, doctors who had declined AD participation and religious leaders.

2.2 Recruitment

All research participants were approached initially by a personalised email that outlined the purposes of the research, the academic auspices of the project, the interview parameters, the ethical protections and consent, the potential value of their contribution, and the assurance of receiving a copy of the research publications. Attached to the email was a CV detailing my research experience. If the participant did not respond within a week, the invitation was followed up by email or phone. Recruitment communications with Québécois participants were in French, with input from a professional interpreter who was also a law student. None of those contacted declined to participate, and only two people omitted to reply.

2.3 Interviews

In total 92 people were interviewed representing the stakeholder roles described above (see **Table 3, Appendix 1**). This sample was considered to contain sufficient perspectives from each key stakeholder group to develop an understanding of how AD access barriers are interconnected. Data ‘saturation’ was not attempted, as that principle is flawed in relation to qualitative research where “no one can be completely sure that no new insights will emerge if more data is (sic) collected”.¹⁷²

A semi-structured interview guide (**Appendix 2**) was developed based on the research questions. The questions in the interview guide were applied as relevant to each stakeholder group; that is, questions clearly irrelevant to the particular participant’s role/s in relation to AD were omitted. As with all interview research, complementary questions were asked to further explore participants’ answers. Additional questions were included as topics of relevance emerged from the interviews. Most interviews were conducted face-to-face and the remainder by Skype or telephone, usually during work hours and at the participant’s

¹⁷⁰ At 270.

¹⁷¹ People not invited were those outside of the roles relevant to the research sample.

¹⁷² Michelle O’Reilly and Nicola Parker “‘Unsatisfactory saturation’: a critical exploration of the notion of saturated sample sizes in qualitative research” (2012) 13(2) Qual Research 190.

place of work. Interviews typically lasted 45-75 minutes, occasionally longer. Two interviews with Québécois participants were in French, with help from the same interpreter; the rest were in English.

Comprehensive notes were taken in each interview. Interviews were audio-recorded with participants' permission and the recordings referred to in the data analysis phase and to extract verbatim quotes (see below). Each participant was sent a written interview record comprising a detailed summary of the information they had provided and invited to write any corrections, deletions or additions directly into the document as 'track changes'. Participants were advised that if they did not reply within three months their record would be accepted as accurate. Approximately half of the participants made additions or minor corrections to their record while the remainder either accepted the record or did not reply.

2.4 The research participants

While the research participants spanned a broad range of stakeholder roles, more than half of them (58 percent) had engaged directly in providing AD as doctors, nurses, mental health professionals or volunteers, most of them many times and some on more than 50 occasions over many years. All of those participating in AD had been involved in supporting people's decision-making prior to their AD requests, often over a period of months with some individuals. While they held a wide diversity of views on particular aspects of AD, the majority strongly supported legal AD in principle. For most, it was the first time that they had reflected openly in a research (or sometimes any) context on the problems in implementing the laws and/or ways in which those issues might be mitigated and the AD laws improved. Some of the interviews were emotional as participants described situations where they had worked with people seeking AD (discussed further in Chapter 5).

3 Cultural considerations

None of the participants represented an indigenous group, despite continuing attempts to identify such stakeholders in the US states and Québec through networks and research groups. Because most early participants identified aspects of national culture affecting their experiences in relation to AD, a question on cultural influences was included in the interviews.

4 Ethical considerations and protections

As required by the University of Auckland Human Participants Ethics Committee (UAHPEC) approval,¹⁷³ all participants gave informed consent (**Appendix 3**) on the basis of the ethical protections and data security arrangements set out in the Participant Information Sheet (**Appendix 3**). Where participants were interviewed by phone or Skype, verbal consent was recorded. Where participants were interviewed in pairs or small groups at their preference, the group agreed to the confidentiality of the discussion and one another's contributions. To ensure anonymity, where participants worked within a relatively small workgroup or an organisation with a small staff, they were asked for permission to identify their statements, if used in the thesis or other publications, as having come from that organisation or as representing a particular role (eg 'hospice manager', 'doctor experienced in delivering AD'). All were in agreement with that approach. Data security has complied with the UAHPEC requirements.

5 Limitations of the methods

A robust triangulation was used to ensure that the aggregated data would be sufficiently representative of both the diverse national cultures involved in the research and the various roles involved in legislating for and implementing AD (see **Appendix 1**).

This thesis does not attempt to make definitive claims about the prevalence of particular views and practices, except where the data and literature in combination demonstrated clear patterns. Likewise, it does not focus on the ethical arguments for and against whether AD should be legalised, but rather on how AD laws can achieve a balance between permissiveness and restrictiveness so that AD can be implemented both safely and with intended accessibility.

E Data analysis and synthesis

The interviews were analysed using a combination of thematic, content and discourse analysis techniques. Thematic analysis is a foundational method for identifying, analysing and reporting themes apparent within qualitative data and identifying patterns amongst those themes.¹⁷⁴ It involves exploring the data for themes and then assessing both the

¹⁷³ UAHPEC Reference Number 011803, approved 13 May 2014.

¹⁷⁴ Virginia Braun and Victoria Clarke "Using thematic analysis in psychology" (2006) 3(2) Qual Res Psychol 77; Patton, above n 23, Chapter 8. Qualitative analysis and interpretation.

frequency with which those themes occur in the data and the extent to which a particular item of data can be viewed as belonging to already identified thematic categories or constitutes a new theme (content analysis). The diverse themes identified are analysed to identify the ways in which they link together. All data are then reviewed for relevance to those categories. Discourse analysis involves a semantic analysis of conversation or text to identify both the overt and underlying meanings of the speaker or writer.¹⁷⁵ In this research, it was used both within the interviews, to pick up on speakers' nuance for the purposes of in-depth and iterative questioning, and by listening repeatedly to the recording of each interview. In combination, these techniques enabled a deep understanding of the data as well as the identification of clear patterns to the access barriers and other implementation issues in AD.

F Reporting the findings

The epistemological approach that I have used in the discussion chapters has been called “arguing evidentially [and] multivocally”;¹⁷⁶ that is, I integrate the interview data together with supplementary information from a broad literature including a wide range of non-academic materials and additional material gained from short personal communications with other relevant stakeholders. Qualitative research does not quantify the numbers of participants who expressed a particular viewpoint or idea; rather, through thematic analysis it identifies key themes in participants' experiences, views and interpretations of phenomena. Footnotes are used in the discussion chapters to distinguish between the data and material from the literature (see p 65).

¹⁷⁵ Deborah Schiffrin, Deborah Tannen and Heidi E Hamilton (eds) *The handbook of discourse analysis* (Wiley, New York, 2008).

¹⁷⁶ Jennifer Mason *Qualitative researching* (2nd ed, Sage, London, 2002). Chapter 9. Making convincing arguments with qualitative data.

Chapter 3. Theoretical perspectives on AD access

Applying a ‘grounded theory’ approach to developing theory from the data involves integrating, where appropriate, existing theoretical frameworks and perspectives. Disciplines influencing AD law-making and decision-making include legal, medical, sociological and psychological. As the best lens for understanding my research findings, I have applied a therapeutic jurisprudence framework together with a social ecology of health model. In combination, these frameworks provide an intelligent medium for understanding the interaction of diverse multi-level influences, from societal to intrapersonal, that affect legislators’ and citizens’ options and decision-making in the context of end-of-life law and health policy.

A Therapeutic jurisprudence

Therapeutic jurisprudence (TJ)¹⁷⁷ was developed by David Wexler and his colleagues in the late 1980s initially as a framework for understanding how the law might contribute to an improvement in criminal rehabilitation and mental health services or in decriminalising ‘victimless’ crimes.¹⁷⁸ TJ’s core premise is that an individual’s or society’s interaction with the legal system can have both positive and negative affects on their wellbeing and that the law should be applied with a fundamental aim and consciousness of having beneficial (therapeutic) outcomes for the parties on whose lives it necessarily impacts, provided that other judicial and legal values are not compromised as a result. It provides a lens for determining to what extent the law, as a social force, has impacts that enhance rather than impair social and psychological benefits for the various parties who draw on it – victims and offenders, plaintiffs and defendants, applicants and adjudicators, and people who are attempting to implement or access laws as they believe those laws were intended. TJ argues that, to the extent that law does not have beneficial impacts, it is not effective or ‘good’ law, *and* that laws and their application should be constantly evaluated for their impacts and effectiveness.¹⁷⁹ The TJ lens employs values-based concepts such as trust, hope, emotional intelligence and relational interaction through which to examine the effectiveness of the

¹⁷⁷ While on principle avoiding abbreviations, therapeutic jurisprudence is known most commonly by this acronym.

¹⁷⁸ David Wexler “Two decades of therapeutic jurisprudence” (2008) 24 *Touro Law Rev* 17.

¹⁷⁹ David Wexler *Moving Forward on Mainstreaming Therapeutic Jurisprudence: An Ongoing Process to Facilitate the Therapeutic Design and Application of the Law* (Arizona Legal Studies Discussion Paper No. 15-10, February 2014).

law, rather than judging its effectiveness through a “flawed adversarial system”.¹⁸⁰ People using TJ view it as a clear paradigm shift in approaches to conceptualising the role of the law, providing a different set of values for evaluating the effectiveness of the law.

1 TJ and AD law

To date TJ has been applied largely to the application and interpretation of law reform, primarily in the social services sector, though more recently in health law reform.¹⁸¹ Although TJ has rarely been applied to the development of new legislation,¹⁸² it is apt for that purpose. Cerminara and Perez examined the then new Oregon AD law from a TJ perspective, exploring its potential psychosocial effects on both people seeking AD and health practitioners, as well as on the wider society.¹⁸³ Through its focus on enabling the wellbeing of stakeholders, TJ is useful in examining not only the impacts of AD laws,¹⁸⁴ but also the effectiveness of the processes required, for example, how intended access may be frustrated not only by implementation factors that were not anticipated when the laws were drafted, but also by core aspects of the statutes’ framing and phrasing. Equally it can be applied to understanding the complex interaction of personal, organisational and institutional factors in implementing controversial laws, for example through focusing on the role of morality and emotions in framing, applying and interpreting the law, or by highlighting the inherent tension where laws need to achieve a balance between enabling their intended purposes and avoiding negative outcomes where stakeholders have evidently opposing or discrepant interests. These tensions are apparent in the attempts of AD laws to balance reasonable access against essential safeguards for people with potential vulnerabilities to misuse of those laws, as well as taking into account the diverse and often conflicting interests amongst people seeking AD, their families, doctors, health providers and societies at large.

¹⁸⁰ Arie Freiberg “Therapeutic jurisprudence in Australia: Paradigm shift or pragmatic incrementalism?” (2003) 20(2) *Law in context* 6, at 6.

¹⁸¹ For example, medicinal marijuana, see Ian Freckelton “Medicinal cannabis law reform: A therapeutic jurisprudence approach” (paper presented to the Aotearoa Conference on Therapeutic Jurisprudence: *Weaving Strands – Ngā Whenua Rāanga*, Auckland, 4 September 2015).

¹⁸² Personal communication, David Wexler, Professor of Law, University of Puerto Rico, San Juan, 20 April 2014.

¹⁸³ Kathy L Cerminara and Alicia Perez “Therapeutic death: A look at Oregon’s law” (2000) 6(2) *Psychol Public Policy Law* 503.

¹⁸⁴ That is, what Xanthaki calls ‘efficacy’, above n 109, at 6.

TJ has been widely embraced in New Zealand and Australia over the past decade or more as a way to consider the application of the law that takes into account the always complex emotional and social contexts in which it is applied.¹⁸⁵ The following examples demonstrate how TJ can be applied to the diverse types of barriers to AD access summarised in Chapter 1 and to be discussed in the following chapters.

Warren Brookbanks has used TJ to explore the skills needed by doctors in examining people for legal (and other) purposes.¹⁸⁶ In discussing a concept of “narrative medicine”,¹⁸⁷ Brookbanks identifies some common decision-making challenges for doctors and lawyers. Because these professions are trained in general to use propositional knowledge, which is objective, dispassionate, independent, replicable and generalisable, they tend to focus on asking questions about tangibles, rather than using “narrative knowledge [which] is subjective, focusing upon the [person’s] understandings of events and actions”.¹⁸⁸ Brookbanks’ analysis highlights the issue that undertaking assessments of a person’s spiritual or existential suffering, which is core to understanding a person’s request for AD, requires skills in eliciting narrative knowledge, which doctors may not be sufficiently trained for or feel either competent or confident to use. Moreover, TJ highlights the importance of doctors understanding that the AD assessment process is a conversation, rather than an examination in the traditional medical sense; the process is relational, a negotiation between the doctor and the person requesting AD, and as such will be complex, time-consuming and emotional for both parties, factors that may not translate easily into legislative provisions or regulations to facilitate reasonable access while still ensuring safeguards.

Ian Freckelton has employed TJ to explore and understand the value of, but difficulties in, applying social values such as compassion in developing legislation for the expanding uses for medicinal marijuana.¹⁸⁹ He discusses how governments, in considering and introducing laws to regulate medicinal cannabis use, have struggled to develop statutes that, on the one hand, take into account the complex and equivocal

¹⁸⁵ Marilyn McMahon and David B Wexler (eds) *Therapeutic jurisprudence: Developments and applications in Australia and New Zealand* (Federation Press, Annandale, 2003).

¹⁸⁶ Warren Brookbanks “Narrative Medical Competence and Therapeutic Jurisprudence: Moving Towards a Synthesis” (2003) 20(2) *Law in Context* 74 at 74.

¹⁸⁷ At 74.

¹⁸⁸ At 76.

¹⁸⁹ Freckelton, above n 181.

research base on the uses and value of medicinal cannabis, while at the same time reflecting relevant but legally ill-defined values, such as compassion, in determining exactly how many and what kinds of restrictions need to be placed on the use of medicinal cannabis to avoid misuse and abuse. He emphasises that there is a “need for law reform in the area to be acceptable to the health practitioner community, lest a medicinal cannabis scheme founder” for reasons related to the ethical positions and accepted practice systems of the prescribing and administering professionals, and presents some ways in which statutes need to be designed in order to be workable in practice.¹⁹⁰ These arguments have immediate relevance to framing AD laws.

Dennis Stolle applied TJ to highlight the importance of understanding the myriad emotions faced by people diagnosed with HIV in developing public health law and regulation that will facilitate compliance, commenting that the psychological progression of people faced with mortality needs to be “taken seriously by the legal system, both at macro levels, such as legislative decision-making, and at micro levels, such as the interactions between individual legal officials and HIV-positive persons involved in legal processes”.¹⁹¹ The same comments could equally apply to legal provisions for decision-making by doctors to enable appropriate assessment of people confronted with a terminal cancer prognosis who, fearing what that might mean in pain and loss of function, seek accurate information about the range of end-of-life options available to them.

2 TJ and medical ethics

TJ aligns well with Beauchamp and Childress’s four key principles of biomedical ethics for examining the arguments for and against legalising AD. The primary motive for legalising AD - that is, to provide a compassionate option for people with truly intolerable suffering - perfectly reflects both the core premise of TJ and the generally accepted bioethics principles of beneficence, non-maleficence, respect for personal autonomy and justice (in this instance equitable access to legal AD) that are used to guide medical decision-making.¹⁹² The policy

¹⁹⁰ At slide 7.

¹⁹¹ Dennis P Stolle “Advance directives, AIDS, and mental health: TJ preventive law for the HIV-positive client” (1998) 4(3) Psychol Public Policy Law 854 at 857.

¹⁹² Tom L Beauchamp and James F Childress *Principles of biomedical ethics* (7th ed, Oxford University Press, Oxford, 2013). Note however that the sufficiency and continuing relevance of these four principles as the ‘core’ bioethics principles has been contested by some bioethics theorists, see for example Susan Sherwin “Looking backwards, looking forward: Hopes for *Bioethics*’ next 25 years” (2011) 25(2) *Bioethics* 75.

developed by the UK Director of Public Prosecution in response to the *Purdy* case, to clarify the situations in which people might or might not be prosecuted for helping a loved-one to end their life,¹⁹³ is a good demonstration of how a governmental legal agency has developed guidance for legal decision-making in accordance with bioethics principles for the wellbeing of both individuals and society at large, and updated those over time as appropriate.

Wexler has recently proposed the TJ concept as one yardstick for assessing the effectiveness of laws that have social reform as an objective.¹⁹⁴ This idea will be discussed in the conclusions chapter in examining the importance of monitoring the implementation of AD laws for the purposes of learning and improvement, rather than only for the purposes of practitioner accountability. From a combined TJ and bioethics perspective, the provisions of a law for AD should, arguably, reflect equitable access (justice), provide a compassionate option for people who have intolerable suffering (beneficence), ensure protections for the potentially vulnerable (non-maleficence) and incorporate facilitating structures and processes that will allow for genuine and well-informed choice (respect for autonomy). Many commentators have suggested that autonomy is especially important at end of life in circumstances where much control over one's life has already been lost.¹⁹⁵

3 TJ as a research tool

In addition to its use as an analytic framework, TJ can also be used as a research framework.¹⁹⁶ The TJ perspective was used in framing the interview questions for this research, in particular to explore and understand some of the issues confronting doctors and nurses in managing AD requests and undertaking AD decision-making, but also to explore the links amongst the upstream influences on AD law-making and decision-making. It will be applied throughout the remaining chapters to examine both the causes of and links amongst various access barriers to AD identified in my research and the effectiveness of previous attempts or viable future options for mitigating those barriers, taking into account the inevitably conflicting interests of the diverse stakeholders in AD.

¹⁹³ Director of Public Prosecutions, above n 70.

¹⁹⁴ Wexler, above n 179.

¹⁹⁵ For example, Sylvia A Law "Physician-Assisted Death: An Essay on Constitutional Rights and Remedies" (1996) 55 Maryland L Rev 292; Collins J in *Seales* at [29].

¹⁹⁶ Nigel Stobbs "How to do therapeutic jurisprudence research" (20 May 2015) <www.mainstreamtj.wordpress.com>.

B Social ecological model of health policy

Social ecological models are an accepted good practice framework for the development of effective public health policy.¹⁹⁷ Social ecology models for health promotion are based on the notion that health interventions are influenced by a hierarchy of social organisation, including institutional structures, systems and processes, that impact ultimately on the types of interventions that are available and the ways in which they are delivered. As a result, the effectiveness of health interventions for individuals or communities will depend on the extent to which health consumers are involved in their development and how well the intervention has been structured to ensure that it will provide the benefit intended. Thus the individual's access to health services will depend on a host of influences that affect the implementation of the intervention. The social ecology of health uses systems theory to understand the ways in which the influences at multiple levels interact for a particular outcome.¹⁹⁸

1 Social ecology of AD law-making and decision-making

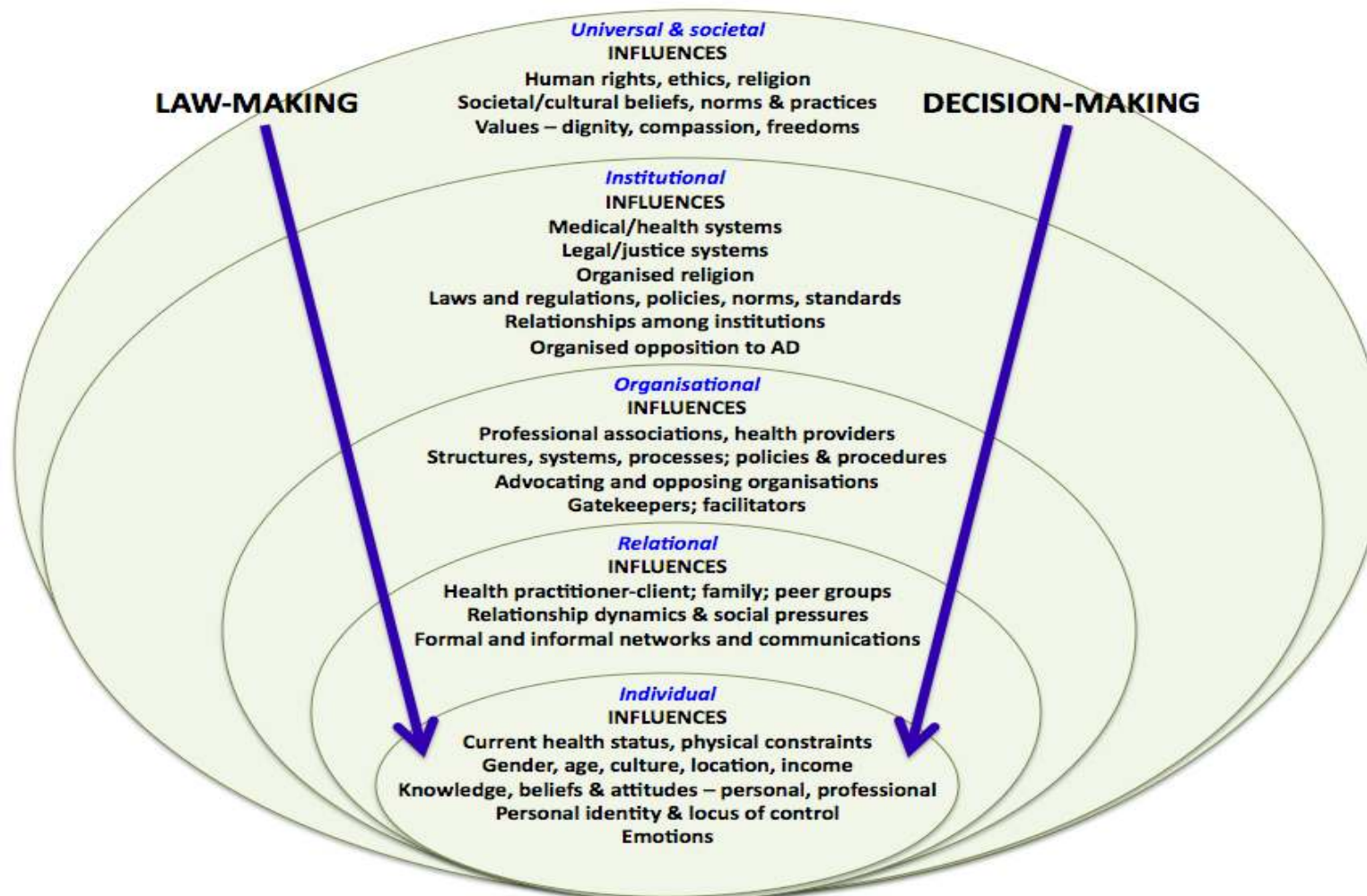
I have developed the model in **Figure 1** (following page) to illustrate the myriad influences that have the potential to either enable or impede a person's access to legal AD, and to affect law-making that impacts on that access, at societal, institutional, organisational, relational and personal levels. A key feature of the existing laws for AD is that they contain an array of provisions that were designed to restrict rather than enable access, explicitly to protect the vulnerable and avoid misuse of the law, and included to persuade sufficient legislators or voters that the law would be safe in operation. **Figure 1** shows how law-making and decision-making for AD respond to both explicit and subtle influences that ultimately enable or impede access. For example, the ultimate reluctance of some doctors to participate in AD may be attributable to a dynamic that flows from bioethical and generational values, through the policy positions of medical associations and employers, subtle collegial pressure and the individual practitioner's personal beliefs, to determine eventual decisions about participation.¹⁹⁹

¹⁹⁷ Shelley Golden and others "Upending the Social Ecological Model to Guide Health Promotion Efforts Toward Policy and Environmental Change" (2015) 42(1) Health Educ Behav 8S.

¹⁹⁸ Daniel Stokols "Establishing and maintaining healthy environments: toward a social ecology of health promotion" (1992) 47(1) Amer Psych 6.

¹⁹⁹ Claudia Gamondi and others "Palliative care physicians' accounts of their attitudes and experiences of the Swiss civil model of assisted suicide: a qualitative interview study" (paper to be presented at the European Association for Palliative Care [EAPC] Conference, Dublin, May 2016).

Figure 1: A social ecology of assisted dying law-making and decision-making



The theme of multi-level influences on end-of-life decision-making and the dynamics of influence across macro and micro levels will be developed in the discussion chapters as a key factor in legislating effectively for AD and implementing AD laws.

C Legislative intent and interpretation

1 Permissive and restrictive intent

A key theme in my research is the tension between intended and unintended barriers, and how intended safeguards can become unintended and significant impediments to reasonable and ostensibly intended access to AD. AD laws are enacted primarily for the purpose of making that option legally available to people, albeit under certain conditions. However several commentators have voiced the view that the majority of the provisions in the existing statutes have been included to placate AD opponents, rather than to facilitate access to AD for the people that the laws are intended to serve, so that access as permitted by the law is frustrated.²⁰⁰ That is, it becomes unclear whether these laws were intended to facilitate or restrict access, even though the overarching intent is to permit legal AD, in part because none of the statutes creates a ‘right’ as such to AD (see discussion below p 53). Many of the procedural requirements in AD laws are clearly intended to impede access specifically for people who may be considered ‘vulnerable’ – people who have mental health issues or may experience some perceived societal pressure to avoid being a burden, or who may be panicked into seeking AD when other effective treatment options appear unavailable to them. In contrast, there is arguably a lack of provisions in the statutes to facilitate access for *prima facie* eligible people, for example, mandatory provision of information about AD as a legal end-of-life option, or a requirement for doctors to refer a request if they have a conscientious objection to engaging, or provisions for breaches of the law where someone acts deliberately to frustrate a person’s access to legal AD.

The intent of AD laws has rarely been tested in the courts. People declined access to them are likely to be too frail and too close to death to initiate and sustain a legal challenge. The ‘mercy-killing’ prosecutions and the challenges to laws criminalising AD have demonstrated that a core concept considered by the courts is compassion as the assister’s driving motive, and the courts in turn have exercised compassion in increasingly lenient judgments and sentences (see p 8). However there have been a few cases where individuals have challenged the AD laws themselves and the courts have made either explicit or, more usually, implied comment on the law’s intent. For example, the intent of the exemption in

²⁰⁰ For example, Lewy, above n 10; Udo Schüklenk “Conscientious objection in medicine: Private ideological convictions must not supersede public service obligations” (26 March 2015) <<http://ethxblog.blogspot.com.au>>.

the Swiss criminal code appears at first glance clear,²⁰¹ because it requires only that the motives of the assisting person are benign. As a result, Swiss proponents of AD have been able to provide it to a very wide range of people who would not be eligible under the laws in other jurisdictions. In *Gross v Switzerland*, where the applicant sought a declaration that her right to AD under Swiss law was being denied illegally, the judgment recognised both a “‘right’ to assisted suicide” under the Swiss law,²⁰² and some constraints on that right as incorporated into the guidelines provided by the medical association that were “intended to prevent organisations which provide assisted suicide from acting unlawfully”.²⁰³ The court also noted that the provision in the Swiss penal code did “not provide sufficient guidelines ensuring clarity as to the extent of the right” to have an assisted death;²⁰⁴ that is, the provision was vague on the circumstances in which it was intended to apply. In *Heringa v Netherlands*,²⁰⁵ a Netherlands appeals court held in 2014 that Mr Heringa, a private individual who had helped his 99-year-old ill mother to take a lethal dose of medication, should not receive any punishment because his motivation was compassion and that was consistent with the intent of the Netherlands statute.²⁰⁶ One commentator suggested that the court “purportedly sought to create a precedent” in order to prompt broader discussion in Netherlands society about whether legal AD should be limited to medical practitioners.²⁰⁷ In a 2015 Netherlands appeals court decision, the court granted 80 year old Cobi Geluk the right to leave a nursing home that had been refusing to process her request for AD, noting that the nursing home personnel could not override Geluk’s right to access the Dutch law and must “respect her wish”, indicating that a key intent of the Netherlands law was self-determination.²⁰⁸

²⁰¹ Code pénal suisse du 21 décembre 1937 [CP] Article 115.

²⁰² *Gross v Switzerland* [2013] ECHR 67810/10, at [11].

²⁰³ At [11].

²⁰⁴ At [65].

²⁰⁵ *Heringa v Netherlands* Arnhem-Leeuwarden May 13, 2015, ECLI: NL: GHARL: 2015: 3444.

²⁰⁶ Dominic Yobbi “Dutch court clears man who assisted in dying mother's suicide” *Jurist* (online ed, Pittsburgh, 14 May 2015). Because the two Netherlands judgments described here are available only in Dutch, these summaries are derived from coverage in the 2014-2015 English-language issues of *Relevant*, the Newsletter of the RTD Nederlandse Vereniging voor een Vrijwillig Levenseinde (NVVE) and other English-language sources.

²⁰⁷ Library of Congress Global Legal Monitor “Netherlands: Precedent Set in Case of Son-Assisted Suicide” (17 June 2015) <www.loc.gov/lawweb/>.

²⁰⁸ *Relevant: Magazine of the Right to Die-NL* (NVVE) “She said: ‘It is my life, is it not?’” (July 2015) <www.worldrtd.net>.

2 Is it relevant, or even possible, to determine legislative intent?

Much rests on the interpretation of the term ‘intent’. Historically, determining legislative intent has been a role of the courts, relying on the “expressed intention” of the relevant legislature as apparent in the statutes.²⁰⁹ However commentators over the past two decades have challenged not only the ability of the courts to discover intent in statutes, since the intent may not be stated explicitly in the statute,²¹⁰ but even the very concept of legislative intent. For example, Michael Kirby has argued that legislative intent is no longer (if it ever was) a valid yardstick for interpreting laws. Kirby referred to Parliamentary intent as a “fiction”,²¹¹ commenting that one cannot assume that a particular statute has a discoverable intention, given that there are virtually always minority opposing voices to any piece of new legislation, and the multiple consenting voices often have diverse motivations for supporting the reform, “so that to talk of a single ‘intention’ is self-deception”.²¹² This diversity of motives for supporting a new piece of legislation is apparent in the Hansard report of the debates for both the 1995 and 2003 Death with Dignity Bills in New Zealand, where MPs’ motives for supporting AD ranged from compassion and human rights to the ethical shift to health consumer autonomy and the need to regulate an existing illegal practice.²¹³ Likewise, due to the language used in a particular statute, and the frequent (and potentially deliberate) absence of definitions of key terms in the ‘Interpretation’ sections, the intention of a law might well be found not only in the text of the statute but in the omission of provisions where they might have been included, or in the deliberate use of vague terminology, with the intention that the phrasing in the statute allow for flexibility in its operation. For example, one person involved in drafting the Netherlands legislation commented that the statute deliberately avoided defining the term “hopeless” (as the required irremediable status of an eligible medical condition), leaving that term to be defined by the doctors applying the law, or by the courts, in recognition that what is medically futile might change over time.²¹⁴ Similarly, the Netherlands law deliberately and strategically omitted an eligibility condition of terminal illness because they saw the

²⁰⁹ Richard Ekins *The nature of legislative intent* (Oxford University Press, Oxford, 2012) at 2.

²¹⁰ DN MacCormick and RS Summers (eds) *Interpreting Statutes: A Comparative Study* (Dartmouth Press, Aldershot, 1991).

²¹¹ Michael Kirby “Towards a Grand Theory of Interpretation: The Case of Statutes and Contracts” (2003) 24 Stat L R 95 at 98.

²¹² Ibid at 97; see John Manning “Textualism and Legislative Intent” (2005) 91(2) Virg L Rev 419 on the ‘textualist’ arguments against attempting to discover the original intent of a statute, except in the broadest terms.

²¹³ Hansard, above n 106 and 107.

²¹⁴ Personal communication, former Netherlands government legal adviser, 15 September 2014.

primary rationale for AD as suffering, not being at end of life. In general, the existing AD statutes do not contain any specific statements of intent; only the Netherlands law states, in its short preamble, a “desire” to “include a ground for exemption from criminal liability for the physician who with due observance of the requirements of due care to be laid down by law terminates a life on request or assists in a suicide of another person, and to provide a statutory notification and review procedure”. The intent of the Québec law to facilitate AD is fairly clear, because it deliberately allows AD as one of two regulated options for a hastened death. The main intention of the sunset clause in the Vermont statute, which would remove many of the restrictive processes in accessing AD, was to encourage the development of explicit standards of care by the medical professional bodies as an ideal governance regime for legal AD, so that the necessary protections against vulnerability would become part of accepted medical practice standards rather than requiring statutory provisions that were difficult for doctors to understand.²¹⁵ The importance or otherwise of clarifying intent in an AD statute is discussed in Chapter 5 (p 227 and 231-232).

Moreover, Ekins points out that once a statute is more than a decade old, given the pace of social change, the original intent of the law may no longer be relevant or appropriate to the contemporary context.²¹⁶ Discussing the fallibility of legal interpretation, Sunstein and Vermeule have outlined a range of institutional barriers that can result in statutory provisions being interpreted in diverse and potentially inconsistent ways by “generalist” judges who are operating within an historical, social and professional context that drives a particular interpretation at a particular time.²¹⁷ Similarly, doctors, who are generally not well versed in interpreting laws, might well be expected to be affected by institutional factors in doing so, interpreting laws in ways that make sense to them as health practitioners and as a response to a particular case at hand, especially if guidelines on interpreting those laws are absent.

In discussing the role of the courts in changing law, it has also been argued, at least in the US, that as the provisions of laws become outdated through social change and are not amended through the legislatures, judges can be left with “no option but to amend statutes

²¹⁵ Personal communication, former Compassion and Choices policy personnel, 23 February 2015.

²¹⁶ Ekins, above n 209.

²¹⁷ Cass R Sunstein and Adrian Vermeule “Interpretation and institutions” (2003) 101(4) Mich L Rev 885.

and fill statutory gaps through interpretation”.²¹⁸ While some courts have been willing to change law in this way (eg in Montana, Hawai’i, New Mexico, Canada, and most recently South Africa), others have ruled either that they will not or cannot.²¹⁹ In *Seales*, Collins J, while acknowledging factors such as the subjectivity of suffering and Ms Seales’ “right not to be deprived of life [as] engaged” in her circumstances,²²⁰ recognised that it was not the constitutional role of the court to amend statute law, as did the UK Supreme Court in *Nicklinson* for the same reason.²²¹ Sunstein and Vermeule point out that, even where a constitution does so allow, not all courts are well equipped to wrestle with the highly complex moral and philosophical arguments, alongside equally complex and typically conflicting ‘expert’ evidence brought into the legal arguments, that are required to resolve legal questions that will have far-reaching implications not only for the lives and deaths of individuals but also for medical ethics and practice.²²²

3 The evolving intent of AD laws

As AD laws evolve across time and place, with people who are drafting new Bills consciously adopting or omitting aspects of earlier statutes and Bills, the apparent intent of a particular Bill will reflect several key factors: the extent to which the authors of a particular Bill have taken an opportunity to research how effective particular provisions have or have not been in operation; local societal mores and culture; the extent of active opposition locally to introducing AD legislation; and the primary goal of a Bill to have sufficient support to pass a first reading or garner more than a 50 percent citizen vote, rather than to incorporate all of the ideal features campaigners might want. Nonetheless, there is a visible trend towards AD Bills being more explicit about their intent to ensure that it is clear.²²³ For example, the ‘model’ statute now espoused by Compassion and Choices at a national level and recommended to support groups in the many US states campaigning to have AD legalised specifically incorporates phrasing such as “humane and dignified” to demonstrate that the intent of the statute is to support compassion and dignity, even though those concepts are not included in any due care provision. In New Zealand, MP Maryan

²¹⁸ Richard A Posner “Pragmatic adjudication” (1996) 18 Cardozo L Rev 1 at 250.

²¹⁹ This option is not available to a court operating within a constitution based on parliamentary sovereignty, such as New Zealand’s.

²²⁰ *Seales* at [12].

²²¹ *R (on the application of Nicklinson and another) (Appellants) v Ministry of Justice (Respondent)* [2014] UKSC 38.

²²² Sunstein and Vermeule, above n 217, at 925.

²²³ Personal communications from co-authors of the last two New Zealand Bills and the Québec and Californian statutes, July 2014-October 2015.

Street's 2012 EOLC specified its intent as (*inter alia*) including the promotion of compassion, dignity and self-determination at end of life, and emphasised that "it would sit alongside the delivery of ... palliative care", rather than attempting to replace it.²²⁴ The General Policy Statement in David Seymour's 2015 EOLC Bill describes its intent as being the avoidance of suffering, self-determination, and protections to avoid misuse.²²⁵

D Health law and risk regulation

1 Risk perception and individual decision-making

Since decision-making is a core aspect of AD that is regulated by the various AD laws, theory from cognition psychology is relevant. The extensive psychology on risk perception and assessment is useful in examining doctors' and mental health professionals' respective assessments of medical prognosis, degree of suffering and mental competence.²²⁶ There is ample evidence that doctors have difficulty determining a prognosis for terminal illness, and that they experience difficulty communicating a terminal prognosis, often for their own emotional reasons.²²⁷ Atul Gawande discusses the problem of the "extreme complexity" in medical decision-making and the impacts on doctors' willingness, as well as their ability, to make evidence-based decisions.²²⁸ He points out that doctors are "not omniscient", but are often expected to be, and also highlights how the complexity of decision-making contributes to the continuing reluctance of many doctors to share decision-making with either health teams or their clients.²²⁹ Exploring the role of emotion in how doctors approach end-of-life medical decision-making, Jerome Groopman describes how "[p]atients and their loved ones swim together with physicians in a sea of feelings" that can result in poor communication when good communication is needed most.²³⁰

²²⁴ End of Life Choice Bill 2012 at 3.

²²⁵ End of Life Choice Bill 2015 at 2.

²²⁶ See for example WMP Klein & ME Stefanek "Cancer risk elicitation and communication: Lessons from the psychology of risk perception" (2007) 57 CA Cancer J Clin 147.

²²⁷ Atul Gawande *Being mortal: Medicine and what matters in the end* (Metropolitan Books, New York, 2014); RG Hagerty and others "Communicating prognosis in cancer care: a systematic review of the literature" (2005) 16 Ann Oncol 1005; Elaine M Wittenberg-Lyles and others "Communicating a terminal prognosis in a palliative care setting: deficiencies in current communication training protocols" (2008) 66 Soc Sci Med 2356.

²²⁸ Atul Gawande *The checklist manifesto* (London, Profile Books, 2010) 8.

²²⁹ At 19. Note the term 'clients' is used in preference to 'patients', see p xvi.

²³⁰ Jerome Groopman *How doctors think* (Houghton Mifflin, Boston, 2008) 58.

Daniel Kahneman's work on cognitive biases and heuristics in decision-making can offer insights into decision-making by doctors where there is a perception of heightened risk.²³¹ Kahneman posits two kinds of thinking – “fast” thinking, which we use most often, is automatic, subconscious, stereotypical and emotional; in contrast “slow” thinking, which we use less often, is effortful, conscious, calculating and logical. Kahneman's research-based theory is that people are habituated to thinking ‘fast’, because that is essential to make the hundreds of everyday decisions in our lives. However in order to reduce complexity, we unconsciously use a battery of cognitive heuristics that bias our thinking. The most common of these, as relevant to AD decision-making, are: the *availability heuristic* – relying on easily available information, rather than seeking out balanced information; the *anchoring effect* – using the first information that we receive as an anchor for judging the value of later information, even if the initial information is biased or inaccurate; *loss aversion* – a tendency to fear losses (eg reputation) more than we value gains; and *framing* – examining a problem in its full context, rather than in isolation from it.

The potential for cognitive bias will be reduced and decision-making improved, Kahneman argues, where decision-makers are required to think slowly. Thaler and Sunstein's ‘nudge’ concept (see below) draws significantly on Kahneman's heuristics, proposing that ‘nudges’ will be effective in part because they reduce complexity by limiting the number of choices and in part because they facilitate slow thinking by juxtaposing options that force people to think about the differences between those options.²³² These theories in combination suggest that AD laws and provisions could be purposely framed to promote more thoughtful deliberation by *all* parties, since the topics for decision predispose more emotional thinking.

2 ‘Nudge’ – risk regulation and behavioural economics

Thaler and Sunstein's nudge concept proposes that human behaviour can be changed in a desired direction, in principle one that will advantage both the individual and society at large, through regulatory or other choice systems that give individuals (or, presumably, organisations) a limited but sufficient range of options that are designed to nudge the decision-maker in a direction desired by the regulation's designer, while still not limiting the decision-maker's choices. While nudges have been criticised as manipulative

²³¹ Daniel Kahneman *Thinking, fast and slow* (Farrar, Straus & Giroux, New York, 2011).

²³² Richard H Thaler and Cass R Sunstein *Nudge: Improving Decisions about Health, Wealth and Happiness* (Penguin, London, 2008).

‘libertarian paternalism’,²³³ nonetheless they have been widely used by social planners to devise regulatory systems that will advantage society at large, including health systems.²³⁴ An example commonly cited is the adoption of ‘opt-out’ rather than ‘opt-in’ systems for successfully encouraging organ donation. Thaler and Sunstein’s argument is that, faced with a limited but ethically sufficient range of options, one of which is evidently intended to have broad social rather than only individual utility, the decision-maker will be nudged to at least consider the option that has more altruistic utility.

Karen Yeung’s application of nudge to regulation and compliance regimes for modifying the behaviour of particular sectors or professions shows how unnecessary barriers might be avoided in accessing AD, without eroding the function of the safeguards in the AD statutes.²³⁵ For example, access might be facilitated where the statute includes an explicit presumption that a person seeking AD is mentally competent until shown to be otherwise not merely in the view of a psychologist or psychiatrist but in a court of law. Nudges might also be used to ensure doctors’ compliance with AD laws and regulations to facilitate fair access, for example, by requiring doctors who decline to support a person’s AD request to register that refusal, be then registered automatically as a non-participating health practitioner, and subsequently invited by an automatically generated prompt to review that stance as a ‘nudge’ to consider participating. Similarly doctors who have once registered an AD assessment certificate could be automatically also registered as a ‘willing’ doctor and potentially available to undertake assessments of others seeking AD. Such choices still allow for conscientious objection ‘opt-out’ and full self-determination of engagement by doctors, but would prompt doctors to contemplate the reasons for their position. A nudge might also be used to help protect the potentially vulnerable,²³⁶ for example, by broadening AD laws to cover all end-of-life treatment options and requiring doctors to discuss *all* options with a client before recording a request in writing for *any* life-ending option.

Nudges can also occur through specifically incorporating ‘default’ settings within statutes or regulations. For example, while some AD laws include provisions for presumed mental

²³³ Thomas C Leonard “Richard H. Thaler, Cass R. Sunstein, Nudge: Improving decisions about health, wealth, and happiness” (2008) 19(4) Const Polit Econ 356 at 356.

²³⁴ Though not without controversy, see Thom Brooks “Should we nudge informed consent?” (2013) 13(6) Am J Bioeth 22; Julian C Hughes, Marie Poole and Stephen J Louw “Nudging the Older Person Into Care: An End to the Dilemma?” (2013) 13(6) Am J Bioeth 34.

²³⁵ Karen Yeung “Nudge as fudge” (2012) 75(1) Mod L Rev 122.

²³⁶ Brooks, above n 234.

competence, there is no corollary presumption of voluntariness or self-determination. The US statutes require that doctors make an attempt to determine whether the person is under pressure to seek AD, presumably including societal pressure, when doctors are not trained in such skills. Sumner points out that the rationale for such checks is weak, since the same checks are not mandated when people choose to terminate treatment, nutrition and/or hydration with the aim of ending their lives, even though the consequences will be the same as with active AD, albeit probably slower to occur.²³⁷ Thus it might be reasonable to presume the absence of coercion unless there are clear indications to the contrary, especially since self-determination can be conceptually linked to mental competence. In contrast, the same US statutes omit specific provisions for assessment time frames or mandatory referral of a request by a conscientiously objecting doctor, on the grounds that existing medical ethics can be relied on to ensure that doctors act in the best interests of their clients, even though that assumption is ideologically inconsistent with respect for personal autonomy.

3 Regulation and social control

Stanley Cohen's theories of social control provide a useful macro-level perspective for examining AD laws, focusing on how the responses of social institutions can have a profound impact on how well law reforms work where those institutions are not sympathetic to the reforms, whether through active opposition or institutional inertia.²³⁸ While Cohen's examples relate to criminal law reforms such as restorative justice and diversion, his explanatory models are useful for examining the institutional impediments to AD access for both people seeking AD and the health practitioners who want to be involved. Cohen's "organisational convenience" model of the gap between intentions and reality demonstrates how institutional impediments to intended reforms can occur at diverse levels, for example: passive impediments such as the lack of engagement by institutions (eg the regulating bodies of the practitioners essential to implementing the reform); the deliberate creation of a policy opposing the reform at an organisational level (eg where service providers enact policy preventing employees from engaging in activities pivotal to the reform); or the creation and dissemination of ideologies that create an unsympathetic environment for the new policy (eg persistent, highly vocal opposition by lobby groups opposing the reform).

²³⁷ Sumner, above n 10.

²³⁸ Stanley Cohen *Visions of social control* (Polity Press, Cambridge, 1985).

Drawing on Daniel Kahneman's ideas, Timur Kuran and Cass Sunstein have developed the concept of an "availability cascade" to describe "a self-reinforcing process of collective belief formation by which an expressed perception triggers a chain reaction that gives the perception increasing plausibility through its rising availability in public discourse". Such cascades can be seen in the 'slippery slope' discourse that can be both the first and last resort of opponents of legalising AD, including medical associations.²³⁹ Kuran and Sunstein argue that these cascades can so influence both public opinion and key decision-makers that they can become an impediment to reasonable regulation, producing "scientifically unnecessary, ineffective, even counterproductive policies [where there is] untruthful and uninformed public discourse",²⁴⁰ resulting in either under-regulation or over-regulation, depending on which voices are loudest. They have proposed governmental structures to give civil servants, including lawmakers, ways to resist undue influence, for example through making evidence-based research and evaluation, such as social or health impact assessments, mandatory for social policy reform. Cohen's "ideological contradiction" model proposes that reform will be impeded at the operational level where there continue to be ideological contradictions in the reform that are not resolved following its implementation.²⁴¹ Such contradictions are very apparent in the ongoing debates around the intended or acceptable scope of AD access, for example in relation to whether it should be available to people with episodic mental illness, and also in the reluctance of proponents of the existing AD laws to admit to issues in implementation or seek to amend the statutes, for fear that doing so will fuel greater opposition and result in the laws being overturned.

As with other kinds of permissive legislation, such as abortion laws, there is always a potential for regulatory safeguards to become excessive in implementation and prevent reasonable access. AD proponents now favour reducing the safeguards in new legislation, arguing that the US implementation experience has demonstrated that they are not needed.²⁴² For example, the Vermont law initially included a 'sunset' clause that would repeal several of the procedural requirements, on the grounds that the US collectively had sufficient experience of safe implementation of the laws in Oregon and Washington to confirm that doctors are capable of screening access to AD based on well established

²³⁹ Timur Kuran and Cass R Sunstein "Availability Cascades and Risk Regulation" (1999) 51 *Stan L Rev* 683.

²⁴⁰ At 742.

²⁴¹ Cohen, above n 238, at 88.

²⁴² This conclusion was based largely on Battin and others' 2007 paper arguing that there was no evidence of vulnerable groups being abused through legal AD; see Battin and others, above n 35.

medical standards of care.²⁴³ Lord Falconer's Bill also contained a sunset clause to take effect 10 years after coming into force. Learning from AD implementation experience, Compassion and Choices at national level has now developed a 'model' statute, recommended for future US states considering AD law, that "does not include the extra burdensome procedural requirements in the Oregon law that we now know do nothing other than make it harder for physicians to participate in the law and for people to access it".²⁴⁴

4 Regulation and compliance

Some legal commentators have analysed doctors' compliance and non-compliance with health laws, including laws either permitting or criminalising AD. Diane Hoffman describes some situations in which doctors may see themselves as entitled to apply their own values in interpreting laws.²⁴⁵ In relation to AD, doctors may feel a moral obligation to relieve suffering that overrides their professional obligation to save life; they may see the prevailing law as unjustifiably restrictive in the context of medical and societal developments and decide that they have an ethical duty to contravene it, as an act of civil disobedience, as have Drs Kevorkian and Nitschke;²⁴⁶ they may do it for a combination of the above reasons, as well as to prompt a criminal prosecution to test the existing law, as Kevorkian did;²⁴⁷ or they may see themselves as private individuals, rather than as service providers, in their relationships with longstanding clients who are now asking them, as a friend or family member, to help end their intolerable suffering. Each of these reasons has been applied by health professionals in relation to AD.²⁴⁸ James Childress developed a taxonomy of non-compliant acts by health professionals that are seen variously as more or less morally justifiable, distinguishing civil disobedience from conscientious objection and "evasive noncompliance", based on whether the act is direct or indirect, public or private, and educative or coercive.²⁴⁹ He describes examples of ways in which doctors have

²⁴³ Kathryn L Tucker "Vermont's Patient Choice at End of Life Act: A Historic Next Generation Law Governing Aid in Dying" (2014) 38 Vt L Rev 687. However this clause has itself since been repealed, apparently due to lobbying by Vermont doctors wanting to retain strong regulation of doctors' delivery of AD; email communication, Board member, Compassion and Choices, 22 September 2015.

²⁴⁴ Email communication, above n 243.

²⁴⁵ Hoffman, above n 143.

²⁴⁶ At 1073.

²⁴⁷ *People v Kevorkian* 639 N.W.2nd 291 (Mich Ct App 2001); see Hoffman (2009) at 1073.

²⁴⁸ See discussion Chapter 4.

²⁴⁹ James F Childress "Civil Disobedience, Conscientious Objection, and Evasive Noncompliance: A Framework for the Analysis and Assessment of Illegal Actions in Health Care" (1985) 10 J Med Philos 63 at 65.

challenged laws in recent decades, noting that they have done so over centuries where laws have failed to keep pace with social change.

Sandra Johnson looked at doctors' claims about "bad laws" specifically in relation to end-of-life decision-making, where 'bad law' was defined as laws that doctors cannot understand, find difficult or confusing to implement or morally objectionable, and that result in poor client outcomes if doctors comply with the law.²⁵⁰ Her analysis of the US AD Bills prior to enactment suggested that particular phrasing of actions or events in the provisions of statutes, or limitations on the scope of the law or the structures that a statute establishes, could all have profound impacts on the degree to which doctors and other health practitioners (eg nurses) might find those laws acceptable and comply with the provisions, or even engage with the law at all, rather than just ignore it in preference for their professional conscience.

E Health law, rights and medical ethics

1 Can there be a right to die with dignity?

Although my thesis topic does not focus on the feasibility of a 'right' to die with dignity, it is discussed here briefly because the concept of human and legal rights is a constant theme in both academic and public discussions around laws for AD. Many new rights, including health rights, have been affirmed internationally by statutes and conventions over the past century. While most theorists agree that the AD laws do not create a legal right to *receive* AD, they have been seen by some as creating a legal right at least to have one's request for AD accepted and actioned as the first step in the legal AD process, since the laws require requests to be recorded. For example, many Swiss view their legal model as based in a human right to dignity and autonomy, rather than as a medical solution,²⁵¹ in relation to a broader issue that involves medical, social, psychological and existential elements, and on this basis Swiss proponents are equivocal about whether to create a specific statute, which would confirm AD as a medical intervention, preferring to rely on the exemption in their penal code and retain oversight by the police rather than by a medical review committee.²⁵²

²⁵⁰ Sandra H Johnson "End-of-Life Decision Making: What We Don't Know We Make Up; What We Do Know We Ignore" (1998) 31(1) Ind L Rev 13.

²⁵¹ Participants' comments; and see *Gross*, above n 202 at [59].

²⁵² Bosshard and others, above n 94.

In contrast, some commentators argue that it is not possible to frame a right to die with dignity, when dignity remains a concept on which there is no consensus, even if it has received some judicial support. Nonetheless, dignity has been described as a “core value” of all societies that are signatories to the European Convention on Human Rights,²⁵³ and Collins J in *Seales* described it as the foundation of human rights, inalienable and “significantly tied up with human autonomy”.²⁵⁴

Historically, the courts have emphasised the right to life as a reason for caution in permitting access to AD.²⁵⁵ For example in Mrs Pretty’s UK legal challenges, reliance on the right to life as founding also a right to die without being prosecuted for assisted suicide was rejected by both the House of Lords and again by the European Court of Human Rights.²⁵⁶ In contrast, the right to life as both a universal human right and as a constitutional right, together with a right to liberty and security of the person, has been the basis for arguing a right to AD, on the grounds that one’s life should not be shortened by suicide prompted by a lack of access to AD when living is no longer bearable. In 2015 the Supreme Court of Canada held in *Carter* that sections 14 and 241[b] of the Canadian Criminal Code, which make assisting suicide a crime, unjustifiably infringed Section 7 of the Charter.²⁵⁷ The Court’s reasoning was based on a body of evidence from a range of sources, including the report of the Select Committee in Québec,²⁵⁸ that the denial of access to AD forces people who are suffering “a grievous and irremediable medical condition... that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition” to take their own lives earlier,²⁵⁹ and in more violent ways, than they would die if AD were legally available. The Court held that the current prohibition of assisted death limits the right to life, liberty and security of the person as it:²⁶⁰

²⁵³ *R (A, B, X and Y) v East Sussex CC and the Disability Rights Commission (No 2)* [2003] EWHC 167, at para 86. Emily Jackson, above n 75, at 25-29, points out that dignity is relied on by both proponents and opponents of AD as a core value supporting their arguments.

²⁵⁴ At [80].

²⁵⁵ For example, *Haas v Switzerland* January 2011, EctHR, and *Vacco v Quill*, above n 76.

²⁵⁶ *R (Pretty) v DPP* [2002] 1 AC 800; *Pretty v United Kingdom* (2002) 35 EHRR 1.

²⁵⁷ Canadian Charter of Rights and Freedoms 1982. Section 7 states that “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.” In contrast, the New Zealand Bill of Rights Act 1990 does not have a specific provision for the right to liberty or security of the person.

²⁵⁸ Assemblée Nationale Québec, above n 33.

²⁵⁹ *Carter*, above 44, at [4].

²⁶⁰ At 8.

... deprives some individuals of life, as it has the effect of forcing some individuals to take their own lives prematurely... [and] denies people in this situation the right to make decisions concerning their bodily integrity and medical care and thus trenches on their liberty... [and] by leaving them to endure intolerable suffering it impinges on their security of the person.

The High Court of South Africa in *Stranham-Ford* reiterated this reasoning in relation to their Bill of Rights,²⁶¹ ruling that the crimes of murder and culpable homicide in that country were “overbroad and in conflict with the said provisions of the Bill of Rights”.²⁶²

The most recent New Zealand authority on this matter is the ruling in *Seales*. Even though Collins J did not, in the event, find that the New Zealand law allowed for Ms Seales to have a medically assisted death,²⁶³ he did conclude that her right to life was engaged by the unavailability of legal assistance to die.²⁶⁴ Arguably a right to die with dignity has already been established in New Zealand by the case law upholding the rights under the New Zealand Code of Rights for people to direct their medical teams to withdraw or withhold life-prolonging treatments. This view was voiced recently by lawyer Andrew Butler, counsel to Lecretia Seales.²⁶⁵ The last word on this question probably still sits with ‘The Philosopher’s Brief’, presented in *Vacco v Quill*, that, for the moment, the “right in question... is only a right to the help of a willing doctor”,²⁶⁶ or what Gerrit Kimsma calls a “claim right”.²⁶⁷

2 Rights, medical ethics and TJ

While there is no right in New Zealand to request AD, section 11 of New Zealand’s Bill of Rights Act 1990 allows, as a right, a mentally competent person to refuse *any* medical treatment, even if it is life-saving and the medical team advises otherwise, and doctors complying with a person’s refusal of treatment are not generally culpable of a criminal offence.²⁶⁸ Rights 7(1) and 7(7) of the New Zealand Code of Rights reinforce s 11, allowing for a mentally competent person to refuse any treatment, including nutrition and hydration,

²⁶¹ Constitution of the Republic of South Africa 1996, Chapter 2.

²⁶² *Stranham-Ford*, above n 49, at [35].

²⁶³ Based on his understanding of the implications of section 4 of the Bill of Rights Act 1990, rejecting any right of the courts to effectively change the current criminal law on assisting a suicide in New Zealand.

²⁶⁴ *Seales*, above n 34, at [12].

²⁶⁵ “Andrew Butler: determining death” (interview, Saturday Morning, Radio New Zealand, 23 January 2016).

²⁶⁶ Ronald Dworkin and others “Assisted Suicide: The Philosophers’ Brief” (1997) 44 New York Rev Books 41.

²⁶⁷ Gerrit K Kimsma “Longevity reversed: Medicide, suicide and laicide after the Euthanasia Law of 2002” (2015) 1 Ethics Med Public Health 220.

²⁶⁸ See the recent decision on s 11 in *Department of Corrections v All Means All* [2014] 3 NZLR 404.

and require the medical team to comply with that decision, even if the clinicians or family disagree with the person's decision. The autonomy principle applies equally to a person's decisions to choose particular treatments, even if that treatment is deemed inappropriate by their doctors (although of course a particular doctor is not obliged to provide such a treatment if they consider it to be futile, clinically inappropriate or inconsistent with their own morality).²⁶⁹ Right 4(4) of the Code sets a general principle that "Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the *quality* of life of, that consumer" (emphasis added), further recognising that quality rather than quantity of life is a core principle.²⁷⁰

While the Code of Rights and the Bill of Rights Act 1990 are important regulatory documents, they are now over 20 years old at a time in history that is unprecedented in terms of both prolonged mortality and the pace of developments in medical interventions that can prolong life even further, when there is sound evidence that longer life at old age is not necessarily matched by extended good health or a will to endure life of poor quality.²⁷¹ Estimates are that in the UK seven percent of all suicides - more than 300 annually - are by people with terminal illnesses,²⁷² and suicide amongst over-80s in Australia is higher than for any other age group.²⁷³ Shifts in medical ethics have challenged doctors with strong religious beliefs or wishing to privilege sanctity of life as the prevailing principle in end-of-life decision-making, impacting on access to AD where it is legal. Given the broad acceptance of personal autonomy as a priority principle in medical decision-making and the evidence that doctors continue to provide AD where it remains illegal,²⁷⁴ one might legitimately ask, from a TJ lens, whether the continuing opposition of medical associations to AD places those organisations and medical institutions, or at least their gatekeepers, out of touch with social change.

²⁶⁹ See Willmott, White and Downie, above n 53.

²⁷⁰ "Optimise the quality of life" is defined in Right 4 of the Code as meaning "to take a holistic view of the needs of the consumer in order to achieve the best possible outcome in the circumstances".

²⁷¹ Fiona Stewart "Testamentary Capacity & Rational Suicide: the Law, Medicine and Safe-Guarding Your Intentions" (Research Project LWC Dissertation, Charles Darwin University, October 2014).

²⁷² "A Hidden Problem: Suicide by Terminally Ill People" (October 2014) Campaign for Dignity in Dying <www.dignityindying.org.uk>.

²⁷³ Stewart, above n 271. Comparable figures are not available for New Zealand, which does not break down the suicide figures further over age 65 or by terminal illness.

²⁷⁴ Hoffman, above n 143; Lewy, above n 10.

F Evaluating health law

It is now internationally accepted good practice in the health sector to undertake health impact assessment to evaluate the likely health and social impacts on individuals and communities of significant proposed health policy reform.²⁷⁵ Likewise, it is usual in the developed world for a significant health policy reform to be thoroughly evaluated from the point of implementation, to identify any implementation problems early on and rectify those. However it appears that a similar process has not generally been applied with actual or proposed AD legislation. The evaluation discipline has a number of practice models and theoretical concepts that could be used to support the development and fine-tuning of laws to facilitate their effectiveness for all stakeholder groups in terms of their implementation and outcomes. Chapter 5 will canvas how evaluation might contribute to the effective implementation of AD laws and the ongoing evolution and development of end-of-life law and regulation internationally, for example through integrating evaluation theory and methodology with therapeutic jurisprudence.

G Applying the frameworks to the research findings

In the following chapters, my research findings are integrated with the literature and discussed in terms of concepts outlined in this chapter. Mirroring the chronological decision-making processes of considering, requesting, being assessed for and receiving AD, access barriers and enablers are examined at each level in the health social ecology, exploring the causal links, identifying the factors that most influence access, and then discussing ways in which the statutes and regulatory systems might be modified or developed to achieve a balance between permissive and restrictive law to reflect the apparent intent of the legislation.

²⁷⁵ Frank Vanclay “International principles for social impact assessment” (2003) 21 IAPA 5; World Health Organisation “Health Impact Assessment” <www.who.int>.

Chapter 4. Assisted dying as a relational decision-making process

A Structuring the discussion

1 Chapter structure

Through the research interviews, supplemented by emerging literature, a range of access barriers was identified, some specific to a particular jurisdiction (eg based on the legislative model or national features), but commonly across all of the selected jurisdictions, albeit in varying degrees and manifestations. I began this research looking at potential access barriers for people seeking AD; however it became evident in early interviews that doctors and other health practitioners wishing to participate in AD commonly experience major barriers that in turn affect the availability of doctors and others to undertake the various AD functions. Pivotal to AD access by seekers or participation by health professionals is decision-making, by individuals or in negotiation, which typically involves multiple stakeholders, including families, doctors and other health and social services practitioners and providers, along the pathway from a person first contemplating AD to ultimate decisions about why, when, where and how to have an assisted death. Decisions are also central to making and implementing the laws, around determining what eligibility criteria, safeguards and accountabilities are or are not needed. The barriers have complex causes and are linked together in an intricate web reflecting the levels of influence in **Figure 1** (p 47), presenting a challenge to determining a structure through which they could be presented simply and without repetition.

Accordingly, the following discussion focuses on issues for all parties involved in AD. It is set out in four Parts reflecting the key phases in AD decision-making: *1. Making the initial decision to request AD; 2. Making a viable AD request; 3. Assessing eligibility; and 4. Administering AD.* The fourth Part also covers reporting and accountability and AD by advance directive, since these can also create access barriers for either seekers or providers.

A primary focus of this research was to identify not only barriers to access but also ways in which proponents have attempted to address or mitigate those barriers, and the extent to which those mitigation efforts have been successful. The following discussion describes how each barrier arises, the apparent causal factors and flow-on impacts, and then examines various mitigation attempts - legislative, regulatory and other - across the selected

jurisdictions to assess how effective those strategies or mechanisms have been. It then explores further enabling strategies that were suggested by research participants and/or other commentators but not as yet tried, together with possible solutions that I have proposed. Within each Part, I discuss barriers and enablers at each level of influence in the social ecology of health model (see **Figure 1**), examining the interaction of influences on each of the decision-makers involved. I have attempted to present the various barriers in an order that reflects clear causal relationships, though that is inevitably complicated by the complexity of the interactions amongst diverse influences.

2 Communicating the research findings

This chapter primarily presents research participants' collective experiences and perceptions of implementing AD, together with their thoughts and ideas around improving AD provision and legislation. Participants' data are integrated seamlessly with information from the literature and from additional informants. This approach is used because it is sensible to present information from triangulated sources together, avoids repetition, and provides all of the evidence on each topic within a single section, building the arguments progressively. Where participant data is supported by other literature, that is indicated in footnotes. Where multiple materials supported research participants' data, I have referenced the most relevant and included additional references in the bibliography. Where my own interpretation, conclusions or ideas are included, I have used the first person voice

To avoid repetition of phrases, people seeking AD are called 'seekers', reflecting their quest for a hastened death, whether or not they ultimately choose or achieve an assisted death. The RTDs that provide AD services to seekers are referred to as 'AD provider agencies', reflecting that aspect of their activities. Quotes from the research participants are given verbatim, including the speaker's grammar.²⁷⁶ They have been selected either to be representative of a stakeholder group involved (eg legislator; doctor; hospice director) or to illustrate a particular issue. Because many of the interview participants were high profile people within their countries or communities, quotes are attributed only to the general stakeholder group, to avoid breaching participant confidentiality and anonymity. Where

²⁷⁶ Note that a majority of participants were not native English speakers, though generally fluent. Repetitions and hesitations ('um', 'ah') have been omitted where doing so does not alter the meaning, following usual practice in qualitative research; see Anne Corden and Roy Sainsbury *Using verbatim quotes in reporting qualitative social research: researchers' views* (University of York, York, 2006). Some words, phrases or participant quotes translated from other languages are indicated as such.

additional description of the speaker is added, it is to indicate that the quote reflects the views of a particular sub-group (eg ‘Doctor providing AD for more than 20 years’). Short quotes within sentences represent research participants’ comments unless otherwise indicated.

Several concepts core to AD implementation issues that are introduced in this Part, such as conscientious refusal and ‘patient autonomy’, are explored in more detail in subsequent Parts of this chapter as they affect subsequent AD decision-making stages.

As a reminder, ‘barriers’ here refers to factors that are *not* intended by the laws; intended safeguards are discussed only where their scope becomes an apparently excessive impediment to reasonable access. Nothing in this thesis takes away from the recognised need for safeguards in AD laws to ensure health provider accountability and protection of vulnerable people.

As a note, the initial draft of this thesis was written prior to the release in mid-December 2015 of the P-TEAG Report.²⁷⁷ Several of the novel legislative provisions proposed throughout this chapter are also represented in that report, reflecting a collaborative conversation between me and Professor Jocelyn Downie, a member of that Advisory Group, as each of us was working on an AD Bill - hers for Canada, and mine as a ‘demonstration model’ statute reflecting lessons from this research for perceived effective practice in AD provision and regulation (see further, **Table 2**, pp 206-217, and Chapter 5).

B Part 1. Making the initial decision to seek AD

The campaign is so binary; polarised between good and evil. The reality is so much more complex, and there is no one impartial to talk to.²⁷⁸

1 End-of-life decision-making

There is little research to date on seekers’ process of deciding to make or first making a request for AD, and yet these may be the points at which seekers are most vulnerable to

²⁷⁷ *Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying Final Report* (Ontario Minister of Health and Long-Term Care and Attorney General, Toronto, 30 November 2015), referred to henceforth as the ‘P-TEAG Report’.

²⁷⁸ “Why didn’t I get a say in my husband Simon’s right to die?” *The Telegraph* (online ed, 9 February 2016) <www.telegraph.co.uk>.

access barriers.²⁷⁹ People do not easily make a decision to hasten their death. Even people with a long-held intention to use AD may experience their final decisions as hard to make.²⁸⁰ Decisions about end-of-life choices involve existential considerations about the value of one's life, as well as practical considerations about when and how,²⁸¹ so where prognosis allows, seekers can take weeks or months to contemplate their initial decision, typically in a highly emotional context. Seekers know that they will have to justify their choice to family as well as doctors and possibly also others such as priests and their communities, and to themselves. When people are considering AD, they commonly call on close family to help them with finding information and discussing their reasons.²⁸² Like most crucial life events, end-of-life decision-making is relational, considering multiple factors including the societal context, health systems, others' reactions, logistics, the progression of the illness and suffering, symptom management, and the seeker's emotional responses to all of those. From micro to macro level there are influences that can impede an initial decision to have AD at the point when the person is trying to become certain whether AD is the best option for them. Many research participants saw this as the stage at which the person is most vulnerable to those myriad influences and most needs support and protection from potential coercion.

2 What motivates hastened death?

The factors motivating a wish for AD are not primarily physical pain or suffering; rather, they are a combination of personal values, personality, experiences of others' deaths, and perception of the likely trajectory of the seeker's illness.²⁸³ US research with families of people choosing AD found that the key reasons were "existential suffering ... related to an aggregate experience of multiple, interdependent losses in physical, psychological and

²⁷⁹ Information on seekers' decision-making is based on proxy accounts from my research participants as well as from families and doctors interviewed in other studies, as referenced. Only one study undertaken with seekers was located, a survey that focused only on seekers' reasons, not their decision-making processes; see Ganzini, Goy and Dobscha, above n 135.

²⁸⁰ Participants' comments; Claudia Gamondi and others "Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: a qualitative study" (2013) *BMJ Support Palliat Care*, 3 September 2013; Robert A Pearlman and others "Motivations for Physician-assisted Suicide" (2005) 20 *J Gen Intern Med* 234; Helene Starks and others "Why Now? Timing and Circumstances of Hastened Deaths" (2005) 30 *J Pain Symptom Manage* 215.

²⁸¹ Participants' comments; Marjorie D Wenrich and others "Dying patients' need for emotional support and personalized care from physicians: Perspectives of patients with terminal illness, families, and health care providers" (2003) 25 *J Pain Symptom Manage* 236.

²⁸² Participants' comments; Starks and others, above n 281.

²⁸³ Ganzini, Goy and Dobscha, above n 135; Phillipa J Malpas, Kay Mitchell and Malcolm H Johnson "I wouldn't want to become a nuisance under any circumstances": A qualitative study of the reasons healthy older individuals support medical practices that hasten death" (2012) 125(1358) *NZMJ* 9; Starks and others, above n 281.

social functioning that were inextricably interwoven and undermined their sense of self, a future, and purpose”.²⁸⁴ Research has demonstrated consistently and across jurisdictions that motivators for seeking AD are those associated with ‘demoralization’ syndrome²⁸⁵ – actual and anticipated loss (physical functioning, personal autonomy, control over one’s own decisions, sense of community, and sense of self and identity), together with concerns about being a burden on others, a knowledge that available treatments are already or will soon become inadequate to control symptoms which will make life unbearable, and a sense of hopelessness.²⁸⁶ Seekers’ main fears are not of physical pain, but of symptoms that will disgust them and remove all remaining sense of dignity or control over their lives, such as uncontrollable rectal bleeding, constant vomiting or extreme and constant nausea, suppurating and untreatable sores, continuous diarrhoea, or dementia.²⁸⁷ Seekers monitor their own progression towards dying very closely, often moving through three identifiable stages: “looming crisis” - recently given a prognosis of 1-6 months, with a realistic expectation of serious loss of quality of life; “dying, but not fast enough” - one month to live and an urgent wish to avoid what to them is becoming an awful death; and “dying and done” - one week to live, symptoms now completely unbearable.²⁸⁸ At all stages, seekers fear losing the capability to assert their AD wish to health carers. They reject both continuous palliative sedation (CPS) and terminal sedation,²⁸⁹ seeing those as “prolonging their indignity and their suffering as well as that of their families”.²⁹⁰

Family accounts of seekers commonly portray them as highly autonomous people who plan for the future, do not fear death per se, have clear ideas about what is and is not acceptable to them, and are sceptical about the value to them of palliative care and practitioners in that

²⁸⁴ Starks and others “Why now? Timing and circumstances of hastened deaths” (2005) 30 J Pain Symptom Manage 215 at 218.

²⁸⁵ Rod Duncan MacLeod, Donna M Wilson and Phillipa J Malpas “Assisted or Hastened Death: The Healthcare Practitioner’s Dilemma” (2012) 4 Glob J Health Sci 87.

²⁸⁶ Participants’ comments; Ganzini, Goy and Dobscha, above n 135.

²⁸⁷ Participants’ comments; Peter Hudson and others “Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review” (2006) 20 Palliat Med 693; Pearlman and others, above n 281.

²⁸⁸ Starks and others, above n 281, at 221.

²⁸⁹ Continuous palliative sedation is the use of drugs to render a person unconscious continuously until death, without necessarily any intention to hasten death; terminal sedation refers to the use of CPS *together with* the withdrawal of nutrition and hydration, so there is a clear intention to hasten death where death is not imminent (e.g. 2-14 days).

²⁹⁰ Participants’ comments; Starks and others, above n 281, at 222. The contested practice of giving patients CPS in lieu of AD, with or without their consent, is discussed in detail on pp 80, 105, 110 and 116-117.

area.²⁹¹ AD is attractive because it avoids the dire dying process they anticipate based on their symptoms.

3 Barriers affecting initial decision-making

Influences from micro to macro levels are constantly interactive as the seeker progresses through their initial decision-making towards making a request. Note that the following analysis assumes that the seeker genuinely wishes to consider AD as an option.

The pattern of barriers is described in this section, mitigation strategies explored next and then suggestions made for more effective avoidance of barriers.

3.1 Personal factors

Personal factors operating against seekers freely considering AD include physical, emotional and psychological factors, personal beliefs and philosophies, personality attributes, factors such as gender, culture, ethnicity, location, age and generation, and features of their medical condition/s and health status, including the fact that they are facing death. Each of these factors can result in difficulty making or expressing their choice, accessing essential information, including diagnostic and prognostic information, demonstrating the legal eligibility conditions or taking part in the assessment processes required.

Cultural, religious and other beliefs around death and dying, including taboos around suicide, may challenge a seeker's consideration of AD. Religious beliefs may prevent seekers from choosing AD, even if they want it, because of theological uncertainties or fears of opposition or accusation from family, priest, congregation, community or even their health care team in communities where religious affiliation is strong.²⁹² Decision-making has been delayed by fears that seekers or their family will be subject to social stigma such as accusations of suicide or murder if family support the person's wish.²⁹³ The lower rate of Belgian AD registrations in the French-speaking Wallonia region (20 percent) than in Flanders has been attributed to cultural factors such as regional religiosity, Wallonian attitudes towards bureaucracy, perceived unwillingness of priests to conduct funerals for

²⁹¹ Starks and others, above n 281; Murielle Pott and others "Les Proches Impliqués dans une Assistance au Suicide" (2011) 26 *Revue Internationale de Soins Palliatifs* 277.

²⁹² Participants' comments; Gamondi and others above n 281.

²⁹³ Participants' comments; "Je veux soutenir Exit...", above n 62.

AD deaths, and no availability of a specific organisation to facilitate AD requests as there is in Dutch-speaking Flanders.²⁹⁴ In addition, a failure of medical systems to provide adequately for diverse cultural and spiritual beliefs and practices around death and dying might result in seekers having insufficient access to culturally relevant people with whom to discuss their wishes.²⁹⁵

Decision-making is made confusing and difficult by the fact that people seeking AD are dealing with impending death and the grief and impotence associated with that,²⁹⁶ along with the uncertainty of what suffering or indignity dying might involve, having to manage the grief of family and friends, and making plans for the aftermath of their death. Personality factors such as assertiveness or shyness, locus of control - how much the person sees themselves as in control of their own decisions - combined with personal beliefs and family roles can all affect the seeker's decision-making.

3.2 Family and others' opposition

Although some people have no family or friends to support their dying, the majority do, and most seekers involve family in their decision-making, out of respect and because they typically rely on them for general care as well as emotional support.²⁹⁷ Family reactions can range from highly supportive to deeply oppositional, and can fluctuate. Unless the family shares a seeker's long-held determination to have AD, family members are normally shocked initially when told of this wish. Family opposition can vary from strong, coercive resistance to emotional reluctance to accept the seeker's choice. Baroness Warnock commented in the House of Lords debate in 2014 that parents remain parents even when dying and will try to avoid actions that will distress their children, including being a 'burden',²⁹⁸ a notion endorsed by other commentators.²⁹⁹ Family members with strong personalities can readily influence people facing death if that person has historically had an acquiescent role in the family dynamics. Oregon research showed that while one sixth of terminally-ill people had talked with family about having AD, only one in 50 then raised

²⁹⁴ Smets, above n 146.

²⁹⁵ External Panel on Options for a Legislative Response to *Carter v Canada Consultations on Physician-Assisted Dying, Summary of Key Findings, Final Report* (15 December 2015); referred to henceforth as the 'External Panel Report'.

²⁹⁶ Elisabeth Kübler Ross *On Death and Dying* (MacMillan Company, New York, 1969).

²⁹⁷ Participants' comments; Gamondi and others, above n 281; Pott and others, above n 292; Helene Starks and others "Family Member Involvement in Hastened Death" (2007) 31 *Death Stud* 105.

²⁹⁸ (18 July 2014) 755 HL 28.

²⁹⁹ See Sheila McLean *Assisted Dying: Reflections on the Need for Law Reform* (Routledge-Cavendish, Abingdon, 2007).

that with their doctor.³⁰⁰ Disagreement amongst family members can result in a seeker changing their decision to avoid leaving a legacy of family conflict, even though that conflict may well continue anyway.³⁰¹ Seekers who anticipate family opposition often decide not to involve family in decision-making,³⁰² even where some family members may be supportive, to avoid family conflict as well as opposition. Doing so can leave the seeker without anyone to talk things through with, advocate for them, find information or help contact an AD provider.

Families are in shock, everyone's grieving and trying to make sense of it all, so it's not an easy time for anyone, and it can bring out the best and the worst in families. *Hospice doctor*

If there is a major disagreement with the family, we [AD provider agency] have to wait, that is not our job [resolving family conflict] and there must be no pressure. So we tell the patient that we can work with them again when there is no more family disagreement, so then sometimes they say, OK, I don't talk with my family now. That is very difficult for them, and it is very difficult for us, because we know that they need their family just now and they will also suffer from that decision. But it is their choice, and they can no longer support their suffering, so we have to respect that. *Participating doctor*

The demographic groups commonly identified as vulnerable to coercion may equally be disadvantaged in access to AD, for example, because of disabilities that make a request difficult, or because of pressure from disability lobby groups opposed to AD. Disability groups are divided on the desirability of legalising AD, with some organisations coming out strongly in favour of AD being available to people with neurological and other conditions that make their lives unbearable.³⁰³ Some disabled people have suggested that they might be put off considering AD due to a sense of loyalty to disability lobbies or to a particular disabled friend, even if AD were their clear personal wish.³⁰⁴

3.3 Socioeconomic factors

Across jurisdictions people who request AD are mostly white, highly educated and in middle-high income brackets.³⁰⁵ Low-income groups may be put off by the actual or perceived costs, be less interested in AD for sociocultural reasons, or have low health

³⁰⁰ Susan W Tolle and others "Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide" (2004) 15(2) J Clin Ethics 111.

³⁰¹ Participant comments; Starks and others, above n 298.

³⁰² Nearly 5 percent in Oregon; see Oregon Public Health Division *Oregon Death with Dignity Act: 2015 Summary Data* (4 February 2016).

³⁰³ Participants' comments; Charles E Drum and others "The Oregon Death with Dignity Act: results of a literature review and naturalistic inquiry" (2010) 3(1) Disabil Health J 3.

³⁰⁴ Participants' comments; Sumner, above n 10.

³⁰⁵ Chambaere and others, above n 119; Hedberg and Tolle, above n 124; Lewy, above 10.

literacy or less ready access to AD information, as to health care in general.³⁰⁶ Low-income people in some jurisdictions are less likely to have a long-term trusting relationship with a regular family doctor, instead seeing rostered doctors in state-funded clinics providing only brief consultations focused on delivering standard health options, which may not include discussing end-of-life options.³⁰⁷ In the absence of research evidence, it is unclear whether lower use is by choice (however that is construed) or due to actual or perceived barriers. The one study identified exploring differential access across ethnic cultures found no statistically significant cultural disparity in attitudes towards AD between Hispanic and other US citizens.³⁰⁸ The researchers surmised that lower uptake rates of Hispanics and African-Americans in the US might be attributed to less education, lower health literacy, greater religiosity, and/or suspicion of white-dominated health institutions due to their historic abuses of ethnic minorities.³⁰⁹

Considering the costs of AD may be a barrier for seekers in the US states and Switzerland if they do not have medical insurance or where insurance does not cover the cost of either the drugs or the assessment consultations.³¹⁰ A recent US proposal for universal state insurance covering AD consultation costs awaits confirmation,³¹¹ and commentators are waiting to see if the Affordable Care Act ('Obamacare')³¹² will affect AD uptake.³¹³ Since early 2014 the Danish manufacturers of the preferred AD drug, pentobarbital, have refused to supply US distributors on ethical grounds following adverse publicity surrounding the mismanagement of death sentence executions there.³¹⁴ The substitute drug, usually secobarbital, is 5-6 times more expensive than pentobarbital, increasing the US cost of a lethal dose from \$US250 to \$US1,500, making it virtually unaffordable for people without medical insurance.³¹⁵ While

³⁰⁶ Kathy L Cerminara "Pandora's Dismay: Eliminating Coverage-Related Barriers to Hospice Care" (2010) 11 Fla Coastal L Rev 107.

³⁰⁷ Participants' comments; Cerminara, above n 307.

³⁰⁸ David V Espino and others "Physician-Assisted Suicide Attitudes of Older Mexican-American and Non-Hispanic White Adults: Does Ethnicity Make a Difference?" (2010) 58 J Am Geriatr Soc 1370.

³⁰⁹ Participants' comments and see also Richard D Branson, Kenneth Davis and Karyn L Butler "African Americans' participation in clinical research: importance, barriers, and solutions" (2007) 193(1) Am J Surg 32.

³¹⁰ Participants' comments; Sheahan, above n 133.

³¹¹ Pam Belluck "Medicare Plans to Pay Doctors for Counseling on End of Life" *Health, The New York Times* (online ed, New York, 8 July 2015).

³¹² Patient Protection and Affordable Care Act (P.L. 111-148) 2010.

³¹³ Gostin and Roberts, above n 30. Demographics had not changed in the Oregon AD statistics for 2015; see Oregon Public Health Division, above n 303, at 5.

³¹⁴ Participants' comments; BioEdge "Embargo...", above n 147.

³¹⁵ Swiss AD costs for non-residents range from \$20,000US all inclusive (eg travel, accommodation); however this research focuses primarily on residents seeking AD.

most AD provider agencies across jurisdictions have systems available for waiving fees based on hardship, that option is not advertised, and costs for the person and their family's travel and accommodation are not covered. For dying people in rural or remote communities with no ready access to an AD provider agency or a health practitioner willing to discuss AD, the effort and costs of travel and accommodation for themselves and a family member for days or weeks may be a barrier to even considering AD, especially if they anticipate other obstacles. The House of Lords debate on Lord Falconer's Bill led to agreement in principle that applications for AD should all be referred to the High Court, apparently without recognising that that process would not only be intimidating to many dying people but would also involve a deterrent cost.

Although some US health insurance companies have now included AD costs in their policies, both opponents and proponents of AD have voiced concerns that doing so may result in people being declined life-prolonging treatment options by insurance providers and offered the cheaper option of AD instead, as happened to one incensed terminally ill Oregon man with only state-funded medical care.³¹⁶

3.4 Disinformation and misinformation

Lack of information and inaccurate information are significant issues in seekers' decision-making. There is a lack of awareness of the law generally amongst health practitioners and the general population, especially populations with less education.³¹⁷ Information about the AD due care and eligibility requirements is often not readily available (see below), so a first step for seekers is to determine those conditions and processes. Some seekers obtain information well in advance by joining RTDs, attending information events, accessing website material and talking with their doctors about their preferences. However the majority will not have done so, especially where AD is recently legalised. In addition to lack of advertising that AD is a legal option, unavailability of accurate or any information about how AD happens, what the process is, who is involved, how long it takes, whether family are permitted to attend, and even "how much cleaning up there is to do afterwards", can all be barriers to seekers deciding to request AD or hasten their death in other ways.³¹⁸

³¹⁶ Collective Eye Films "How to Die in Oregon" (2011) <www.imdb.com>.

³¹⁷ Hoffmann, above n 143; Johnson, above n 143.

³¹⁸ Participants' comments; Pestinger and others "The desire to hasten death: Using Grounded Theory for a better understanding 'When perception of time tends to be a slippery slope'" (2015) 29(8) *Pall Med* 711.

Seekers' uncertainty about exactly how painful or undignified their condition will become, and how soon,³¹⁹ can delay making an AD request until it is too late.

Doctors' reluctance to talk with people truthfully about what dying is likely to involve for them, ostensibly to avoid frightening the person,³²⁰ can make it difficult for seekers to obtain information about the likely progression of their illness and the potential severity of symptoms, resulting in them leaving their quest for information too late. Many doctors lack skills in communicating terminal diagnoses accurately.³²¹ In the absence of accurate information, seekers can either underestimate or exaggerate the potential for intolerable suffering or the level of likely difficulty in qualifying for AD, making decision-making potentially ill-informed. Many doctors decline to have end-of-life conversations with their clients until they are already seriously ill, if at all, for reasons of time, employer policy, personal morality or a generalised reluctance to talk about death and dying.³²²

Death and dying are generally difficult topics for discussion and some cultures, such as the US, are seen as especially "death-denying", attributable to multiple factors including an increasing invisibility of death as the majority of people die in hospitals rather than in multi-generational households. Across jurisdictions AD is still regarded widely as a taboo topic so that the general public and health professionals in many places are reluctant to discuss it publicly in neutral forums, and most debate is initiated by AD opponents, often with the aim of discouraging people from participating. Despite 20 years of experience in Oregon and The Netherlands that demonstrate that the safeguards against potential abuse are highly effective,³²³ continuing highly publicised claims of a 'slippery slope' affect both potential seekers and their families.³²⁴ These "availability cascades" are characteristic of the response of 'anti-euthanasia' groups not only to public discussion of AD but also to coverage by the media, including social media, typically of individual instances of AD or an expressed wish for it.³²⁵ Commonly the messages communicated by these groups are specifically designed

³¹⁹ Ibid.

³²⁰ Participants' comments; Groopman, above n 230.

³²¹ For a comprehensive review of the literature, see Hagerty and others, above n 227; Wittenberg-Lyles and others, above n 227. See also discussion p 76-77.

³²² Ibid; Dale G Larson and Daniel R Tobin "End-of-life conversations: evolving practice and theory" (2000) 284(12) JAMA 1573. For a detailed discussion of this problem, see Gawande, above n 227.

³²³ Battin and others, above n 35.

³²⁴ Participants' comments; Gamondi and others, above n 281.

³²⁵ Benatar, above n 38. See also discussion of the 'slippery slope' concept and claims by AD opponents, pp 1-2 above.

to deter people from seeking AD, including information that was described by Griffiths and colleagues as typified by “Imprecision, exaggeration, suggestion and innuendo, misinterpretation, misrepresentation, ideological ipse dixitism,³²⁶ and outright lying and slander (not to speak of bad manners)”.³²⁷ With websites now commonly used, opponents’ information is frequently supported with images emphasising alleged misuse of AD.³²⁸

There is a lack of accessible informed, evidence-based education and information on AD available to either the medical profession at large (as distinct from participating doctors attached to AD provider agencies) or the general public. In no jurisdiction until Québec has an AD statute required government health authorities to ensure the availability of accurate and sufficient information to the public (section 8), so that most health authorities provide little or no website or brochure information. No statute to date has expressly delegated responsibility for health practitioner education on AD legal requirements, implementation or how to discuss AD with clients,³²⁹ and only in The Netherlands and Québec have the medical professional bodies taken any responsibility for doing so. The US jurisdictions considered producing information materials but lacked any allocated budget. The information provided by the AD provider agencies is usually confined to brief facts about AD, rather than guidance on how to navigate the systems or find a doctor willing to discuss AD. Even that information can be hard to access for people not familiar with internet use, no longer having computer access if they are hospitalised, or simply not knowing the agencies’ names. As a result, people commonly seek information from informal sources by asking equally uninformed friends or carers.

If they manage to get our number [AD provider agency], we often spend hours on the phone just correcting misperceptions. What usually happens is they can’t find anything on the health department website or anything, so they google and end up with information from the wrong websites, and often that’s from the anti-euthanasia lobbies, which is all about deliberate fear-mongering to put people off. ... We’ve no idea how many people actually want physician-assisted dying but don’t get it because it’s not on the menu at the [religious] hospice facilities. *Provider agency medical director with 12 years participation*

³²⁶ Unjustified assertion.

³²⁷ John Griffiths, Alex Bood and Heleen Weyers *Euthanasia and law in the Netherlands* (Amsterdam University Press, Amsterdam, 1998) 28.

³²⁸ See for example <http://www.lifenews.com/2015/12/15/ontario-governments-euthanasia-report-protects-physicians-but-not-patients/>; <http://www.bioedge.org/bioethics/the-case-for-expanding-physician-assisted-death-to-psychiatric-cases/11640>; <http://www.genethique.org/en/euthanasia-quebec-who-pushes-button-syringe-64330.html#.Vncfe1I7yUc>; <http://www.lifenews.com/2015/12/07/canada-asks-court-to-delay-implementation-of-new-law-allowing-assisted-suicides/>

³²⁹ Such delegation is recommended in the P-TEAG Report, above n 277.

Seekers with concerns about whether AD might nullify an insurance policy or a will can be reluctant to contact insurers or lawyers to clarify those queries. Access to information or support can be further limited due to hospice or hospital organisational features such as scheduled visiting hours, strictly scheduled doctor visits and lack of privacy.

If they live more than an hour from [state capital], there's probably no one locally who will help them. If they come to [capital], they have to leave their family at home, so they have no one with them, and it could still be weeks or months with their family driving down every weekend or staying in motels. *And then they're at the mercy of the hospice and its policies. Participating doctor*

3.5 Health practitioner opposition and disengagement

Because currently only doctors can provide AD, disengagement or disapproval from doctors can have a major impact on the seeker's access to accurate information, and on morale. Across jurisdictions, a majority of end-of-life care services,³³⁰ both facilities and in-home services, are provided by faith-based organisations whose policies commonly contractually prohibit any participation in AD by employees, including merely discussing AD or referring clients to AD provider agencies. This prohibition, permissible under the US statutes, has increased recently with secular providers amalgamating with faith-based providers for economic reasons, further decreasing the availability of AD information or discussion opportunities. Because entry to hospice care in the US requires a maximum six month prognosis of a terminal illness, as do the AD laws, a majority of US seekers are likely, by dint of circumstance, to be using hospice doctors who are prohibited from all AD participation.³³¹ Because the US laws are state legislation, seekers in federally-funded hospitals encounter the same staff prohibition and rely on 'under the radar' referral arrangements between those hospitals and the AD provider agencies. Even though employment law in the US prohibits employers from discriminating against employees for their actions outside of working time and premises, it can be difficult to determine what constitutes off-site and out of hours work when doctors routinely make home visits and have flexible on-call arrangements, and in any event, no doctor wants to risk a costly legal battle with an employer and a reputation that will make future employment difficult to find.³³²

³³⁰ Estimated by research participants as 80 percent or more in the US jurisdictions.

³³¹ Courtney S Campbell and Margaret A Black "Dignity, Death, and Dilemmas: A Study of Washington Hospices and Physician-Assisted Death" (2014) 47 J Pain Symptom Manage 137.

³³² Participants' comments; Johnson, above n 143.

Even where health practitioners are not gagged from participating, seekers often experience major reluctance from their current doctor to discuss AD as an option. Oncologists are commonly reluctant to discuss AD because their goal is cure or prolonging life, and most transfer medical care to a palliative care doctor once treatment is deemed futile. Increasing medical specialisation and subspecialisation means that the seeker may have an oncologist, a palliative care specialist and possibly other specialists, with their family doctor involved minimally or not at all. For seekers resident in facilities, there may be no obvious person with whom they can discuss an end-of-life care plan unless advanced care planning is institutional policy.³³³

Doctors who oppose AD may voice their disapproval, eroding the seeker's assertiveness. Only the Québec statute (s 31) requires disengaging doctors to refer to another doctor, and even it places no outside time limit on that.³³⁴ Coercion can occur in subtle forms. Palliative care doctors are known to be commonly opposed to AD, more so than other doctors,³³⁵ and to decline to discuss AD until all other treatment options have been tried,³³⁶ often deterring the seeker through protracted and exhaustive investigation of their reasons and delaying a request in time. For example, Swiss palliative care doctors have been known to automatically refer a seeker for psychiatric assessment, on the grounds that a request for hastened death is ipso facto evidence of depression, and most require a seeker to explain and substantiate their reasons over a period of days or weeks before the doctor may finally advise the person that, due to conscientious objection, they will not assist the AD request.³³⁷ This amounts to doctors (and other palliative care practitioners) gatekeeping, since AD assessments are normally undertaken on referrals of seekers to the AD provider agency EXIT and do not require the hospice doctor to do any assessment whatsoever. Moreover, participants commented that end-of-life service providers will not always allow AD provider personnel, volunteers or doctors on the premises to provide seekers with information and discussion.

³³³ Ibid.

³³⁴ See further, Part 2.

³³⁵ Gamondi and others, above n 199; Seale, above n 128.

³³⁶ This process is called the 'palliative filter', see Jan L Bernheim and others "State of Palliative Care Development in European Countries with and without Legally Regulated Physician-Assisted Dying" (2014) 2 Health Care 10.

³³⁷ Participants' comments; Gamondi and others, above n 199.

3.6 Aspects of the laws

The existing statutes laws contain little to proactively support potentially eligible seekers' early decision-making. All of the existing AD statutes and Bills to date have included provisions to protect people from being coerced into requesting AD, but not from being coerced *out of* AD. The Québec law requires doctors to give seekers "all information needed to make an informed decision" (section 5), including other treatment options. It also requires all hospices to provide written policy on end-of-life care to all clients and their family before clients are admitted (section 13), and also requires health and social services agencies to "inform the population living in its territory of the end-of-life care services available and the manner of accessing them [including the] options of end-of-life patients" (section 18). However it does not specify how that information is to be made available, nor a time requirement, and there are no checks or penalties for ensuring that the requirements are met by the designated agencies.³³⁸ Many Québec providers have already publicly boycotted these requirements.³³⁹ Apart from Québec, there is no requirement in the statutes that the relevant health authorities disseminate information about AD.

Having only ingestion available can be a significant barrier to even considering AD.³⁴⁰ Some seekers have been deterred on being told by health practitioners opposing AD that gagging, vomiting or choking are possible, in particular people with lung and heart conditions who are already experiencing difficulties with breathing. Having to self-administer drugs may be impossible for people with severe arthritis or tremors, coordination problems or simple physical weakness.

3.7 The "maze"

The myriad factors described above can aggregate to deter people from asking for or even about AD. A combination of illness, exhaustion, opposition from doctors and nurses, not knowing about the legal or other requirements for AD, inaccurate information about the progression of their illness, or just wanting to grasp hold of every good remaining minute of life, can create a "maze" that can result in many people leaving their request until it is too

³³⁸ As distinct from annual audits on whether the provider has produced a policy document, section 8.

³³⁹ "Québec's split over euthanasia a warning for Canada" *Toronto Star* (Toronto, 6 September 2015).

³⁴⁰ Participants' comments; Claudia Gamondi and others "Legalisation of assisted suicide: a safeguard to euthanasia?" (2014) 384 *Lancet* 127.

late to process it.³⁴¹ If there are additional institutional or organisational barriers to obtaining information or support, these can create an obstacle course that is impossible for a seeker to navigate, especially if they do not have anyone to advocate for their wishes (see further in Part 2).

4 Effective measures enabling initial AD decision-making

4.1 What are the ideal conditions for initial AD decision-making?

To make their decision about whether to formally request AD, seekers take into account information about myriad factors – medical, familial, their own and others’ emotional reactions, and potentially legal factors such as the effects on insurances and wills. Making sense of complex information may be impeded by the seeker’s physical as well as cognitive situation. Kahneman’s work on decision-making has shown that the optimum conditions for making decisions that have potentially serious ramifications for ‘Humans’ - that is, people who are susceptible to ‘fast’ thinking heuristics due to the nature and context of the problem under consideration - are an environment and processes that facilitate ‘effortful’ thinking. Because the AD decision-making context is highly emotional for all parties, an environment is needed that enables seekers to make well-considered decisions with sufficient information and moral/emotional support, and without coercion.

As AD laws have been implemented, various strategies have been developed to mitigate barriers to initial decision-making, mostly initiated by the AD provider agencies in response to either anticipated or emerging issues.

4.1.1 Early consideration and expression of preferred end-of-life treatments

The international research canvassed comprehensively in this thesis demonstrates very little focus on seekers’ personal attributes versus their medical eligibility. However research participants identified a number of seeker attributes that might facilitate a formal request, in particular having a clear and persistent wish for AD. Having a long-held wish was associated with and facilitated by a set of factors that tended to coincide: living in a relatively secular community, having secular beliefs, and having family and friends who shared the belief in AD; higher education levels; having good information about what AD

³⁴¹ Participants’ comments; Chambaere and others, above n 119; Marianne C Snijdewind and others “A Study of the First Year of the End-of-Life Clinic for Physician-Assisted Dying in the Netherlands” (2015) 175 JAMA Intern Med 1633.

involves and how it works; strong internal locus of control that allows the seeker to resist opposition, personal criticism and disapproval; having a family doctor who supports AD and knows about the person's wish well in advance of their dying phase; and having an advocate or sufficient personal assertiveness to make and persist in an AD request. These factors also often coincided with membership of an AD provider agency.

Despite having a long-held determination to use AD, a lack or loss of any one of the above factors could create a point of vulnerability that might allow barriers to amass. For example, where a person's illness takes a rapid downhill turn that results in admission to a faith-based hospice, involving a change to palliative care practitioners who oppose AD or are prohibited to discuss it, together with a standard visit by a chaplain, or where a person requests AD and is instead immediately given sedation, ostensibly for anxiety, even a person strongly committed to AD may no longer have the personal resources to persist with their request. Accordingly, to genuinely facilitate access to AD, the most effective vehicles will be through legislation and regulation or support agencies.

About half of our patients tell us at arrival that they want assisted suicide. They have their family agreeing, and they have already arranged everything with EXIT and even sometimes their farewell party and the date. They tell us all these things in front of their family so it is evidenced. But even so, it can be a big problem when the time comes and the family all realises that it [AD] is really going to happen. Then it's a very important part for the doctor to help everyone talk together, or to work apart with the family if the patient asks us for that. It's very emotional. *Swiss palliative care doctor participating in AD*

Having communicated one's AD intent coherently and repeatedly well in advance of serious health decline, for example through a signed and recent advance directive or other advance care planning, reinforced the seeker's intent to both professionals and family. Having a *written* advance directive, even if it did not include an AD instruction, clarified the person's beliefs and wishes around not prolonging life and/or rejecting palliative and terminal sedation as acceptable options, and increased the likelihood of family acquiescence to their choices. The AD provider agencies commonly recommend written advance directives to members (see further Part 4).

4.1.2 Avoiding opposition and building support

Avoiding opposition and distraction are important decision-making strategies for seekers, who do this in a range of ways, by informing family members selectively or not at all, declining to speak with chaplains, counsellors and social workers, and avoiding potential

doctor opposition by asking nurses about the AD stance of doctors and declining to consult with those who may be opposed to AD. Research shows that nurses may be both more likely than doctors to support AD in principle and to participate in it, depending on the particular role, and varying across jurisdictions.³⁴² Nurses are usually the health professional first approached by seekers in facilities, because they have the most frequent contact with the clients and notice their decline. Swiss research which found that women living alone were more likely than married women to request AD interpreted that finding as potential female vulnerability,³⁴³ but it might equally be interpreted as single women experiencing less spousal opposition. Additional seeker actions that were effective in overtly reinforcing their wishes included threatening to suicide if denied AD, declining further treatment and/or nutrition and hydration, and joining an RTD.

People planning to have AD often advocate actively for it, to ease the pathway for future seekers, holding farewell parties for family and friends and inviting doctors and nurses to attend, and sometimes inviting them to also attend the death itself. In The Netherlands, acceptance has grown to the point where AD has become “almost a tradition” in some families, with an expectation that family members may request AD when end-of-life suffering becomes unbearable, further contributing to a wide acceptance of AD as a standard end-of-life option.³⁴⁴ Recent years have seen dying people using social media and the internet to promote both legalising AD and normalising its use in jurisdictions where it is already legal.³⁴⁵

4.1.3 Structured advocacy supports

Having an advocate was important for obtaining information, moral and emotional support to assert the seeker’s wishes, and fending off more or less subtle opposition from health practitioners. Family, doctor and nurse advocates were most valuable because they could less easily be denied seeker access by people challenging the seeker’s wish than AD provider agency volunteers.

³⁴² Malpas, Wilson and Oliver, above n 87; “Warning to Britain as almost half of Belgium’s euthanasia nurses admit to killing without consent” *MailOnline* (online ed, London, 10 June 2010).

³⁴³ Nicole Steck and others “Suicide assisted by right-to-die associations: a population based cohort study” (2014) 43 *Int J Epidemiol* 614.

³⁴⁴ Participants’ comments; Winstone Ross “Dying Dutch: Euthanasia Spreads Across Europe” *World, Newsweek* (online ed, New York, 12 February 2015).

³⁴⁵ For example, AD provider agencies in both Oregon and Washington saw ‘spikes’ in requests for information and advocacy following Brittany Maynard’s much publicised assisted death in 2015.

Structured advocacy and support by AD provider agencies occurs in all jurisdictions with legal AD in force except Québec and was recognised by research participants as pivotal to supporting seekers' initial decision-making (as well as to later requests, assessment and AD administration). Seeker support for initial decision-making is provided directly through volunteers providing information and witnessing the required forms, and indirectly through website and brochure information that is simple, evidence-based and fine-tuned over years for suitability to seekers and families. This approach reflects the non-partisan methods used generally in mentoring and reflective process for various professions and used by professional ethicists and mediators, providing arguments for and against without favour. All of these agencies have highly experienced volunteer doctors available to discuss the pros and cons of various end-of-life options dispassionately from both medical and social perspectives.³⁴⁶ They provide their support volunteers with intensive and ongoing training in the medical, ethical and pastoral aspects of end-of-life care, together with legal knowledge and skills required for a role that demands caution in relation to professional boundaries, to ensure that they remain non-partisan and provide information and not advice. Agency support volunteers were seen as especially valuable during decision-making where the seeker has no family or chooses to not enlist them.

The AD provider agencies also work at the institutional and societal levels to support access to AD and see their membership systems as valuable ways of informing the public accurately about AD. In Switzerland AD is only available to people who are registered members of a provider agency and all new members are sent a portfolio of information. If people join with the express purpose of seeking AD immediately, they receive priority attention, but must still read the information provided before the agency doctor will begin to action their request. Some AD provider agencies run conferences each year to which members are invited to bring family members and others as part of a broader education strategy where topics can include how to discuss AD within the family or how to assert your wish for AD in an oppositional context. In addition, the AD provider agency Dignitas believes that a particular value of its free telephone information and counselling service is that the agency recognises wanting to end one's life as a rational decision in certain contexts

³⁴⁶ While some might argue that these agencies have a vested interest in supporting a choice of AD, the agencies would reject those claims and reiterate that their role is above all to support seekers to reach a choice that is entirely their own.

and respects each person's reasons for considering it, so callers are not rejected, belittled or patronised but feel they are being taken seriously. In this sense, all of the AD provider agencies see themselves as suicide prevention services, knowing that AD seekers often have a suicide back-up plan in case they are declined AD, since declines and even delays can result in suicide.³⁴⁷

EXIT Suisse Romande argues that its membership system ensures that the Swiss eligibility criteria for AD keep pace with public attitudes, since those criteria are determined by the membership, reviewed by regular member surveys and modified or endorsed at each annual general meeting. Applying this process EXIT expanded eligibility in 2013 to include people with multiple disabling medical conditions related to old age rather than requiring a terminal illness (though always requiring evidence of unbearable suffering).

You know, our (Swiss) system works well. Our organisations are well known, they have good websites, and everyone who wants assisted suicide must first be a member. It can't be hurried. We [provider agencies] are strictly monitored by the police and so we must do everything correctly, or they will shut down our service... Because we must be not-for-profit our fees are low, and we will not charge people when they don't have the money... Our volunteers have a lot of training and they stay with us for many years, so we know they are the right people to help the patients... Even so, we would like to have a law, because then more doctors would want to be involved. There are not enough doctors doing it now, so it can be hard on us [participating doctors]. *Director AD provider agency*

The two national US RTDs - Compassion and Choices and Death with Dignity - are collaborating to make AD free, negotiating with the suppliers of Nembutal, the nationwide health insurance companies and the relevant state and federal health authorities. Some progress has already been made, with the two largest health insurers on the US West Coast now covering AD and appointing specialist staff for dealing with AD requests, and the national health insurer Medicare now considering coverage for end-of-life consultations.³⁴⁸ No legislation to date has provided explicitly for free AD.

4.1.4 Education and guidance for doctors

To facilitate appropriate doctor participation, practice guidelines are needed for responding appropriately to seeker requests for AD information and advice, including guidance on responding ethically and accurately. To date the Québec statute is the only one that provides specifically for a medical body to develop standards-based protocols for implementing AD

³⁴⁷ Participants' comments; Snijdewind and others, above n 342.

³⁴⁸ Participants' comments; Belluck, above n 312.

(s 32). To protect and support its members, the Royal Dutch Medical Association (RDMA) volunteered its collaboration in implementing (and drafting) the Netherlands law, as has the Collège des Médecins in Québec. The Belgian Orde der Geneesheren³⁴⁹ became engaged after significant pressure from members. The SCEN organisation mentors doctors new to AD, but normally not until a doctor has begun to action a formal request. However across jurisdictions there are only broad or no authorised or evidence-based guidelines for responding specifically to seekers' *initial* inquiries about AD, and "minimal exploration of how clinicians might respond initially to a statement from a patient regarding a desire to die".³⁵⁰ For example, the Swiss SAMW Guidelines on ethical conduct for end-of-life care do not provide specific guidance for doctors receiving AD requests,³⁵¹ leaving it to the conscience of the individual. Doctors are nervous about relying on guidelines developed by voluntary organisations or self-appointed 'working groups' that have no formal authority, or may not know that such guidelines exist.

4.1.5 Enablers in the legislation

More recent AD laws and Bills have included provisions that enable a supportive decision-making environment, such as not requiring seekers to discuss their choice with others, requiring that the doctor not discuss the person's choice with family unless consented, and ensuring referral systems where health professionals refuse to respond to a request for information. However the phrasing in the statutes is sometimes vague or potentially confusing to a non-lawyer,³⁵² and there are few provisions to address the various barriers identified here. Research participants in all jurisdictions wished the laws had included more provisions to facilitate seekers' decision-making and access generally, but they were universally reluctant to attempt to amend the current legislation for fear that such attempts would be branded by opponents as a fundamental failure of legalising AD and used as an opportunity to campaign to overturn the law.

³⁴⁹ Now the Orde der Artsen.

³⁵⁰ Hudson and others, above n 288, at 693; they reviewed 64 clinical guidelines documents across jurisdictions. According to research participants this situation has not changed in the past decade, see further Part 2.

³⁵¹ Swiss Academy of Medical Sciences "End of Life Care" (2013) <www.samw.ch>.

³⁵² Participants' comments; Jackson, above n 75.

5 How might legislation and regulation further enable access to AD?

5.1 What should and shouldn't a statute include?

There is a balance to be achieved between under- and over-regulating, and between what provisions are ideally included in a statute rather than in institutional regulations or organisational policy. Arguments are made that statutes may become unwieldy and more difficult for laypeople to understand if they contain too much detail, and that it is not for the legislators to determine fine detail and risk trespassing on the preserve of the health professions; rather, that detail is better represented in supplementary regulations compiled by health authorities with practice standards and guidelines provided by the medical regulating bodies and/or professional colleges.³⁵³ Contrary arguments from research participants were that if detail is not included in the statute, then there is a gap in guidance for those organisations interpreting the law for the health professionals who must implement it, and in the absence of an explicit delegation of responsibility, the health authorities may well decline or simply omit to produce and publish supplementary regulations. Moreover, leaving it to those bodies runs the risk that there will be a plethora of supplementary regulation that is inconsistent and/or vague, resulting in practitioners declining engagement for safety reasons. For example in Australia, where abortion law is represented through a confusing array of criminal codes, state or provincial regulation and a profusion of practice standards, doctors and others have called repeatedly for one clear statute for the whole country.³⁵⁴ In Switzerland, doctors participating in AD have lobbied specifically in the past three years to have national legislation or, failing that, cantonal legislation to clarify the legal procedures to ensure doctors can comply with them and not risk litigation or professional reprimand.³⁵⁵

Research participants involved in drafting the existing AD statutes agreed that, as a general principle, the statute itself should contain as much detail as possible, for several reasons: to ensure that the law is feasible operationally; to clarify detail at the Bill stage, so protections for all stakeholders will be evident; to demonstrate to members of the relevant legislature that both sufficient protections and feasibility have been taken into account, and so each stakeholder group can identify what the impacts will be for them; for the allocation of a

³⁵³ Christopher Reynolds *Public Health Law and Regulation* (Federation Press, Sydney, 2004), Chapter 5: A risk-based approach to regulation.

³⁵⁴ Lachlan J de Crespigny and Julian Savulescu "Abortion: time to clarify Australia's confusing laws" (2004) 181(4) *Med J Aust* 201.

³⁵⁵ "Vaud to get first Swiss assisted suicide law" *SWI* (online ed, Zurich, 17 June 2012) <www.swissinfo.ch>.

sufficient implementation budget; and so that supplementary regulations and guidelines will have sufficient guidance from and be consistent with the statute. Legal commentators have noted that, because health practitioners struggle to understand law, it is important that the statutes make visible the protections for doctors engaging in AD, even where doing so offends the core principle in legal drafting of avoiding redundancy.³⁵⁶ For example, doctors (and others) need to see the phrase “immunity from *criminal and* civil liability”, even if, to a lawyer, that is apparent from the provisions for amending existing criminal laws. Health practitioners may need to be reminded that a person asking to die, however frail they may appear, must nonetheless be presumed competent unless the opposite is demonstrated.³⁵⁷ Accordingly, the AD laws and Bills have become more detailed over time, reflecting a learning from weaknesses in existing AD laws that have resulted in doctor reluctance to engage in AD because of the lack of both procedural clarity and visible practitioner protections. Recent exploration of the role of legal drafting in law reform has focused on the disjoint between the areas of knowledge of the drafter and those of the policy advisor in relation to the reasons underlying the need for the reform or a sufficient understanding of the context in which the law will operate, resulting in laws that often do not work. Two common “fall-back methodologies” for drafting that can have this result include “copying law from another jurisdiction and compromising between competing interest groups”,³⁵⁸ both of which apply to the current AD laws in the US and Europe where the various statutes have borrowed in large part from the Oregon and Netherlands statutes. If the AD statute is not considered the place for much of the regulatory material, it nonetheless needs to clarify who has responsibility for ensuring that regulations are developed. There are also strategic considerations around what should or should not be included in a Bill in order for it to pass a first or subsequent readings.

However a goal of this research was to identify ideal provisions needed in a law. Given the powerlessness of seekers in relation to organisations and institutions, and an evident

³⁵⁶ Ann Seidman and Robert B Seidman “ILTAM: Drafting Evidence-Based Legislation for Democratic Social Change” (2009) 89 BUL Rev 435; David Mellinkoff’s classic text on drafting, *Legal Writing: Sense and Nonsense* (Scribner’s Sons, New York, 1982), has seven core rules, the last of which is “Cut in half!”; see also New Zealand Government “Parliamentary Counsel Office’s Drafting Manual” Chapter 3. Principles of clear drafting <www.pco.parliament.govt.nz>.

³⁵⁷ Some lawyers struggle with this presumption, see PDG Skegg “Presuming Competence to Consent: Could Anything be Sillier?” [2011] UQLawJI 1; nonetheless it is a right under the New Zealand Code of Rights, Right 7(2).

³⁵⁸ Seidman and Seidman, above n 357, at 450. Some pros and cons of legal transplantation are discussed in Chapter 5.

preference amongst health practitioners to have clarity about the requirements for due care, research participants, including lawyers, believed that ‘more is better’ when it comes to regulation; that is, given the nervousness of all professionals around participating in AD, there is safety and reassurance in clarity – the more clearly the legal requirements and processes are spelled out, the more likely it is that health practitioners will participate. (This issue is covered in subsequent Parts.) I have not attempted to determine here what should be in supplementary regulations rather than the legislation itself; rather, those decisions should be made through the involvement of the relevant statutory bodies regulating health practitioners and/or their professional associations, as has occurred in Québec and The Netherlands.

Many of the influences described above, such as aspects of personality and family relationships, can not realistically be addressed directly by legislation. However it is essential that lawmakers take into account institutional and organisational factors that may operate against fair access to a law for significant numbers of those whom it is intended to serve.

5.2 Key areas for improving the legislation to enable initial decision-making

Six main enablers were identified where the laws currently *fail prima facie* eligible seekers in their initial decision-making, especially if the seeker does not have a clear documented history of wanting an assisted death. They are: appropriate health practitioner response to information requests; provision and dissemination of sufficient, relevant, unbiased information, and advice where sought; facilitating decision-making and preventing coercion against seeking AD; facilitating affordability; ‘user-friendly’ administration methods, taking into account cultural preferences and taboos in relation to medical treatments and death and dying; and regulating for practice standards and guidelines. Key enablers needed to support constructive seeker decision-making in an optimum environment are discussed below, together with suggested statutory and/or regulatory provisions that might address each. Those provisions are each indicated with a reference in bold square brackets [§] and then summarised in **Table 2**. Because suggestions for enabling provisions are identified in and accumulate across the several Parts of this chapter, **Table 2** has been located at the end of the chapter (pp 206-217).

Table 2 organises the suggested provisions in categories as they might be organised in a statute, so the bracketed references in the sections that follow indicate first, the Part of this chapter in which they are first suggested, and then the category of provision in which they are organised (eg suggestion [§1.I] will be located in section I of **Table 2**).

5.2.1 Appropriate health practitioner response

Currently there is a variable and often unpredictable response by health practitioners generally to seekers' requests for information and advice. Common suggestions by lawyers and politicians interviewed, and other key informants, were that, first, the legislation should be framed to legislate for end-of-life care generally, including palliative care [§1.II], as has occurred in Québec, and second, it should include explicit provisions setting out health consumers' rights to autonomous decision-making [§1.II], including the right to refuse both medical and pastoral treatments [§1.II]. A particular value of the former recommendation is that it acknowledges explicitly the role of palliative care in end-of-life care and positions AD as a standard option amongst other palliative care options,³⁵⁹ thus normalising it. This approach is being pursued purposefully by increasing numbers of palliative care specialists in The Netherlands, Belgium and Switzerland.³⁶⁰ The arguments for including explicit provisions setting out consumers' rights to their own choices were, firstly, that paternalistic conduct by doctors and other health practitioners may occur more frequently with frail clients at end-of-life, and secondly, that seekers and families may not be aware of their rights as health consumers so should be advised of them in early AD discussions with health practitioners.

Some doctors interviewed astutely identified their own reluctance to pick up on "invitations" from clients to start a conversation about AD because it challenged their personal philosophies or because they interpreted a client's wish for a hastened death as professional inadequacy on their part, and some also recognised that their reluctance to discuss AD could be an added disincentive to people making an eventual request for a treatment option that is, after all, legal.³⁶¹

³⁵⁹ Participants' comments; Bernheim and others, above n 337; Quill and Battin, above n 278.

³⁶⁰ Participants' comments; Kenneth Chambaere and Jan L Bernheim "Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience" (2015) *J Med Ethics*, 3 February 2015; Gamondi and others, above n 199.

³⁶¹ Participants' comments; Gamondi and others, above n 199.

Many commentators have noted a lack of health practitioner guidance on how to respond appropriately to AD inquiries,³⁶² resulting in seekers needing persistence to pursue a wish for AD, especially in palliative care and hospice settings. US research participants consider it a priority to overcome the gagging of staff in hospices and strongly recommended that future laws include provisions closing this loophole by making conscientious refusal available only to individuals, not whole organisations [§1.V]. The Québec law has done this in part, but legislators left an option for privately funded end-of-life care providers to object to providing AD services at their facilities. They are already regretting that, as Québec's mostly faith-based end-of-life care providers have taken up that option virtually en masse.³⁶³ In Oregon and Washington, where doctors in faith-based hospices are normally contractually prohibited from any AD participation, one response to requests has been to invite seekers, or family where the person is too sick to leave the facility, to go with the doctor to the nearest Starbucks café to have a discussion. Hospice staff supporting AD have developed 'underground' staff networks to ensure that seekers have real opportunities for accessing AD. Staff involved in these practices are aware that they are risking being sacked or sued by their employer, but go ahead regardless in order to act in accordance with their professional conscience. Social work staff in particular struggle with the prohibition, which they see as being a direct violation of their code of ethics, and some have made formal complaints and registered the issue with their professional associations, but without a formal response yet by those organisations. Just two of the larger secular hospice providers have managed to negotiate for the prohibition to not apply to staff in their facilities and programmes, but that arrangement is tenuous and conflicts can occur when amalgamated staff groups work with the same seeker.

It's awful for everyone, there's this underlying tension that you try to keep from the patient because they need to just be able to concentrate on deciding what's best for them and their family. I mean, they're dying... And it's not like you can just quit and find another job close to where you live, and even if you could - and some of the really good people have - but then, you know, who's going to be there for these people? So we work around it. If it came to the crunch and someone was sacked, maybe then the associations would stand up. *Hospice director*

Research participants believed that clear health practitioner practice guidelines were needed for responding to all end-of-life care inquiries, including a focus on the ethical and practical aspects of responding to seeker requests for or about AD [§1.XI]. These need to be

³⁶² Participants' comments; Hudson and others, above n 288.

³⁶³ Participants' comments; "Québec's split over euthanasia...", above n 340.

authorised by the relevant health practitioner regulatory bodies, preferably in consultation with the professional associations, and cover AD practice along with other end-of-life care treatments [§1.XI]. Ideally the legislation might provide that any request to discuss AD needs to be recorded as such to set in train an appropriate response from the health care team [§1.VI]. Ethicists in the UK and US have also suggested that the professional associations and colleges have a moral responsibility to support their members where AD is legalised, and that not doing so abrogates that responsibility and also impedes important debate on what constitutes good practice in this area (discussed further in Part 2).³⁶⁴

Training and education for all relevant professionals in how to respond to seekers' inquiries also needs to be mandated by the legislation [§1.XI], to ensure availability for those wishing to participate in AD. Doctors across jurisdictions identified a need for such training,³⁶⁵ which is typically only available currently through informal 'apprenticeship' arrangements provided by the AD provider agencies (see Part 2). A recent survey by the Royal Australasian College of Physicians (RACP) found that nearly 90 percent of doctors wanted training on communications skills to be part of the core medical curriculum.³⁶⁶ Doctors and nurses engaged in AD commonly find themselves in the role of counselling or becoming the negotiator with family members who may be reluctant to accept a person's wish to have AD, without having training in these skills. In addition, doctors want more training in understanding what constitutes quality of life, versus just staying alive, and what kinds of interventions are most valuable to people at end of life. As more people are living into their late 90s or beyond, doctors are having to learn how to talk appropriately with mentally competent people much older than themselves and how to understand what matters to people at those lifestages.³⁶⁷ The Indigenous Physicians Association of Canada recently proposed an itinerant team comprised of "local health care providers" to be available for indigenous people who request AD.³⁶⁸

³⁶⁴ Richard Huxtable and Alexandra Mullock "Voices of discontent? Conscience, compromise and assisted dying" (2015) 23(2) Med Law Rev 242 at 262.

³⁶⁵ Participants' comments; Gamondi and others, above n 199.

³⁶⁶ Royal Australasian College of Physicians "National conversation essential to improving end-of-life care" (media release, 25 May 2015).

³⁶⁷ Participants' comments; Gawande, above n 227.

³⁶⁸ External Panel Report, above n 296, at 87.

5.2.2 Provision and dissemination of information

The information needed by seekers includes AD availability, clinical diagnosis and prognosis, and information about AD procedures and their feasibility for a particular individual. The provision of information to individuals can be regulated by requiring doctors to discuss AD as part of canvassing end-of-life treatment options generally [§1.III] and providing robust systems to cover conscientious refusal by doctors to inquiries [§1.V]. Legislation can delegate responsibility to the statutory authorities regulating the relevant health and social services professions and the practice standards for those professions,³⁶⁹ to provide for the development of essential practice standards, guidelines and protocols for AD procedures [§1.XI].

There are several elements to the provision of public information that should be addressed by the laws to ensure access to it, specifically ensuring that AD information is: readily available and accessible; accurate and evidence-based; easy to understand; disseminated effectively to reach all sectors of the population; and the delegated responsibility of an appropriate health authority as part of core service provision [§1.III]. Ideally the statutes should delegate clear responsibility, and budget, to national or regional health authorities within relevant jurisdictions for making information about all legal end-of-life options readily available to the public, as most do in developed countries for health services generally (eg abortion, mental health services) [§1.III]. Dissemination should provide for both online information and paper information for people who can not easily access the internet, for example in facilities or programmes providing services for terminally ill people as well as aged care [§1.III]. Information should be both standardised, to ensure that it is accurate, and localised, so that it refers to local agencies and information sources that will be readily accessible. It should also be accessible to cultural and linguistic minorities [§1.III].

5.2.3 Facilitating decision-making and preventing coercion

AD statutes should ideally provide for the reasonable availability of doctors supportive of AD for the purposes of initial seeker conversations prior to requesting AD [§1.V]. For example, New Zealand's abortion law requires a Supervisory Committee to maintain a list

³⁶⁹ In New Zealand these would be primarily the Medical Council of New Zealand (doctors), the Nursing Council of New Zealand (nurses), the Pharmacy Council of New Zealand (pharmacists; see the Health Practitioners Competence Assurance Act 2003), and the New Zealand Psychologists Board.

of certifying consultants (s 30) that is sufficient for the demand (s 30(2)). It also requires that, to be registered as abortion consultants, doctors must not be “coloured by views in relation to abortion generally that are incompatible with the tenor of [the] Act” (section 30(5)).

Ideally AD laws would provide that health professionals also must not attempt to influence the seeker’s choices, but rather only provide information that is evidence-based, comprehensive and not biased by the practitioner’s personal (versus professional) views [§1.III]. In recent years, to address apparent paternalism in medical practice, standards have been developed to guide practice where doctors experience a discrepancy between their personal beliefs and those of clients, recognising that this can potentially disadvantage people seeking controversial health options. The *Good Medical Practice* guidelines of the Medical Council of New Zealand (MCNZ) closely reflect those in other countries, advising that a doctor’s “personal beliefs, including political, religious and moral beliefs, should not affect your advice or treatment. If you feel your beliefs might affect the advice or treatment you provide, you must explain this to patients and tell them about their right to see another doctor”, and that doctors must not “express your personal beliefs to your patients in ways that exploit their vulnerability or that are likely to cause them distress”.³⁷⁰ The equivalent UK guidelines go further, advising that doctors who conscientiously object “must not imply or express disapproval of the patient’s lifestyle, choices or beliefs”.³⁷¹ These guidelines clarify a distinction between conscientious objection and refusal to provide a treatment, and violation of a person’s autonomy of choice. Medical ethicists have highlighted a parallel distinction between a practitioner’s personal conscience and their professional responsibility to provide a treatment that is legally available.³⁷² The courts have upheld this distinction in relation to health practitioners being required to undertake acts that are sufficiently distant from the act that is objectionable to them, regarding referral as a core aspect of a health practitioner’s duty of care,³⁷³ applying the principle of non-abandonment.

³⁷⁰ Medical Council of New Zealand “Good Medical Practice” (April 2013) <www.mcnz.org.nz>, sections 19-21.

³⁷¹ General Medical Council “Personal beliefs and medical practice” (25 March 2013) <www.gmc-uk.org>, section 52.

³⁷² Huxtable and Mullock, above n 365; Eva LaFollette and Hugh LaFollette “Private Conscience, Public Acts” (2007) 33(5) J Med Ethics 249.

³⁷³ *Greater Glasgow Health Board (Appellant) v Doogan* [2014] UK SC 68; *Halligan v Medical Council* High Court Wellington CIV-2010-485-222, 2/12/2010.

Ethicists have suggested that health practitioners with a conscientious objection have a responsibility to “make their objections known, ideally in advance, in a suitably non-judgmental and non-confrontational fashion”.³⁷⁴ Nonetheless, while it may be generally understood that such guidelines should have quasi-regulatory effect, they have not been developed into Codes with regulatory force.³⁷⁵ In the absence of clear legal mandatory guidance, responsibility for adhering to recommended standards is left to the individual practitioner. Given the vulnerability of a dying person, the conscientious refusal provisions in AD statutes need to not only be very clear, but also balanced by provisions that make it the corollary responsibility of the practitioner, not the seeker, to make available a response facilitating the person’s rights to information [§1.V], and that health practitioners opposed to AD declare that opposition as a conflict of interest to seekers [§1.V]. An ideal seeker support system might involve the optional availability of a trained and registered independent ‘end-of-life mentor’ to all people expressing a wish to consider AD, or indeed to all people making end-of-life decisions. Any opposition to such a system, for example on either budgetary or philosophical grounds, could be challenged on the principles of personal autonomy and informed consent, and that such supports are already considered ‘best practice’ in end-of-life care services, for example through social workers, counsellors and chaplains. To date none of these facilitation systems is either mandated or facilitated by AD statutes or supplementary regulations to assist a seeker’s initial decision-making (as distinct from making a formal AD request, discussed in Part 2).

Some provisions in current AD statutes were viewed as “appropriate but not sufficient” in scope. For example, where the attending doctor must suggest to the person that they talk with family or a counsellor, they should be required to advise not only the seeker but also the family that, for privacy and autonomy reasons, such conversations are not obligatory [§1.IV]. Most Western countries have privacy codes that prevent a health practitioner from discussing a person’s medical condition or wishes with others, including family, without that person’s consent, and make doing so punishable as a breach of privacy. However family may not be aware of that, so practice guidelines should make it the doctor’s responsibility to affirm the seeker’s privacy to family, whatever the doctor’s professional philosophy (eg the palliative care principle of treating the whole family) or the depth of

³⁷⁴ Huxtable and Mullock, above n 365.

³⁷⁵ Contrast, for example, the *New Zealand Code of Health and Disability Services Consumers’ Rights Regulations 1996* and the *Health Information Privacy Code 1994*, both issued by government-appointed Commissioners, set out as legal regulatory documents and intended to have legal force.

family concerns. Given diverse family reactions, the doctor could be required to obtain the seeker's prior approval in writing where possible, specifying with which family members the doctor may discuss the seeker's details. Research participants commented on distant extended family members sometimes frustrating a seeker's wish by "hijacking" an over-consultative doctor. Protections against undue influence need to be addressed by specific statutory provisions for breaches of the law, accompanied by appropriate penalties for breaches [§1.XII].

Pressure on a seeker to not have AD can take various forms, from overt opposition to more subtle disapproval, and through acts of either commission or omission. The seeker's initial decision-making can be disrupted by delays, for example where doctors insist on lengthy and exhausting interrogation of the seeker's reasons or on discussion with family, or by delaying advising the seeker that they are not willing to discuss AD. Seekers may be deterred completely by the unavailability of an unbiased doctor with whom to discuss their wish. The AD laws all contain provisions for conscientious refusal by doctors, as is appropriate. However they do not protect seekers against the "calculated obstruction" identified by commentators on the experience of implementing abortion and contraception laws.³⁷⁶ The statutes need strong provisions for referral of a request for AD information that cannot be defeated by a doctor's claim of conscientious refusal [§1.V]. Presumption of competence is not present in all AD statutes, but arguably should be, to deter doctors from referring seekers for spurious psychiatric assessment even before they have lodged a formal request [§1.II] (see further, Part 3). While early commentators proposed mandatory psychiatric assessment, those suggestions have mostly been retracted (see detailed discussion, Part 3).

None of the existing statutes specifies maximum time frames for recording seeker requests (or for any other procedural requirements for AD), on the grounds that doctors' ethical responsibility will ensure that they respond quickly to seekers' needs. However the research evidence does not support that assumption,³⁷⁷ and there is an absence of data on how many seekers are rejected without a formal request ever being recorded. Most research participants believed that there should be specified maximum time frames for recording a

³⁷⁶ MK Collins "Conscience Clauses and Oral Contraceptives: Conscientious Objection or Calculated Obstruction?" (2006) 15 Ann Health L 37 at 38.

³⁷⁷ Participants' comments; Gamondi and others, above n 199.

seeker's request or inquiry, and that all requests for or about AD should be recorded, to prompt action by the health care team [§1.VI].

Many commentators also believe that the statutes or regulations should provide for education for families on how to respond to seekers' initial wishes, requests and experiences of having AD, to avoid a potential for acute distress or lasting upset.³⁷⁸ Although it is recognised that families do not generally experience significant adverse emotional impacts from attending an assisted death (rather, the opposite),³⁷⁹ there has been no research with families where seekers starve themselves or suicide as a result of being either formally declined or informally denied AD.

5.2.4 Affordability

To date none of the laws has made AD free, even though terminal sedation and other options that are intended to bring about death, which arguably would cost more, will be covered by either a health insurer or the state. It is possible to argue for free AD availability on economic grounds alone,³⁸⁰ but the relevant reasons are equity and compassion – that is, if CPS and terminal sedation are available at no cost, why should AD not also be covered? [§1.VI] This would immediately remove one apparent access barrier for people with low income. The recently published PTEAG report recommends that all AD services, including consultations, be free to people who are entitled to public health services in Canada (Recommendations 4-5).

5.2.5 'User-friendly' administration methods

Legislation needs to allow for a range of AD administration options, so that seekers are not deterred from seeking AD by lack of an administration option that will accommodate their personal circumstances and anxieties (see Part 4). Many AD experts now believe that the best administration method is intravenous line, physically triggered by the seeker (including, for example, an affirmation by eye-blink or grunt as instruction to a person assisting the seeker), for a range of logistical, ethical and psychosocial reasons (see Part 4)

³⁷⁸ Participants comments; Starks and others, above n 298.

³⁷⁹ Gerrit K Kimsma "Death by request in the Netherlands: facts, the legal context and effects on physicians, patients and families" (2010) 13 Med Health Care Philo 355; Pott and others, above n 292. The exception is where problems occur with self-administration by ingestion, see discussion in Part 4.

³⁸⁰ Participants' comments; Ezekiel J Emanuel and Margaret P Battin "What are the Potential Cost Savings from Legalizing Physician-Assisted Suicide?" (1998) 339 New Engl J Med 167.

and in particular because it avoids connotations of being “put down” by injection that might deter potential seekers.

5.2.6 Provision for an AD service infrastructure

Several research participants recommended that AD ideally be positioned as a ‘service’ [§1.I]. Doing so would indicate the requirement for implementation features that normally accompany a health service, such as health authority oversight, establishment of a delivery infrastructure, development of protocols (eg easy availability of guidelines and forms online) and budget for implementation, creation of a provider fee structure, monitoring and evaluation of the service/s, and inclusion in the relevant medical education curricula. It would also reinforce the application of the person’s rights under the relevant jurisdiction’s existing health service rights already understood by doctors (for example, the many rights in New Zealand’s Code of Rights that refer explicitly to rights to “services”).³⁸¹

5.2.7 Evaluation of early AD implementation

A key proposal that I wish to make in this thesis is for AD laws to provide explicitly for early formative evaluation, to determine their operational effectiveness consistent with the intention of the law, in recognition that implementation will not be perfect at the outset and will need adjustments [§1.XIII]. Formative evaluation routinely assesses service access issues by obtaining input from people who have not accessed a service even though they might be regarded as potential clients. Health authorities worldwide acknowledge the need for formative evaluation of new policy initiatives as standard practice, and also commonly undertake health impact assessment prior to new initiatives, to identify potential adverse consequences of implementing new policy.³⁸² While the Netherlands government did budget for monitoring research, and the Québec law provides for a review by the statutory commission created by their statute, to date no jurisdiction has undertaken a formative evaluation of its AD law’s implementation.

6 Beyond regulation?

There are several areas where regulation through a law may simply not be feasible. For example, a statute cannot require a doctor to tell a person the whole truth about their medical condition, because there may not be a single ‘truth’ or the doctor may not have

³⁸¹ Rights 1[3]), 2, 3 and 4 of the Code all refer to “services” provided to consumers.

³⁸² Discussed further in Chapter 5.

sufficient diagnostic data available. Nonetheless a statute could require doctors to discuss the likely trajectory of the symptoms in the context of the alternative treatments available [§1.III], because each of those treatments will need to be justified based on symptomatology.

However desirable in principle, a law probably cannot prevent special interest groups from publishing material that is inaccurate compared with the evidence (though that might make an interesting legal experiment), but good end-of-life decision-making can be facilitated in other ways.

6.1 Promoting good ‘industry’ practice

Advance care planning (ACP) in health care is now accepted good practice in many developed nations, including New Zealand, encouraging the public and health practitioners to have early discussions about people’s wishes for their end-of-life care. Although it has been developed only recently in some countries, aged care and health providers are increasingly embracing ACP as standard practice, to have clarity about a client’s preferences, to plan for treatment requirements, to support clients and families, and to avoid conflict with families or complaints against the provider. A 2015 survey by the Royal Australasian College of Physicians (RACP) found that only 17 percent of doctors knew their clients’ preferences for end-of-life care and end-of-life conversations “did not happen routinely”, commonly resulting in terminally ill people continuing treatments that did not coincide with their wishes.³⁸³ Several New Zealand District Health Boards (DHBs) have introduced ACP as required practice.³⁸⁴ In contrast, in most of the research jurisdictions ACP remains informal practice only and is not yet widely used.³⁸⁵

6.2 Facilitating discussion at the societal level

Research participants were unanimous that there needs to be a louder, broader societal discussion of AD and end-of-life care generally, so that people have more information about the pros and cons of the various options, the stigma associated with ending one’s

³⁸³ Royal Australasian College of Physicians, above n 367.

³⁸⁴ Personal communication, New Zealand Ministry of Health; see for example “Advance Care Planning” Counties Manukau District Health Board <www.countiesmanukau.health.nz/for-patients-and-visitors/advanced-care-planning/>.

³⁸⁵ Participants’ comments; Koen Meeussen and others “Advance care planning in Belgium and The Netherlands: a nationwide retrospective study via sentinel networks of general practitioners” (2011) 42(4) J Pain Symptom Manage 565.

suffering is reduced or neutralised, and people are encouraged to have early consideration and conversations about all end-of-life options. The stigma currently inhibiting discussion at the personal level might be addressed by the kinds of government de-stigmatisation campaigns in many developed countries currently to address stigma about mental illness, in particular depression.³⁸⁶

7 Summary

Without data on how many people contemplate AD, it is difficult to estimate how many may be denied an opportunity to explore it as an option. The data on public approval of AD as an end-of-life option, generally 65-75 percent of the populations surveyed in recent years,³⁸⁷ suggests that where it is legal, people should have non-partisan information available to them and the opportunity to discuss AD with health practitioners who are in principle supportive of all legal end-of-life options. Part 2 explores the issues related to making a formal AD request in compliance with the laws.

C Part 2. Making a viable AD request ³⁸⁸

Vulnerable patients are asking us to listen to their requests with an open mind and heart and to keep their values and priorities at the center of the decision-making process. ... They need committed medical partners who will help them explore all potential alternatives but also address the reality that sometimes death is not the enemy.³⁸⁹

1 Trends in AD uptake

Uptake of AD is growing steadily across jurisdictions, with incidence increasing by around 10-15% per year for the past 3-4 years in Europe and the US states, and roughly doubling or more in the past decade.³⁹⁰ Research participants attributed the increases in the US largely to word-of-mouth, rather than any enabling structures, though in the European jurisdictions

³⁸⁶ Improved suicide prevention services might also deter people with depressive conditions from seeking AD. The Swiss AD provider Dignitas views itself primarily as a suicide prevention service, providing free telephone counselling to hundreds of callers each year requesting AD.

³⁸⁷ Hendry and others, above n 62; these authors reviewed 94 surveys across 24 countries, surveying variously terminally ill people, people from potentially 'vulnerable' groups, people with particular religious affiliations and the general public.

³⁸⁸ As in Part 1, the discussion throughout this Part reflects research participants' interview data, supplemented from the literature as indicated in footnotes.

³⁸⁹ Timothy E Quill and Margaret P Battin *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (JHU Press, Baltimore, 2004) 330.

³⁹⁰ Chambaere and others, above n 116; Oregon Public Health Division *Oregon's Death with Dignity Act - 2014* (Oregon Health Authority, 12 February 2015); Washington State Department of Health *2015 Death with Dignity Act Report* (25 March 2016).

enabling efforts by the AD provider agencies were seen as highly instrumental in these increases.

The AD provider agencies believe that this growth is likely to be exponential for at least the next 10 years as the baby-boomer generation ages. In addition, the reasons for requests are diversifying, at least in Europe, with fewer of them being due to cancers or cardiovascular disease and more - up to 30 percent in some jurisdictions – due to psychiatric conditions, multiple advanced co-morbidities related to old age, and/or ‘life fatigue’.³⁹¹ In the last two years approaching one third of Swiss citizens accessing AD were not terminally ill but had multiple non-terminal conditions causing major suffering.³⁹² There is also a pervasive shift in the paradigm for end-of-life treatment, with people now wanting to avoid medicalised and hospitalised deaths and expecting doctors to be willing to at least discuss AD.³⁹³ Despite apparent increases in requests, without recent studies of decline rates it is entirely possible that those have also doubled.

2 Making a formal request

Once seekers have made their decision to formally request AD, they are typically very sure of their wish. For example, in Swiss palliative care settings up to 60 percent of even repeatedly declined requests for assisted dying persisted or fluctuated until death.³⁹⁴ Nonetheless, across jurisdictions between one and two thirds of initial requests either are declined by the first doctor or lapse because the seeker dies.³⁹⁵ The proportion of declines and non-referrals may be higher, since it is not possible to identify all instances where doctors either ignore or dismiss a seeker’s initial requests or delay investigating them as the person is dying.³⁹⁶ The AD request is not a single event, but a phase, as seekers must make

³⁹¹ Participants’ comments; Regional Euthanasia Review Committees *Annual Report 2013* (The Hague, September 2014); Snijdewind and others, above n 342.

³⁹² Felicity Capon “Dramatic Increase in Assisted Suicides in Switzerland” *Health, Newsweek* (online ed, London, 12 March 2015).

³⁹³ Participants’ comments; Jane Seymour and others “Using continuous sedation until death for cancer patients: A qualitative interview study of physicians’ and nurses’ practice in three European countries” (2014) *Palliat Med*, 25 July 2014.

³⁹⁴ Edouard Ferrand and others “Evolution of requests to hasten death among patients managed by palliative care teams in France: A multicentre cross-sectional survey” (2012) 48(3) *Eur J Cancer* 368; Keith Wilson and others “Desire for euthanasia or physician-assisted suicide in palliative cancer care” (2007) 26(3) *Health Psychol* 314.

³⁹⁵ Chambaere and others, above n 119; Penney Lewis and Isra Black *The Effectiveness Of Legal Safeguards In Jurisdictions That Allow Assisted Dying* (The Commission on Assisted Dying: Briefing Paper, January 2012); Bregje D Onwuteaka-Philipsen and others “The Last Phase of Life: Who Requests and Who Receives Euthanasia or Physician-Assisted Suicide?” (2010) 48 *Med Care* 596.

³⁹⁶ Onwuteaka-Philipsen and others, above n 395.

repeated requests. The US statutes have set minimum requirements of 15 days for the three requests needed.³⁹⁷ The European jurisdictions have no specified time frame, so the critical influences on timing are doctors' and other health practitioners' responsiveness, availability and discretion. No statute sets minimum times for professionals to record or respond to requests, making seekers highly vulnerable to their responsiveness.

In principle seekers have two options available for having a request actioned. If their currently attending doctor declines to provide AD, seekers can contact an AD provider agency to help them find a doctor willing to action a request.³⁹⁸ However where the seeker is not already a member of an RTD or where AD is newly legalised, they may not understand the requirements clearly.

Based on data for legal prescriptions written - around 1-4 percent of all deaths across jurisdictions (see p 219, including footnotes) - it is widely believed that only a small minority of people seek AD. In contrast, studies of desire for hastened death amongst people with terminal cancer have found that around 10 percent will, at some point, express a wish to hasten death,³⁹⁹ whereas doctors interviewed estimated that around half of the people admitted to their facilities or programmes raised AD as a possibility for them, often at admission.

This Part looks at barriers to making a viable AD request in compliance with the statutes. The influences are multi-level and interactive, with multiple parties involved and strong institutional influences that vary in degree by jurisdiction, due to aspects of the statutes, local health systems and what services are provided by the AD provider agencies. The main impediments are: personal and relational factors; not knowing what is required; the framing of the statutory requirements; waiting times for requests; and above all, difficulties in finding a doctor who will first recognise and then action a request. These barriers are discussed below in a rough (overlapping) chronology of the AD request process. Note that

³⁹⁷ In principle this overlaps with the assessment process, discussed in Part 3; in fact some doctors may delay undertaking the assessment until the final request has been received, due to ignorance of the legal requirements, personal factors or employer policy; see Lewy, above n 10.

³⁹⁸ No agency provides such services in Colombia or South Africa.

³⁹⁹ William Breitbart and others "Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer" (2000) 284(22) JAMA 2907; Barry Rosenfeld and others "The schedule of attitudes toward hastened death" (2000) 88(12) Cancer 2868.

the pattern of barriers is canvassed first and followed by discussion of the mitigation strategies, actual and potential.

3 Barriers to a viable AD request

3.1 Personal factors

The same factors that can impede initial decision-making remain present during the request phase. Seekers may still lack accurate information, making them vulnerable to misinformation and health practitioner biases or ignorance. They are generally emotionally fragile and tired as well as impaired by an increased symptom load and fear of what is to come, making it difficult to remain assertive in their requests. Physical frailty, due to age, pre-existing disability or the person's medical condition/s, can prevent them from being able to express their wishes clearly, sign the necessary documents, or even have sufficient energy or voice to make a request.⁴⁰⁰ Because some seekers remain constantly hopeful of a magic remission of symptoms, they may defer a formal request for emotional reasons.

Living in a rural or remote community can be a barrier for seekers too ill to travel, since such communities tend to have stronger religious affiliation, fewer (if any) doctors and therefore less likelihood of locating one let alone two sympathetic doctors.⁴⁰¹ Initial requests in Netherlands rural areas occurred a third less than in cities,⁴⁰² despite widespread availability of home-based hospice services, and research participants noted the same pattern across jurisdictions. Doctors who participated in AD often said they limit their participation to 3-4 times per year, due to the emotional effort, further narrowing the chances of finding an available doctor in a conservative community.

Making a request successfully can be affected by age, generation and gender.⁴⁰³ For example, women now in old age were raised in a generation that bowed to the wishes and status of usually male doctors, making them more vulnerable than men to paternalistic

⁴⁰⁰ Participants' comments; Marijke C Jansen-van der Weide, Bregje D Onwuteaka-Philipsen and Gerrit van der Wal "Granted, Undecided, Withdrawn, and Refused Requests for Euthanasia and Physician-Assisted Suicide" (2005) 165 Arch Intern Med 1698.

⁴⁰¹ Participants' comments; Marijke C Jansen-van der Weide, Bregje D Onwuteaka-Philipsen and Gerrit van der Wal "Requests for euthanasia and physician-assisted suicide and the availability and application of palliative options" (2006) 4 Palliat Support Care 399.

⁴⁰² RI Marquet and others "Twenty five years of requests for euthanasia and physician-assisted suicide in Dutch general practice: trend analysis" (2003) 327 BMJ 201.

⁴⁰³ Sumner, above n 10.

behaviour.⁴⁰⁴ One nurse interviewed described how a woman client's repeated requests over two years to have AD were only taken seriously after the woman's husband had died, resulting in her no longer having someone to look after her at home. Research has established that women are much more often diagnosed *and* misdiagnosed with depression,⁴⁰⁵ and depression is one of the most common reasons for doctors declining requests at first instance.⁴⁰⁶ Seekers with no close family or friends can have difficulty verifying their identity to Swiss provider agencies which require that another person identify them, and the same barrier can occur where the law requires that two people witness the person's request and confirm that they are competent to make it.

3.2 Family opposition

Because seekers must make multiple 'voluntary' requests (that is, free from apparent coercion, in the doctor's assessment), there are weeks during which family opposition can impede the necessary final request. Even though seekers are not required to consult with family, doctors generally take family views into account. Some statutes require the attending doctor to encourage a seeker to discuss their wish with family members, but do not also require advice to the seeker (or the family) that such discussion is not mandatory. Where family reluctance is expressed as grief, an exhausted seeker can end up having to counsel their own family, one by one, over weeks.

Seekers aware of family opposition may avoid them altogether during the waiting period between requests. Where family opposition is apparent, palliative care and family doctors may experience a conflict of interest, resulting in doctors siding with the family and the seeker being pressured out of their wish for AD.⁴⁰⁷ In Switzerland, palliative care doctors sometimes consult with family even without the seeker's consent, on the grounds that the philosophy of palliative care is to treat the whole family, not just the person. They also commonly "recommend"⁴⁰⁸ that the seeker continue to see family, even knowing that the family is oppositional, and may support the family to "suggest" that the seeker "reconsider" their request, out of concern that family members may be adversely affected emotionally

⁴⁰⁴ Participants' comments; Sumner, above n 10.

⁴⁰⁵ Bonnie J Floyd "Problems in accurate medical diagnosis of depression in female patients" (1997) 44(3) Soc Sci Med 403.

⁴⁰⁶ Ganzini, Goy and Dobscha, above n 135.

⁴⁰⁷ Participants' comments; Gamondi and others, above n 281.

⁴⁰⁸ As previously, short quotes within sentences are from research participants unless otherwise indicated.

and socially by an assisted death contrary to their wishes.⁴⁰⁹ In Belgium and The Netherlands, family doctors with divided loyalties to the seeker and other family members have sometimes put subtle pressure on seekers to reconsider their request to avoid doctor conflict later with the family.⁴¹⁰

Where family conflict is apparent, the support agency may withdraw their support, at least until the conflict is resolved, to avoid the agency becoming embroiled in the conflict and damaging its ethical reputation. Resolving family opposition can delay requests until it is too late to process them, potentially resulting in the seeker suiciding or starving themselves.

Sometimes we have seen the family come back much later and they have changed their mind and now they want us to quickly help their mother die because now they see the agony, but then it is too late because we can't hurry through the checks. So our volunteers know to work with the family too, but often they [family] are thinking of themselves, they want to keep their parent as long as possible and so they don't see how much they [parent] are suffering. *Swiss AD provider agency*

3.3 Disinformation and misinformation

Across jurisdictions, seekers tend to make their first inquiries to a nurse or family doctor. For reasons discussed in Part 1, seekers and health practitioners alike rarely understand the legal requirements for formal AD requests without previous AD experience.⁴¹¹ Key factors delaying a formal request included well-intended but inappropriate cautions about AD from people in the health care team, a lack of accurate information about the trajectory of the person's illness or symptoms, or the common practice by doctors of overestimating the prognosis period, apparently to avoid the dying person feeling hopeless. Apart from in Québec, end-of-life providers are not required by law to advise actual or potential clients of their policy on whether they permit AD on their premises, so facility residents can be frustrated when they decide after admission to request AD. In the US jurisdictions and Switzerland seekers are often given misinformation about the request requirements and other aspects of AD by professionals opposed to AD, whether out of ignorance or through a deliberate focus on the negative aspects of the AD process.⁴¹²

I can end up talking with people for more than an hour the first time they call, just letting them know what they have to do and how long it will take and about the forms and so on, and some people can be quite shocked at how long it's going to take... They've been told a

⁴⁰⁹ Participants' comments; Gamondi and others, above n 199.

⁴¹⁰ Participants' comments; Chambaere and others, above n 119.

⁴¹¹ Participants' comments; Buiting and others, above n 126.

⁴¹² Participants' comments; Gamondi and others, above n 199; Gordijn and Janssens, above n 133.

lot of incorrect things about AD, you know, like it [medication] tastes awful and they'll gag, so their last moment in life will be horrible, and it'll be painful and how they can vomit or lose bowel control so it'll be awful for their family and such, so we just keep on going through that and putting them right on the facts. Mostly whoever they've talked with up till then didn't know what they were talking about, so we have to put them straight from the get-go, especially about the timing. *AD provider agency administrator*

Although the material published by the AD provider agencies attempts to provide a balance and focus on the voluntariness of AD, it remains difficult for seekers to find any evidently non-partisan description of actual AD operation and requirements.

3.4 Legal requirements for formal requests

As discussed earlier, the requirements in the statutes have been formulated generally to restrict rather than actively facilitate access. Health practitioners not regularly involved with AD processes tend to be unfamiliar with the requirements of the law, including the immunities provided, so act conservatively to avoid inadvertently breaching it and attracting sanction from employers or a professional association whose policy continues to oppose AD. Most jurisdictions require one of the requests to be made on a prescribed form, but where AD requests are not frequent, staff may not know how to access them and witnessing requirements can result in delays finding appropriate witnesses. Where staff are unaware of minimum timing requirements, they may inadvertently delay the process by not recording the initial request while they seek out the form. If the initial request is not undertaken in compliance with the legislation, it can result in a US seeker losing two weeks and having to repeat the process, which is not only distressing but runs the risk of a late seeker developing a medical condition (dementia, stroke) that renders them ineligible to make the final request. Further delays can occur where statutes are unclear about whether the first or a subsequent request has to be on the prescribed form, causing confusion and excessive form-filling and arranging of witnesses. The Swiss AD provider agency EXIT's request system requires the seeker to write their reasons in their own words, which can be a barrier for people with physically debilitating medical conditions or whose medications make concentration difficult.

Most statutes require that the formal requests are made to a doctor, because under the laws only doctors can undertake AD assessments, even though arguably any registered health practitioner could record a request, especially since doctors are generally less available than nurses. Where the law does allow for another practitioner to record a request, many

provider organisations have internal policy requiring the first or all requests to be made to the attending doctor specifically, even though that person may not be visiting daily.

3.5 Discontinuity of care

Depending on jurisdiction, many people at end of life are no longer seeing their family doctor, but rather specialists with whom they have only a recent relationship. Oncologists and other specialists tend to refer clients on to palliative care once medical treatment is deemed futile, but that may be only weeks or sometimes days before the person's death due to some doctors' reluctance to acknowledge when further treatment is futile. Seekers can be reluctant to request something from their usual doctor that they know will be hard for that person, so asking a new doctor may be even more difficult. Moreover, determining exactly who the 'attending' doctor is for the legal request requirements can result in delays.⁴¹³

3.6 Recognising requests for AD

There is considerable confusion across jurisdictions as to what constitutes a request for AD, which allows for requests to be ignored by health practitioners, wittingly or otherwise. Doctors encounter difficulty in distinguishing the clarity of AD requests due to seekers' cognitive or other frailties impairing their communications.⁴¹⁴ Many palliative care doctors are disinclined to recognise AD requests as such, routinely differentiating a request for AD from a request for information about AD and then responding to both as if the person seeks only information, no matter how clear the person's words.⁴¹⁵ Some doctors respond by ignoring the request and providing substitute treatments.

Those doctors who don't approve [of AD] but don't want to say so, they will just say, 'Don't worry, dear, I'll make sure you don't have any pain'. But there could be a lot of things wrong with that. If she [seeker] really wants euthanasia, they [doctor] must listen to that, it is their ethical responsibility. And maybe pain is not the real problem, it is her dignity and her self-respect. Even if she just isn't sure yet, the doctor must assume that she wants to talk about it. Some people are afraid to ask their doctor because they know they are asking something that is very hard for him to do. So it is very dishonest – that doctor is not respecting the patient's wishes. And once he says no, then probably that patient will feel that they can not ask another doctor... Sometimes those doctors will give the patient some sedation so they will not ask again. *Participating Netherlands doctor*

Barriers in language or nuance can occur between health practitioners and seekers because one or the other is a migrant. In Switzerland, where many hospital and hospice staff,

⁴¹³ Participants' comments; Gamondi and others, above n 281.

⁴¹⁴ Ilinka Haverkate and others, above n 119.

⁴¹⁵ Gamondi and others, above n 199.

including doctors, are now from predominantly Catholic or Muslim countries, the language barrier can result in staff failing to recognise a seeker's AD request, whether genuinely or by choice.

To avoid their request being disapproved or declined at the outset, seekers in palliative care facilities or programmes commonly couch an initial request in subtle phrasing - "I'm ready to die", or "I just want this to be over" - "shopping around" for doctors who are supportive of AD requests and sometimes making multiple subtle approaches to various staff before finding one who acknowledges their request.⁴¹⁶ While some commentators have criticised that strategy as manipulative, others see it as defensible and even inevitable when only a minority of doctors is engaging in AD.⁴¹⁷ Doctors interviewed who provided AD regularly treated every request for information as an initial request for AD on grounds that there is no disadvantage to the seeker in so doing, the seeker's anxiety is relieved immediately, and recording the request does not commit the seeker to any further action.

3.7 Timing

Clinging to what good life remains and/or ignorant of the wait requirements, many seekers delay making a request until they urgently want to die. Delayed referrals to hospice are a major factor in belated initial AD requests, occurring commonly because of specialists' reluctance to concede that further treatment would be futile.⁴¹⁸ The requirement in the Benelux statutes for both a subjective judgment by the seeker and a clinical judgment by the doctors of 'unbearable' suffering is potentially self-defeating. If seekers apply too early, they may be seen as not yet eligible, but a delayed request may come too late to process in time to meet their now urgent need.

However a major factor in delayed requests was tardiness or failure to refer by health practitioners who oppose AD or are prohibited from responding to AD requests.⁴¹⁹ Although ordinary medical standards of care require a professional receiving such a request to advise the person if they are unwilling to action it, only the Québec statute includes a requirement for referral to another professional and the referral has no time requirement. None of the

⁴¹⁶ Participants' comments; Amy Sullivan, Katrina Hedberg and David W. Fleming "Legalized physician-assisted suicide in Oregon—the second year" (2000) 342(8) *New Engl J Med* 598.

⁴¹⁷ Participants' comments; Huxtable and Mullock, above n 365.

⁴¹⁸ Participants' comments; Gamondi and others, above n 199.

⁴¹⁹ Participants' comments; Gamondi and others, above n 199; Groenewoud and others, above n 134; Sheahan, above n 133.

statutes either specifies a maximum period for recording a request or includes an independent monitoring system to ensure timely processing.⁴²⁰ Further delays occur in the US jurisdictions due to the 15-day “cooling off” period.

3.8 Doctor unavailability

The greatest barrier to making a viable AD request is the unavailability of doctors willing to action them. Up to 95% of doctors across jurisdictions were unavailable to action an AD request when it was first legalised. Fewer than four percent of eligible Oregon doctors participated in AD in the first 10 years,⁴²¹ and the percentage was similar in The Netherlands and Belgium in the same introductory period, even though AD had been practised there for many years.⁴²² After 20 years of legal AD in Oregon, research participants estimated doctor participation in *any* aspect of AD as less than 10 percent of eligible doctors.

Internationally doctors remain significantly less supportive of legalising AD than the general population, attributed often to their feeling ethically or professionally compromised.⁴²³ Nonetheless AD is known to occur widely as an illegal and unreported practice,⁴²⁴ including in New Zealand,⁴²⁵ ‘passive’ methods of hastening death by the withdrawal of treatments, nutrition and hydration are both legal and commonly practised worldwide,⁴²⁶ and increasing proportions of doctors gradually become willing to engage in

⁴²⁰ As exists, for example, in the abortion laws, due to the first trimester limitation on availability.

⁴²¹ Stevens, above n 131. By 2015, fewer than one percent of licenced doctors in Oregon had written an AD prescription in any year since legalisation, contrasted with 60 percent of Dutch doctors having done so in the same period since legalisation; see Eva Elizabeth Bolt, Marianne C Snijdewind, Dick L Willems, Agnes van der Heide and Bregje D Onwuteaka-Philipsen “Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living?” (2015) 41(8) J Med Ethics 592; Oregon Public Health Division “Oregon Death with Dignity Act Annual Reports, 1998-2015” (2016) <www.public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>. Research participants in Europe estimated that around one half of family doctors in their countries have received at least one AD request, and recent research confirmed that figure as 77 percent of randomly surveyed physicians in The Netherlands, see Ezekiel J Emanuel, Bregje D Onwuteaka-Philipsen, John W Urwin and Joachim Cohen “Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe” (2016) 316(1) JAMA 79.

⁴²² Bregje D Onwuteaka-Philipsen and others “Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey” (2012) 380 Lancet 908.

⁴²³ Ruaidhri McCormack, Margaret Clifford and Marian Conroy “Attitudes of UK doctors towards euthanasia and physician-assisted suicide: A systematic literature review” (2012) 26 Palliat Med 23; see Seale, above n 128.

⁴²⁴ Lewy, above n 10.

⁴²⁵ Kay Mitchell and R Glynn Owens “National survey of medical decisions at end of life made by New Zealand general practitioners” (2003) 327 BMJ 202.

⁴²⁶ Lewy, above n 10; Jackson, above n 75.

legal AD over time as the implementation data show no significant evidence of predation on vulnerable people and few or no doctors being prosecuted.⁴²⁷ However the uptake is slow.

In the experience of research participants engaged in providing AD, the four medical specialisations most likely to receive requests for AD are family doctors, palliative care doctors, oncologists and general medicine doctors in hospitals. Doctors tend to fall into three rough (but dynamic) groups in their AD availability: those fully or in principle supportive of AD and willing to act on a request (including referring to another doctor); those firmly opposed to AD and unwilling to participate; and those ambivalent about their willingness to engage in AD activities.⁴²⁸ The latter group form the majority, and their ambivalence makes their availability unpredictable to themselves, seekers and others, sometimes resulting in doctors abandoning a request process part way through. It appears that significant numbers of doctors are not necessarily unwilling to provide AD, but are deterred by a complex interaction of factors that make participation unattractive.

The three strongest predictors of doctors' and nurses' unwillingness to engage in AD, and of declining to accept requests, are religiosity, being a palliative care professional and holding paternalistic attitudes towards medical decision-making.⁴²⁹ These factors appear to coincide frequently in end-of-life decision-making generally, with families often feeling pressured and even manipulated by doctors and other health practitioners.⁴³⁰ However many doctors are simply confused about the moral arguments and lack opportunities to talk or think them through clearly due to a lack of reasoned professional debate.⁴³¹ Despite significant research demonstrating that the 'slippery slope' concerns have not eventuated in any jurisdiction that has legalised AD,⁴³² and that in fact eligibility assessments are

⁴²⁷ Chambaere and others, above n 119; Onwuteaka-Philipsen and others, above n 422.

⁴²⁸ Participants' comments; and Gamondi and others, above n 199.

⁴²⁹ M Berghs, B Dierckx de Casterlè and Chris Gastmans "The complexity of nurses' attitudes toward euthanasia: a review of the literature" (2005) 31 J Med Ethics 441; McCormack and others, above 423; Yanna van Wesemael and others "Process and Outcomes of Euthanasia Requests Under the Belgian Act on Euthanasia: A Nationwide Survey" (2011) 42 J Pain Symptom Manage 721.

⁴³⁰ Katherine Curnow "Information, Power and Relationships: Minimising barriers to access to justice for end of life disputes" (2014) 25 ADRJ 137.

⁴³¹ Participants' comments; Sheahan, above n 133.

⁴³² Assemblée Nationale Québec, above n 258; Battin and others, above n 35; Frances Norwood, Gerrit Kimsma and Margaret P. Battin "Vulnerability and the 'slippery slope' at the end-of-life: a qualitative study of euthanasia, general practice and home death in The Netherlands" (2009) 26(6) Family practice 472; Y Tony Yang and Farr A Curlin "Why physicians should oppose assisted suicide" (2016) 315(3) JAMA 247.

becoming more stringent over time,⁴³³ those concerns continue to influence doctors to decline participation or even actively oppose legalisation.⁴³⁴

Medical technology has developed faster than social mores, so some doctors find it difficult to recognise the point at which medical care is no longer a best (versus feasible) option.⁴³⁵ Medical futility is a relatively new and contested concept and only recently introduced into medical curricula in many countries.⁴³⁶ Many doctors resist the ethical shift from sanctity of life to personal autonomy and do not understand that quality of life is subjective and cannot always be defined medically. The cognitive dissonance involved in these ethical challenges results in many doctors absenting themselves from AD by calling on conscientious refusal, though they may not truly object to AD in principle. For example, many more doctors are willing to be the consulting doctor than the doctor who writes the prescription and/or administers the death. Research participants identified a cluster of reasons for reluctance to be the attending doctor, including: time; costs to the doctor; feeling an ethical obligation to attend the death if they have written the prescription; an emotional involvement that they fear; and in particular a sense of feeling directly responsible for the person's death (discussed further in Part 4). They also identified a greater reluctance of specialists than family doctors to accept AD requests and attributed that to specialists' focus on symptom management rather than caring for the whole person.

The most of our volunteer doctors are retired family physicians, because they're used to treating the whole person and they know how to work inside a relationship that's going to be emotional, so they're not scared by that, and they're not scared by what their colleagues think or by the church or being called murderers. They're compassionate people who've seen lots of their patients die before and they're not afraid to be truthful about dying. What we'd love would be if the oncologists and the palliative care doctors would come on board too, so people don't have to hunt around to find us when they're already dying. *AD provider agency volunteer doctor*

Professional stigma or censure, whether by colleagues, employers, one's professional association or one's clients and community, appears to be a major disincentive to doctors' participation in AD and only lessens when a critical mass of doctors in a medical community begins to engage in AD activity. Doctors operate in a collegial context and are subject to peer pressure. Fear of professional censure is especially strong where the relevant

⁴³³ Chambaere and others, above n 119.

⁴³⁴ Benatar, above n 38; Penney Lewis "The Empirical Slippery Slope from Voluntary to Non-Voluntary Euthanasia" (2007) 35 J Law Med Ethics 197; Sheahan, above n 133.

⁴³⁵ Participants' comments; Bernheim and others, above n 337; Gawande above n 227; Jackson, above n 75.

⁴³⁶ Bernheim and others, above n 337.

medical professional bodies remain overtly opposed to AD participation,⁴³⁷ as do most internationally,⁴³⁸ with doctors perceiving that if they make a genuine mistake in providing AD activity their association will not support them, in fact the opposite. However doctors also fear loss of employment opportunities, privileges and rights where their employers or colleagues are opposed to AD participation. Where staff in amalgamated hospices are unclear about whether they can action a request, they act conservatively to avoid sanction. Many hospitals and rest homes in the European jurisdictions prohibit AD on site out of concern that requests for AD might be interpreted as the hospital's failure to provide adequate palliative care, and have policy "preferring" their staff to not engage in AD. While some cantons in Switzerland have countered this by introducing legislation that requires facilities to allow AD on site unless they have advised clients of their policy before providing services, many doctors in these facilities avoid involvement in AD due to their own fears of "being seen as Dr Death" or criticism from colleagues. Across jurisdictions, the names of participating doctors are not listed on AD provider websites so as to avoid harassment from opponents. Likewise, provider agencies do not advertise after-hours phone numbers or the addresses of venues where AD takes place, to protect both seekers and other participants from harassment or worse.

We've had the whole example of what happened with the abortion laws, doctors and staff being physically assaulted, their property vandalised, their families being bullied and harassed, it was dreadful, so we go to quite some lengths now to make sure that our volunteers are protected from that, otherwise we wouldn't have any! *AD provider agency director*

Some specialists are more afraid of professional stigma than of criminal prosecution, worried that colleagues will see them as failures, pariahs or simply as "lazy" or "don't care about my patients".⁴³⁹ Not all of the statutes contain protections for doctors from sanction by employers or professional bodies, and even where they do, doctors may not be aware of them without education about legal aspects of the laws,⁴⁴⁰ as with end-of-life laws generally.⁴⁴¹ Though employment law allows for doctors to pursue actions for constructive dismissal or harassment, US research participants identified fear of subtle coercion (disapproving insinuation, being passed over for promotion) as deterring doctors from

⁴³⁷ Dieter Birnbacher and Edgar Dahl (eds) *Giving Death a Helping Hand: Physician-assisted Suicide and Public Policy. An International Perspective* (Springer, New York, 2008); Sheahan, above n 133.

⁴³⁸ Birnbacher and Dahl, above n 437.

⁴³⁹ Participants' comments; Gamondi and others, above n 199.

⁴⁴⁰ Lewis and Black, above n 395.

⁴⁴¹ Meisel, Snyder and Quill, above n 118; Benjamin P White and others "Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment" (2014) 201 Med J Aust 229.

engaging in legal AD. As a relatively new medical specialisation, palliative medicine wants to avoid becoming the specialisation that “kills” its patients.⁴⁴²

Doctors may fear prosecution or reprimand due to an inadvertent failure to comply with the legal requirements. Without formal training or authorised guidelines, doctors can perceive the likelihood of that happening as quite high. Safe participation is available through aligning with an AD provider agency, but many doctors remain reluctant to do so for fear of a negative impact on their reputation, employment or income. Some Swiss doctors interviewed who were pro-AD in principle will not engage currently because there is no legislated protection against professional reprimand, their professional body remains strongly opposed to AD, authorised guidelines are lacking, and “there is always the Damocles Sword that you can be accused if they [police] decide that it [assisted suicide] was not justified”. In The Netherlands, where euthanasia had been quietly sanctioned by the health and police authorities before it was legalised, rates of euthanasia actually fell dramatically in the first few years following legalisation, while rates of continuous deep sedation rose equally dramatically,⁴⁴³ apparently in response to doctors’ nervousness around now being formally accountable.⁴⁴⁴ In Belgium, many doctors provide CPS rather than AD, apparently to avoid the accountability requirements.⁴⁴⁵ In the US, the great majority of doctors remain unwilling to participate in AD even though more than half nationwide now support legal AD in principle.⁴⁴⁶ High profile prosecutions where doctors have *not* used legal AD nonetheless contribute to doctors’ fears that they might make a mistake that will end their careers.⁴⁴⁷ Moreover, doctors do not want to risk public exposure of an alleged peccadillo, not only because of the risk to reputation, but also because of the “potentially bankrupting” impacts of litigation,⁴⁴⁸ especially where their indemnity insurance may not extend to AD functions.

⁴⁴² Personal communication, Board member, *palliative ch* (Swiss palliative care association).

⁴⁴³ Onwuteaka-Philipsen and others, above n 422.

⁴⁴⁴ Participants’ comments; Judith AC Rietjens and Agnes van der Heide “Continuous deep sedation for patients nearing death in The Netherlands: Descriptive study” (2008) 336 *BMJ* 810.

⁴⁴⁵ Participants’ comments; Joachim Cohen and others “Cultural differences affecting euthanasia practice in Belgium: One law but different attitudes and practices in Flanders and Wallonia” (2012) 75 *Soc Sci Med* 845; Smets, above n 146.

⁴⁴⁶ Lesley Kane “Medscape Ethics Report 2014” *Medscape News and Perspectives* (16 January 2014) <www.medscape.com>.

⁴⁴⁷ Participants’ comments; “The Issue: Euthanasia after Tuitjenhorn” *Erasmus University English News* (18 November 2013) <www.eur.nl>.

⁴⁴⁸ Participant’s comments; Johnson, above n 143.

You still have to be brave here [US] to get involved, and most people just aren't willing to take the risk. Pretty much all of the basic institutions in the health sector, from the medical associations to the insurance companies to the billing arrangements, they all set up obstacles to being involved in physician-assisted dying in one way or another. *US health law academic*

The lack of accredited training and guidelines endorsed by the appropriate regulatory organisations also deter AD participation.⁴⁴⁹ Only in The Netherlands and Québec have medical professional bodies produced or facilitated practice standards and/or guidelines for AD implementation (see p 130-132). AD practice has not been developed as a 'standard of care' within general medicine, on the spurious grounds that only a tiny percentage of the population seeks it. In the US, the few guidelines available until recently were produced by self-appointed working groups and typically contained high-level advice, referring to general medical knowledge and broad bioethics principles.⁴⁵⁰ David Orentlicher and colleagues published some "clinical criteria" for AD at the end of 2015, but these also, while useful as an outline of the clinical requirements per se, are high-level and contain little on the 'how-to' and complexities of an effective response to an AD request.⁴⁵¹ The authors note that "the statutes provide insufficient guidance for physicians in their assessment of the patient's decision-making process ... [and] say nothing about the kinds or doses of medication that should be used".⁴⁵² The SAMW Guidelines on ethical conduct for end-of-life care do not provide specific guidance for doctors receiving AD requests,⁴⁵³ leaving it to the conscience of individual doctors and allowing them to delay referral indefinitely.

None of the US states with legal AD has or is considering either undergraduate or continuing professional education on AD for doctors, psychiatrists or psychologists. In 2015 the only information about AD in the medical curricula was provided by Compassion and Choices volunteers when invited occasionally to address undergraduate classes. The only accredited continuing education on AD that US research participants were aware of was

⁴⁴⁹ Participants' comments; Berniek AM Hesselink and others "Education on end-of-life care in the medical curriculum: students' opinions and knowledge" (2010) 13 J Palliat Med 381; Lewis and Black, above n 395.

⁴⁵⁰ For example, Reginald Deschepper and others "Communication on end-of-life decisions with patients wishing to die at home: the making of a guideline for GPs in Flanders, Belgium" (2006) 56 Br J Gen Pract 14; The Task Force to Improve the Care of Terminally-Ill Oregonians "The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals" (2008) <www.ohsu.edu>.

⁴⁵¹ David Orentlicher, Thaddeus Mason Pope and Ben A Rich "Clinical Criteria for Physician Aid in Dying" (2015) 18 Journal of Palliative Medicine DOI: 10.1089/jpm.2015.0092 Supplementary material. Note that it is generally accepted that a statute should not include kinds or doses of medications.

⁴⁵² Ibid at 1.

⁴⁵³ Swiss Academy of Medical Sciences "End of Life Care" (2013) <www.samw.ch>.

provided by ELNEC,⁴⁵⁴ a national project administered by the American Association of Colleges of Nursing. In Belgium and The Netherlands, AD education and training are provided largely through doctor support systems run by the SCEN and LEIF organisations (discussed p 125 ff), and AD coverage in their medical school curricula is focused on the legal eligibility criteria, not on the procedural logistics or psychological/emotional aspects.⁴⁵⁵ In Switzerland, practice guidelines and training for AD are provided through mentoring participating doctors.

Multiple factors at the macro/institutional level deter health practitioner participation. In addition to disengagement by medical professional bodies, none of the statutes to date includes a requirement that a government health authority have general oversight of AD implementation, establish an implementation infrastructure or provide budget for implementation, such as would normally be standard practice for a new service.⁴⁵⁶ As a result, delivery infrastructure in most jurisdictions to date has been developed and provided by the not-for-profit AD provider agencies who develop their own infrastructure policy and must either fund-raise (rarely viable, given the focus of the services) or pass operational costs on to seekers.⁴⁵⁷

Doctors can also be deterred by time and costs. Without clarity about billing, many US doctors feel embarrassed to bill the client, but reluctant to absorb the considerable time required in their employer's work, and cannot bill the seeker's insurer directly unless they have a private practice and the seeker's insurance covers AD. Some health insurers require both assessing doctors to be company-approved, and also limit the types of consultation covered and the claimable amounts, creating further bureaucratic obstacles to doctor participation. Attempts by health insurers to recruit assessing doctors have been attacked by opponents of AD, accusing the insurers of wanting to kill off clients for profit reasons.⁴⁵⁸ Rural doctors rarely undertake the insurers' approval processes because of perceived limited

⁴⁵⁴ The End-of-Life Nursing Education Consortium <www.aacn.nche.edu/el nec>.

⁴⁵⁵ Participants' comments; personal communications from curriculum advisors at the Universities of Ghent and Amsterdam.

⁴⁵⁶ The Québec statute designates some specific monitoring functions and determination of "policy directions" to the Minister of Health, sections 19-23.

⁴⁵⁷ SCEN receives some government support.

⁴⁵⁸ Participants' comments; Wesley J Smith "Doctors of death: Kaiser solicits its doctors to kill" *National Review Online* (online ed, New York, 19 August 2002).

demand for AD in their locale, creating a self-perpetuating lack of available doctors in rural communities.

You know, really it feels wrong to be thinking about the money for these poor people who just want to die without appalling suffering, but once it gets out that you're willing to help, soon enough there's a lot of folks come calling, and then just for your own mental health you have to prioritise, which also feels like a disservice to them in the circumstances – it's very hard to turn people away. I'm not about making a profit out of this, for heaven's sake, but it's really *very* time-consuming because they're needy and the family's needy and you [doctor] have to be *so* sure. So I can't do it *all* out of love." *Participating doctor*

However some research participants thought that doctors "hide behind" their lack of skills to avoid the 'cognitive strain' described by Kahneman when people confront moral dilemmas.⁴⁵⁹

If they have the willingness, then they'll develop the competence. Yes, we need better training, and it [AD provision] needs to come out of the closet, but really there's nothing to stop someone who feels strongly enough from getting involved. Sure, we [AD provider agency] don't advertise on TV, but they know where to find us. *Palliative care doctor participating in AD*

I sometimes wonder if there's something wrong with me that I don't mind doing it [providing AD services]. *Participating doctor, 20 years*

3.9 Gatekeeping - failure to refer, delays and substitution

Gatekeeping by individual health practitioners, whether intentional, well-intended or otherwise, is a major barrier to making a viable AD request. Doctors' orientation to addressing medical/physical symptoms can result in referral to palliative care, rather than actioning the AD request, whereas mental health professionals and social workers tend to focus on psychological motives, such as a desire to control the circumstances of death or a belief that life is now pointless, resulting in pursuing the AD request.⁴⁶⁰

Significant delays by doctors in actioning AD requests remain common across jurisdictions.⁴⁶¹ While all except the Netherlands statute have a conscientious refusal provision for health practitioners,⁴⁶² conversely none requires health practitioners to advise a client of their opposition to AD or a moral conflict of interest, nor to desist from discussing

⁴⁵⁹ Kahneman, above 231.

⁴⁶⁰ Ganzini and others, above n 123; Pasman and others, above n 125.

⁴⁶¹ Sheahan, above n 133.

⁴⁶² The Netherlands statute omitted a specific provision, because it was already well understood that a doctor can conscientiously object to undertaking any medical procedure (except of course to save a person in a life-or-death medical emergency).

AD with a seeker given their bias, so it remains unclear just how many initial or repeated requests are stymied either by doctors ignoring requests or seekers declining to discuss their wish with a clearly oppositional attending doctor.⁴⁶³ As noted earlier, only the Québec law requires declining doctors to make a referral (section 31). The Belgian statute requires doctors to make a referral only if the seeker requests it explicitly (section 14), and the other statutes place the onus for finding another doctor on the seeker. Only the Belgian statute requires doctors to give reasons for declining requests (section 14), and no statute provides for information to seekers about whether or how they may reapply.⁴⁶⁴ None of the statutes provides for referral where there is no health practitioner available in a facility or service to action a request, an omission now used by Québec hospices to opt out of AD altogether (see Part 1).⁴⁶⁵ In the absence of a legal requirement to make a referral, the right of conscientious refusal can easily result in “the patient’s values and preferences becom[ing] subordinated to the physician’s”.⁴⁶⁶ While good practice guidelines would expect a doctor to refer an AD request, like any other legal and reasonable treatment request, to a professional who will action it, in many instances that does not occur. Palliative care doctors in all jurisdictions were identified as routinely “tak[ing] their patients hostage” by responding to AD requests with information criticising AD and recommending only treatment alternatives, and delaying seekers’ formal requests for days or weeks,⁴⁶⁷ a response described by James Childress as “evasive non-compliance”.⁴⁶⁸ Some palliative care doctors with a strong Christian belief considered it their duty to take into account the spiritual and redemptive benefits of suffering for both seekers and their families.

I’ve seen some very valuable things happen for families in those last days and hours, especially for families with some old problems in their relationships... If they had assisted suicide then none of that would happen and the family would be left with many problems. One research here [Switzerland] shows that the families often have the symptoms of post-traumatic stress disorder after a [assisted] suicide, so it is our duty to give them time to talk about those things.... *Palliative care doctor*

Many research participants perceived that this kind of paternalism was common in end-of-life care due to the particular emotional frailty of dying people and their families, together with some of the philosophical tenets of palliative medicine and the normative role of

⁴⁶³ Participants’ comments; Lewis and Black, above n 395; Loggers and others, above n 137.

⁴⁶⁴ The Tasmanian Bill requires the former of these (section 20) but not the latter.

⁴⁶⁵ Owen Dyer “‘Euthanasia kits’ are prepared for Quebec doctors as palliative care centres rebel on right to die” (2015) 351 BMJ h4801.

⁴⁶⁶ Sheahan, above n 133, at 47.

⁴⁶⁷ Participants’ comments; Gamondi and others, above n 199; Onwuteaka-Philipsen and others, above n 395.

⁴⁶⁸ Childress, above n 249.

medical specialists as the ultimate clinical decision-makers. Oregon researchers found that doctors responding to patients' requests frequently found those conversations challenging to their communications skills, their willingness to talk about dying and AD, and their expertise, with some seeing clients' rejection of their recommendations for alternative end-of-life options as a failure on their part.⁴⁶⁹ Doctors can be unwilling to refer a 'problem' case to a colleague or feel concerned that they might look either incompetent or, ironically, judgmental.⁴⁷⁰

As described earlier, some doctors simply avoid explicitly declining a request. When the seeker is later ready to die and reiterates their request, they find that the initial request has not been recorded, leaving insufficient time then for the assessment process or resulting in seeker ineligibility due to incipient dementia or confused thinking as a result of increased medications in the interim. Many first requests are declined by doctors on grounds of perceived mental incompetence, rather than referring the seeker for a competence assessment.⁴⁷¹ Although these practices were known to occur often, and even though the Oregon statute makes it an offence to frustrate a seeker's request (s 127.995(2)), no research participant knew of any doctor who had been reprimanded or even questioned over the practice. Ironically, the failure of a seeker to pursue their request further often reinforced the declining doctor's belief that the person did not really want AD.⁴⁷²

A related gatekeeping strategy identified by research participants across jurisdictions was the use of CPS in place of AD by doctors unwilling to engage in AD. Amongst palliative care doctors, who commonly hold the belief that good palliative care is sufficient to address all suffering, AD requests often result in doctors giving sedation, mild at first and then increased, ostensibly to address pain and other refractory symptoms,⁴⁷³ but presumably knowing that doing so will be likely to impair mental competence. Kahneman describes this response as 'substitution', where someone avoids the actual question - 'can I provide AD?' – and substitutes a question that is easier (for them) to answer – 'how can I relieve this

⁴⁶⁹ Dobscha and others "Oregon physicians' responses to requests for assisted suicide: a qualitative study" (2004) 7(3) *J Palliative Med* 451.

⁴⁷⁰ Participants' comments; Chambaere and others, above n 119; Smets, above n 146.

⁴⁷¹ Participants' comments; Van Wesemael and others, above n 429; Lorenz Imhof and others "Content of health status reports of people seeking assisted suicide: a qualitative analysis" (2011) 14 *Med Health Care Philos* 265.

⁴⁷² Participants' comments; Smets, above n 146.

⁴⁷³ Participants' comments; Gamondi and others, above n 199; Smets, above n 146.

person's suffering and still act within my own morality?'. This strategy is also common amongst doctors in Wallonia, who commonly give sedation involving large overdoses of sedatives such as morphine and benzodiazepine and then characterise that treatment as CPS so that they do not see themselves as providing AD and are therefore not required to report on an assisted death.⁴⁷⁴

It's a way for doctors to give euthanasia with, you say, a clear conscience, and they don't have to fill in the certificates or make a report. So that way they don't have to be nervous about if they have obeyed the law, because the law doesn't apply to them. We have even heard from families that the patient was told that they couldn't have euthanasia because they didn't have a terminal illness, but I think every doctor in Belgium knows by now that the patient doesn't have to be terminally ill. It's their [doctors'] way to avoid the law. But if it isn't what their patient wanted, then it's very unethical, I would even call it dishonest. The best would be if deep sedation was also regulated. *Belgian ethicist*

Many research participants commented on the role of 'big pharma' and the aged care industry in keeping dying people, often comatose or dementing, alive as long as possible, often against the wishes of their families and to the dismay of the staff caring for them.⁴⁷⁵ Some thought it no coincidence that the most vocal opposition to AD came from religious organisations that had significant investment in the hospice industry, or that senior office holders and other influential people in many medical associations who were in a position to influence policy also had strong affiliations to churches overtly opposing AD.⁴⁷⁶ A 2014 US report drew attention to "warehouses" of dying people and the role of the aged care industry in that situation,⁴⁷⁷ concluding that "Financial incentives built into the programs [for] people with advanced serious illnesses - Medicare and Medicaid - encourage providers to render more services and more intensive services than are necessary or beneficial",⁴⁷⁸ and that "timely referral to palliative care appears slow".⁴⁷⁹ The report recommended urgent improvement in advance care planning to avoid inflicting prolonged and painful deaths on vulnerable people. To ensure genuine respect for personal autonomy, many commentators

⁴⁷⁴ Kenneth Chambaere and others "Differences in Performance of Euthanasia and Continuous Deep Sedation by French- and Dutch-Speaking Physicians in Brussels, Belgium" (2010) 39 *J Pain Symptom Manage* e5; Smets, above n 146.

⁴⁷⁵ Participants' comments; see also Mary Adelaide Mendelson *Tender Loving Greed: 2009 notes* (One-Off Press, Prescott, Arizona, 2009); Peter Whoriskey "'Warehouses for the dying': Are we prolonging life or prolonging death?" *Washington Post* (online ed, Washington, 12 December 2014).

⁴⁷⁶ For example, presidents, board members and members of ethics committees.

⁴⁷⁷ Institute of Medicine of the National Academies *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life: Key Findings and Recommendations* (2014).

⁴⁷⁸ Chapter 5 (no page numbers provided).

⁴⁷⁹ *Ibid.*

wish to see CPS and terminal sedation regulated as AD is,⁴⁸⁰ as has occurred in Québec's statute (ss 24-25) and is being considered in the forthcoming Canadian legislation.⁴⁸¹

3.10 Issues for participating doctors

Approximately half of the research participants were doctors who (amongst other roles) have been involved in delivering AD services. They emphasised a range of challenges for doctors engaging in AD that can also become barriers to continuing their participation, in particular the emotional impact from the lead-up, administration and then after the death, which results in many doctors limiting their availability.⁴⁸²

You have to love your patient a little bit to do this for them, because this is not a natural job for a doctor. Most doctors can only do it only three or four times a year, and we [SCEN] have very careful processes to be sure that everyone who does it [AD] receives some counselling after. They must have that. Sometimes I have known the person for more than 30 years, and of course you have very strong emotions as you go with them through making their decision, so it is like a good friend dies and it was *you* who made that to happen, and it needs some time to get over it. *Participating Netherlands doctor with 20 years AD participation*

4 What enables a viable AD request, and what more is needed?

There appear to be three crucial actions in having an AD request accepted for processing: a clear, assertive, persistent initial request by the seeker; making the multiple requests required within the required time frame; a doctor both willing and competent to recognise and action the request. The various jurisdictions have developed a range of strategies to facilitate making a timely request and having it actioned, with varying degrees of effectiveness.

As for Part 1, critical enablers needed to support effective and timely actioning of AD requests are summarised in **Table 2**, together with suggested legislative and/or regulatory provisions that might address each.

⁴⁸⁰ Participants' comments; Livia Anquinet and others "Similarities and differences between continuous sedation until death and euthanasia – professional caregivers' attitudes and experiences: A focus group study" (2013) 27 Palliat Med 553; Udo Schüklenk and others "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) 25(S1) Bioethics 1.

⁴⁸¹ P-TEAG Report Recommendation 1.

⁴⁸² Participants' comments; Sheahan, above n 133.

4.1 Making a clear formal request

The key factors in successfully expressing a request are the seeker knowing what is required legally and having the capability to meet those requirements, and a doctor who will recognise and record the request. Seeker attributes identified as enabling a request being accepted are a higher education level, having an advocate, having no current or previous depressive symptoms, being under age 80, and being male.⁴⁸³ Having an advance care plan and choosing an end-of-life provider that clearly supports AD are together probably the best guarantee of having an AD request actioned.

Without statutory provisions delegating responsibility for public information access, the information on the relevant government health agency websites is generally limited to lists of hyperlinks to the required forms, with little or no clarification of the due care requirements or processes.⁴⁸⁴ The most comprehensive information is found on the respective AD provider agencies' websites,⁴⁸⁵ which publicise AD availability and request requirements. All provider agencies have freephone numbers for easier contact, though only during working hours, and some send out free information packs. EXIT Suisse Romande has a DVD available for purchase that explains the request and assessment requirements, and Compassion and Choices in Oregon advertises for sale the film *How to die in Oregon*,⁴⁸⁶ which illustrates all of the processes required. Some European providers offer regular seminars and conferences open to the public. The Swiss RTD membership system was designed to ensure, inter alia, that both the general public and active seekers receive accurate and simple information about the request, eligibility and assessment requirements, variously based on each provider's homegrown policy.

Although these agencies make essential information available, they are constrained by limited finances and typically rely on online communications, which may not be an accessible medium for many of the current over-70 generation. The seeker must initiate contact with the agency, directly or indirectly, to avoid accusations that the agencies are

⁴⁸³ Onwuteaka-Philipsen and others, above n 395; except in Switzerland, where females received AD somewhat more often, see Steck and others, above n 344.

⁴⁸⁴ See for example <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>; www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct.

⁴⁸⁵ The relevant Netherlands Ministry has brief general material about AD on its website, see Ministry of Health, Welfare and Sport "Euthanasia" www.government.nl.

⁴⁸⁶ Collective Eye Films, above n 317.

purposely influencing vulnerable people. Not everyone in an end-of-life care facility will have access to a phone to call the agency for clarification, and in no jurisdictions has the relevant health authority published paper materials. Brochures are expensive and difficult to disseminate in a targeted way where a majority of the end-of-life providers are faith-based organisations that decline such materials on their premises. Internet access may be difficult, and the website home pages typically contain a lot of information and euphemistic language that can make it confusing for seekers to identify what, exactly, is provided. The provider agencies acknowledge that the websites are most useful to people planning well in advance of need and less useful to seekers at end of life. Moreover, a review of the information on the websites undertaken as part of this research revealed that it is sometimes confusing and occasionally internally inconsistent or outdated.

None of the statutes requires any government health authority to make accurate, or any, information about AD available to target audiences. As an innovation, the Québec statute alone delegated responsibility to end-of-life providers for having written policy on all end-of-life treatment options available in their facilities and home-based services, “consistent with ministerial policy directions”, and for providing that information to both actual and prospective service users and staff (ss 8, 13 and 15). However given the widespread boycott by those organisations of the new law,⁴⁸⁷ possible because the conscientious refusal provision only applies to wholly government-funded providers, those information provisions may be stymied. As long as faith-based providers continue to decline participation in legal AD, stronger provisions are needed in both existing and new statutes. Provisions intended to enable access by seekers are ineffective if the conscientious refusal clauses allow providers to opt out of all participation without referring [**\$1.V**].

A key factor in the credibility of public health information to health practitioners and the general public is government endorsement.⁴⁸⁸ Since the groundwork for compiling sound, evidence-based information has already been done by the AD provider agencies, it would be straightforward for a statute to require the relevant national or regional health

⁴⁸⁷ Dyer, above n 465; personal communication, Yves Robert, Secretary, Collège des Médecins du Québec, Québec, January 2016.

⁴⁸⁸ Krisandra S Freeman and Jan H Spyridakis “An examination of factors that affect the credibility of online health information” (2004) 51(2) Technical Communication 239. Whole websites are now dedicated to providing guidance on which internet sources are credible, and they generally advise, rightly or wrongly, that government sources can be considered credible; see for example “How to Search & Determine Credible Sources on the Internet” Who is hosting this? <www.whoishostingthis.com>.

authorities,⁴⁸⁹ in collaboration with the statutory health practitioner regulatory bodies, to produce and facilitate dissemination of evidence-based information about AD, including the required processes, clearly explained, and the forms [§1.III]. Such information should be tailored respectively to these key audiences and disseminated through media appropriate to each, as commonly occurs with health services generally [§1.III]. As in Québec, end-of-life providers should be required to make that information available as standard practice to all actual and prospective service users, as well as on request [§2.III].

Taking a lead again, the Collège des Médecins in Québec is constructing a communications strategy to develop audience-specific information about AD and guidelines for both seekers and health practitioners on facilitating appropriate access. Consistent with Collège policy, that information will be in both official languages. Research participants across jurisdictions stressed the importance of having information available in all languages commonly used in the jurisdiction, which could also be mandated in the statute [§1.III] and implemented at minimal cost given that many AD provider agencies already provide such information in multiple languages.

Most of the AD statutes set out provisions to ensure that people with physical or medical disabilities preventing writing can receive proxy assistance to sign the required written request, but there is no equivalent provision for people unable to speak, such as people with mouth cancers or various neurological conditions inhibiting clear speech. Ideally, a statute would also permit an ‘oral’ request to be made through an interpreter or sign language, so that people with impaired speech can still convey their requests in compliance with the law [§2.VI]. Alternatively, requests might be filmed to demonstrate voluntariness and informed consent and digital recordings kept of those events [§2.VI]. Where interpreters are needed, the statutory provisions should exclude anyone from that role who is not sympathetic in principle to AD for the particular seeker [§2.VI]; for example, religious officials have been found to not always faithfully represent the wishes of people for whom they provide informal interpreter services, in particular women.⁴⁹⁰

Statutory provisions to enable health practitioners’ willingness to acknowledge an AD request and action it, including referral, could include recording of *all* requests, recording

⁴⁸⁹ The term ‘health authority’ henceforth refers to a national or regional government health authority.

⁴⁹⁰ Personal communication, Belgian ICU doctor working with Muslim migrant communities.

all *first* requests in writing and registering them with the health authority, a mandatory response to action a first request,⁴⁹¹ mandatory provision of information on *all* end-of-life treatment options in response to a first AD request, and a broad definition of a ‘request’ [§1.VI]. These provisions would help ensure that seekers who are insufficiently assertive or articulate to bring their request to the attention of a reluctant doctor will have that request, however ambiguous, actioned for at least the purposes of discussion. Compassion and Choices volunteers’ first advice to seekers is to ask to have their *every* request recorded on their medical records, as evidence of a persistent wish, and to ask to view that record at each occasion. Given human fallibility and staff with busy workloads, together with the frequent physical, emotional and sometimes cognitive frailty of seekers, recording of a seeker’s first request in writing, within a required time frame (24 hours), and then also lodged with a health authority via an online mechanism, would ensure that a process was initiated to provide the seeker with comprehensive information about all end-of-life options from a doctor supportive in principle of all of those options [§1.III]. There is no disadvantage or coercive impact from such a recording regime, since seekers can withdraw a request or simply let it lapse at any time, and all statutes require the assessing doctors to ensure that there has been no undue influence on the seeker’s decision-making. It also gives doctors permission to have a broad discussion with seekers about end-of-life options and encourages that conversation at an early stage.

Standardised forms are provided in most jurisdictions, either by statutory regulations or by the AD provider agencies, to ensure that the request is clear. The Netherlands do not require a written request (except for minors), but both doctors and seekers generally prefer that one is made through an advance directive, because that clarifies the seeker’s broad treatment wishes unequivocally, and verbal requests must be recorded, placing the onus on the health practitioners to maintain the record. While this system works well generally, omitting a written request leaves seekers vulnerable where the end-of-life provider opposes AD or a seeker changes provider.⁴⁹² As in Switzerland, advance planners protect against opposition by joining the NVVE to lodge an advance directive confirming their wish for AD.

⁴⁹¹ For example, the New Zealand abortion law requires that the first doctor receiving an abortion request “arrange for the case to be considered” (section 32(1)).

⁴⁹² See Cobi Geluk case, p 43.

Nurses and volunteers interviewed highlighted the importance of having a “champion” or supporter to make sure requests were actioned.

I think without me and one other nurse, she [seeker] could not have received her wish. Even with us helping her it was a very long time, because the doctors did not see that she was clear in her wish... because they did not see her in the day or at the meals, and when they did see her, that would make her very angstig [nervous], so they would think that she was not sure. But we knew that she was sure, because when we talked with her she was calm, and she would say this wish every day, so we would say, OK, you must tell the doctor again, and she could feel strong from that help. Many women are like this when they are with the doctor. *Netherlands hospice nurse*

The potential for mandating the availability of a seeker advocate has not been explored previously, but research participants showed interest in this concept, recognising that the current AD provider agency advocates are a crucial enabler for many people seeking AD, but are hampered in that role by lacking any legal mandate to enter hospice premises or support seekers when family oppose. The volunteer role varies somewhat across jurisdictions but is well developed in each place, including job descriptions with clear role boundaries, codes of ethics, robust training programmes to ensure accurate knowledge of the legal and practical requirements, mentoring systems to ensure volunteer safe practice and personal safety, and recruitment practices that have a preference for people who have professional experiences in the health or social services sectors. A government-mandated advocate system might be contracted to the AD provider agencies, as are many other health support programmes currently, and provided at low cost by continuing to use volunteers. To make advocacy available in all instances, the statute would need only to provide for the relevant health authority to fund (potentially partially) and have oversight of contracted advocacy services, and establish a requirement that all first requests require recording, which would in turn trigger a registered advocate to contact the person making the request. This role would relieve families of the advocacy burden and ensure that seekers were aware of the requirements for their request to be actioned and for them to receive accurate and non-partisan information. It would also avoid compromise to conscientiously objecting health practitioners, whose participation would not be needed. The recent P-TEAG Report recommends a ‘patient navigator’ to undertake such a role (see p 137).

4.2 Making the requests in time

Four main factors can make a timely AD request problematic: people’s wish to hold onto life and their reluctance to make a formal request before they and their family are ready

emotionally; doctors' tendency to exaggerate the prognosis estimate; confusion over the legal request requirements; and doctors' unwillingness to action AD requests on conscience or other grounds. The first three factors can be addressed through good provision of information and training for health practitioners (see below). However the statutes need to provide for avoiding delays due to conscientious refusal by health practitioners without early referral.

4.2.1 Addressing conscientious refusal

Many theorists and ethicists now propose that health care professionals, having chosen these professions in awareness of the fiduciary obligations, have a responsibility to facilitate, if not carry out, acts in the best interests of the person,⁴⁹³ arguing that "Patients are entitled to receive uniform service delivery from health care professionals [and] ought not to be subjected to today's conscientious objection lottery",⁴⁹⁴ especially in countries where the population is dispersed over vast distances limiting doctor access.⁴⁹⁵ Some are making a distinction between conscientious objection based on universal moralities and that based solely on religion,⁴⁹⁶ suggesting that "Conscience clauses today are by and large a concession of special rights to Christian health care professionals, at least in secular Western democracies".⁴⁹⁷

To date the statutes have framed their conscientious refusal provisions so that not only individual practitioners but also whole organisations are able to opt out of AD participation entirely and without a requirement to refer to another doctor, provider or facilitating agency, creating possibly the biggest single barrier to requests being made in time for effective processing. That is, evasive non-compliance frustrates not only the seeker's wish but the very purpose of the laws. Following the *Carter* decision, the College of Physicians and Surgeons of Ontario, anticipating this problem based on earlier responses to abortion legislation, issued a directive under its Professional Obligations and Human Rights policy that, based on the fiduciary responsibility of a doctor to act in the "patient's best interests",

⁴⁹³ Carolyn McLeod and Jocelyn Downie "Let Conscience Be Their Guide? Conscientious Refusals in Health Care" (2014) 28(1) *Bioethics* ii.

⁴⁹⁴ Udo Schüklenk "Conscientious objection in medicine: Private ideological convictions must not supersede public service obligations" (26 March 2015). <<http://ethxblog.blogspot.com.au>>.

⁴⁹⁵ External Panel Report, above n 296.

⁴⁹⁶ Margaret Otlowksi *Voluntary Euthanasia and the Common Law* (Oxford University Press, Oxford, 2000); Daniel Weinstock "Conscientious refusal and health professionals: does religion make a difference?" (2014) 28(1) *Bioethics* 8.

⁴⁹⁷ Schüklenk, above n 200.

conscientious objectors must make “an effective referral... in good faith, to a non-objecting, available and accessible physician, other health-care professional, or agency”.⁴⁹⁸ The policy is already being challenged by faith-based opponents of AD.⁴⁹⁹ Commentators generally conclude that there is a need for more discussion to find a solution that will meet the interests of all parties.⁵⁰⁰

Several statutory provisions would help to ensure that seekers’ wishes are not frustrated solely because of what James Childress describes as “evasive non-compliance”.⁵⁰¹ Conscientiously objecting or opposing doctors should be required to declare that position and its implications to seekers at first request for information or discussion and offer to refer the seeker immediately [§1.V], so that “any ongoing treatment of the patient [will] be provided in a non-discriminatory manner”.⁵⁰² Ideally, the statutes would also invite refusing doctors to register their refusal to AD participation with a health authority and their employer [§1.V], so as to make their opposition and unavailability known to seekers, avoid their being compromised by requests, and reduce the potential for frustration of seekers’ goals by health practitioners who purport to be well-intended. To diffuse the argument made by some doctors that referral itself constitutes an act supporting AD, practitioners declining a seeker’s request might be required only to advise their refusal, explicitly and within a specified time limit, to both the seeker and a point of registration (employer or online ministry register) [§2.V],⁵⁰³ that will then act on that refusal to provide a timely response to the seeker. Of course a refusal could be retracted at any time, and registering such a refusal should not (could not, feasibly) be mandatory, but where a doctor registers a refusal in an individual instance, their name could be added automatically to the register of refusing doctors, with an annual invitation inviting them to have it removed [§2.V]. Where the majority of health practitioners in an end-of-life provider’s facility or programme are registered as refusing, the provider should be required by the statute to have a locally feasible system for an effective referral [§1.V].

⁴⁹⁸ College of Physicians and Surgeons of Ontario “Professional Obligations and Human Rights Policy Statement #2-15 (September 2008, Updated 2015) <www.cpso.on.ca>.

⁴⁹⁹ BioEdge “Ontario doctors squeezed on conscientious objection to assisted suicide” (18 September 2015) <www.bioedge.org>.

⁵⁰⁰ Participants’ comments; Jacquelyn Shaw and Jocelyn Downie “Welcome to the Wild, Wild North: Conscientious Objection Policies Governing Canada’s Medical, Nursing, Pharmacy, and Dental Professions” (2014) 28 *Bioethics* 33.

⁵⁰¹ Childress, above n 249.

⁵⁰² P-TEAG Report, above n 277, Recommendations 32-33, at 44.

⁵⁰³ See for example the Québec statute s 31 requiring notice to the employer or “designated person”.

Ideally, statutes would delegate responsibility to appropriate medical regulatory bodies to ensure that medical guidelines and standards are developed specifically for refusal and referral that emphasise the importance of doctors adhering to “good medical practice” principles of desisting from imposing personal beliefs on seekers or expressing disapproval overtly or covertly [§1.XI].⁵⁰⁴ The statute might adopt the provision of New Zealand’s abortion law that doctors participating in AD not be “coloured by views in relation to [health service] generally that are incompatible with the tenor of [the] Act” (section 30(5)).

Requiring all end-of-life providers to make their policy on AD provision known to both actual and potential service users also needs to be mandated, as in the Québec statute, and ideally the parameters of that policy should also be regulated, so that it is clear exactly which procedures may and may not occur under the particular provider’s policy [§2.III]. The importance of doctors knowing their employer’s policy was recognised early by some providers. The Seattle Cancer Care Alliance in Washington developed policy on AD participation even before their legislation came into force, advising doctors specifically that they could initiate conversations about AD with clients. Some federally-funded hospitals in the US states providing end-of-life care initiated referral relationships with the AD provider agencies, realising that they were likely to receive AD requests. In Belgium, the umbrella organisation for Catholic end-of-life providers, Caritas, requested all member providers to develop clear policy to avoid misunderstandings between health practitioners and service users. In addition to enabling seekers’ requests, such provisions may help in persuading ambivalent providers to consider effective collaborations with permitting providers or even to reconsider their policies, especially as the future demand for end-of-life care will come from an increasingly secular population in virtually all jurisdictions where AD is legal currently and where Bills are pending debate. In Flanders, the AD provider agency initiated a collaboration with the three palliative care associations, recognising that a rejection of AD by palliative care practitioners was causing significant distress to seekers, that resulted in a joint strategy for responding to seeker requests and modified policy by those associations. Since 2013 half of assisted deaths in Flanders occur with some support from palliative care doctors, permitting deaths in palliative care facilities and involving almost all palliative care

⁵⁰⁴ Medical Council of New Zealand “Good Medical Practice” (April 2013) <www.mcnz.org.nz>, ss 19-21; General Medical Council (UK) “Good medical practice” (25 March 2013) <www.gmc-uk.org>, s 52.

facilities and programmes in Flanders.⁵⁰⁵ Swiss palliative care doctors were keen to have a discussion of this kind with EXIT.⁵⁰⁶ Hospice personnel interviewed identified some relaxing of the prohibition in Catholic facilities on staff participation in AD, attributing that partly to the strength of individual staff who have quietly persisted in exercising their professional ethics, partly to the RTDs having brought the issue to public attention, and significantly to an awareness that the baby-boomer generation are highly informed consumers generally. Discussion within and across the end-of-life care professions can be facilitated through the legislation by requiring the regulatory bodies to produce practice standards and guidelines [§1.XI], since they are unlikely to do so without consulting with the medical associations and colleges.

None of the existing statutes has a clear complaints or appeals process for seekers who believe that their requests are being avoided or delayed unnecessarily. The Québec statute has a general provision for complaints (s 48) that can be made by “any person” about the statutory requirements of providers. In principle that might permit a seeker to complain that they have not been provided with sufficient information about AD on request, but the process and available remedies are not specified (discussed further in Part 3).

4.3 Finding a willing and competent doctor

There will always be a cohort of doctors who remain morally opposed to AD; however the research on doctor support for AD in principle suggests that at least half of doctors in most jurisdictions are potentially willing to become involved.⁵⁰⁷ There was a consensus amongst doctors interviewed that, to participate in AD services, doctors need above all to feel morally comfortable, competent and safe, and to achieve that, they need ethical permission and reassurance, knowledge, skills and experience, and clarity about immunities against punitive sanction. Key factors identified as promoting doctor engagement were clear immunities from prosecution and stigma, the endorsement of a medical professional body, strong guidelines, good training and mentoring for becoming involved in AD in a graduated way through hands-on experience, and a supportive delivery infrastructure to ensure all of these factors. These features could all be provided for through statutory provisions for the

⁵⁰⁵ Paul Vanden Berghe and others “Assisted dying - the current situation in Flanders: euthanasia embedded in palliative care” (2013) 20(6) *Eur J Palliative Care* 266.

⁵⁰⁶ Gamondi and others, above n 199.

⁵⁰⁷ Seale, above n 128; Kane, above n 446; William Lee and others “Survey of doctors’ opinions of the legalisation of physician assisted suicide” (2009) 10(1) *BMC Med Ethics* 2.

government health authority to have responsibility for ensuring “sufficient” and “competent” assessing doctors [§2.V], as does the New Zealand abortion legislation (see p 165).

4.3.1 Immunities and compliance

Statutory immunities are pivotal to professionals participating in AD. All statutes provide explicit or implicit (Québec) immunity from criminal liability provided that actions are undertaken “in good faith” (US and Swiss provisions) and/or without negligence (Switzerland, Netherlands and Belgium). The US statutes provide explicitly for doctor immunity from both criminal and civil liability in relation to all AD functions including expressly attendance at an assisted death (s 127.885 §4.01(1)), and also provide immunity from “censure, discipline, suspension, loss of license, loss of privileges, loss of membership or other penalty for participating or refusing to participate in good faith compliance” with the statutory provisions (s 127.885 §4.01(2)). Despite these express immunities, the continuing opposition of the medical associations in both states and federally keeps doctors anxious about participation.⁵⁰⁸ The Swiss Penal Code provision (Article 115) does not protect doctors from civil liability or professional sanctions, and the opposition of SAMW deters doctor engagement. In contrast, even though the Netherlands and Belgian statutes do not provide immunity from civil prosecution or professional sanction, the intimate involvement of the RDMA in the implementation of the law encourages confidence that doctors who either read the RRC reports or engage a SCEN doctor are unlikely to make mistakes that attract litigation or reprimand.

Research participants believed that enhancing doctor participation required explicit statutory provision for criminal and civil immunity and for immunity from a range of potential sanctions by employers and professional bodies [§2.V]. Those provisions needed to extend to participating mental health professionals and other health care practitioners taking part in any AD role or function [§2.V], whether the medical and other professional bodies were engaged in AD regulation or not. Making immunities visible is a feature of the US statutes and more recent Bills, which also include protections against doctors being sanctioned by their professional bodies provided they comply with the law in good faith. In the Benelux statutes civil and criminal immunities are ensured through amendments to the

⁵⁰⁸ Participants’ comments; Birnbacher and Dahl, above n 437.

penal codes, but not otherwise stated in the statute. To allay doctors' fears in Québec, where the statute contains no explicit criminal or civil immunities and Canadian federal law in 2014 still made assisting a suicide a crime, the Québec Attorney-General made repeated public reassurances that doctors in Québec complying with the new law would not be prosecuted.⁵⁰⁹

There is a conceptual inconsistency in the current laws in that they protect health practitioners from being required to participate in AD but not from explicit or implicit coercion from others (colleagues, employers) to abstain. Ideally, to encourage participation, an AD statute should contain not only immunities from civil and criminal liability but also visible protections for participating practitioners from negative sanction or pressure from employers, colleagues and professional associations [§2.V]. These protections need to be supported by both penalties for overt or implied coercion to prevent health practitioner participation and an easily accessible process for complaints about such attempts, for example through a health ombudsman or a complaints body established by the statute [§2.V] (see Part 3).

To genuinely facilitate seekers' and health practitioners' access, research participants wanted the laws to have "teeth". Compliance mechanisms are weak in the existing statutes, apparently on the assumption that health practitioners will honour the principles of client-centred care and autonomy. While each jurisdiction does have a reporting requirement for completed assisted deaths, none contains any mechanism for complaining about the failure of a health practitioner to record or refer an AD request. Research participants believed, and the law recognises generally, that statutory provisions mandating particular actions are likely to need an effective enforcement mechanism, or the provisions themselves are of little use. Sandra Johnson suggests that penalties for doctors who fail to comply with the law should where appropriate be educative, rather than punitive, and graduated to the severity of the breach [§1.XII].⁵¹⁰ While this may be problematic where doctors have a conscientious objection to education on AD participation, acceptable options might include training as an appropriate conscientious refusal response. A statutory requirement that end-of-life care providers have AD policy consistent with the statute and make it known to staff

⁵⁰⁹ Paola Loriggio "“No repercussions” for Quebec assisted-dying law under new Liberal government” *National Post* (online ed, Toronto, 5 November 2015).

⁵¹⁰ Johnson, above n 143.

could also protect participating health professionals from coercion [§2.III]. The absence of complaints and appeals provisions in the statutes is discussed further in Part 3.

4.3.2 Education and training

Training for AD participation is currently provided across jurisdictions by the AD provider agencies on an ‘apprenticeship’ basis. However good that training might be, the lack of accredited education and training in AD practice was identified by research participants as a major disincentive to participation. Internationally there is an expectation that medical training will be formally accredited through both national and international accreditation providers, and doctors and health providers alike rely on accreditation standards as an indicator of quality education and evidence-based knowledge.⁵¹¹ These expectations apply to both undergraduate and continuing medical education, and doctors generally expect that the latter will be linked to their registration programme. In contrast, the AD training available is largely apprenticeship-based and delivered by doctors who are not trained or employed as medical educators. Although apprenticeship might in fact be an ideal training model for AD participation (see below), it can lack credibility to doctors who are already fearful of making mistakes that could cost them their livelihood.

A best practice approach to providing AD training would be to include it in the core medical and nursing curricula for end-of-life care. However that area is seen as seriously and chronically under-represented in medical and nursing curricula internationally.⁵¹² Swiss palliative care doctors interviewed were keen to have training in how to respond to AD requests appropriately, feeling that they currently lacked skills for that role. End-of-life medical academics across jurisdictions commented that AD is raised inevitably by health practitioners wanting to discuss it in both undergraduate and continuing education contexts. The training being developed by the Collège des Médecins in Québec recognises the need for it to be holistic, focusing as much on the emotional and spiritual as logistical aspects of the AD process.⁵¹³ Some commentators have suggested that guidelines and training for participating health practitioners need to have a multidisciplinary focus, acknowledging the

⁵¹¹ Participants’ comments; Hans Karle “Global Standards and Accreditation in Medical Education: A View from the WFME” (2006) 81(12) Acad Med S43; World Federation For Medical Education *Basic Medical Education: WFME Global Standards for Quality Improvement. The 2015 Revision* (WFME, Ferney-Voltaire, 2015).

⁵¹² Participants’ comments; Christine Cowgill “Urgent Need for Better End-of-Life Training” *Today’s Geriatric Medicine* (November-December 2015) <www.todaysgeriaticmedicine.com>.

⁵¹³ Personal communication, Collège des Médecins, August 2015; Dyer, above n 465.

roles of not only nurses but also other participating professionals such as social workers and nurse aides.⁵¹⁴ To date only the Québec statute has included provisions for AD training for doctors to be the responsibility of a statutory body,⁵¹⁵ although the SCEN training in the Netherlands (discussed below) has credibility because it is endorsed by the RDMA. As a minimum, the statutes need to delegate responsibility to the relevant medical registration bodies for development of accredited practice standards, robust practice guidelines and training programmes for AD [§1.XI].

4.3.3 Recruitment and capacity-building

Doctor recruitment occurs in four main (overlapping) ways: a small minority of doctors with a strong personal conviction actively initiate engagement through the AD providers; some doctors engage through responding to seeker requests; some are recruited by colleagues; and some are invited to engage when they make seeker referrals. For doctors wanting information about the legal requirements or other processes, the US AD provider agencies' websites advertise a *Doc2Doc* programme that includes a free information pack and a free phone consultation with one of the agency's experienced volunteer doctors; the European AD providers recruit more by word-of-mouth.

While enlisting willing doctors remains an issue in all jurisdictions, engagement appears highest in The Netherlands, due significantly to the establishment of the SCEN organisation.⁵¹⁶ SCEN was established in 1997, initially as a pilot project, in recognition that, given the strength of the family doctor system in The Netherlands, it was likely that they would be called on most to provide legal AD and most would need support. The project was set up by NVVE in collaboration with the RDMA, with some government funding, to train and register mostly family doctors to undertake the consulting doctor role under the Netherlands statute and to mentor other doctors to undertake the attending doctor role. Although some administrative roles are paid, SCEN doctors provide their services for a small stipend, making the service low-cost. SCEN doctors receive initial 3-day training and regular update training in all of the legal and medical requirements for AD under the

⁵¹⁴ Els Inghelbrecht and others "The role of nurses in physician-assisted deaths in Belgium" (2010) 182 CMAJ 905; GG Van Bruchem-van de Scheur and others "The role of nurses in euthanasia and physician-assisted suicide in The Netherlands" (2008) 34(4) J Med Ethics 254.

⁵¹⁵ The Association des conseils des médecins, dentistes and pharmaciens du Québec (ACMDPQ).

⁵¹⁶ For a detailed description of SCEN functions, see Marijke C Jansen-van der Weide, Bregje D Onwuteaka-Philipsen and Gerrit van der Wal "Implementation of the project 'Support and Consultation on Euthanasia in The Netherlands' (SCEN)" (2004) 69 Health Policy 365.

Netherland statute and in the practical aspects of providing AD services, as well as in how to mentor other doctors. If they demonstrate proficiency, they become registered as SCEN doctors. Allocation of SCEN doctors is rostered so that they will be independent from the requesting doctor. Initial contact is limited to daytime working hours, but once assigned to a case, the consultant provides as much support as needed to the requesting doctor, including attending assisted deaths. Many doctors interviewed commented that this apprenticeship approach to training is vital, both to ensure that doctors' first AD experience is closely monitored and mentored for safety reasons, but also because the experience of participating in or attending an assisted death is "life-changing" and commonly encourages future participation.

When a GP calls us to see a patient, we always ask them how they would like to be involved, do they want to have a part in the examination [assessment] or even give the injection. Of course, we [SCEN] are not supposed to be the, you call it the attending doctor, so we always try to encourage the GP to at the least be involved in the examination. And then later maybe they will feel comfortable also to hold the patient's hand, even if they are not the person who gives the injection. So this is how we bring more doctors to take part, one step at a time. *SCEN doctor*

We all could see that taking the drink was her strongest moment in these last years. Those other doctors [previously declining] were there because she asked them and they have the courage to be there, and after that they changed their view. And it started a new talk between the doctors and the nurses about maybe this was the right thing also for some other patients who have asked [for AD]. *Netherlands psychiatric nurse*

Evaluation of the pilot showed it to be so successful and popular that SCEN was established as a not-for-profit organisation in 2002. The brilliance of the SCEN concept is its strategy, that is, to build doctor engagement as well as provide training, and that it simultaneously addresses several potential barriers to doctors' participation. With a primary purpose of capacity-building, it provides recruited doctors with support through education, advice and mentoring, which in combination ensure safe practice. It has the backing of the RDMA, thus ensuring quality guidelines and training, as well as good governance for the organisation. Registration of SCEN doctors requires that they continue to demonstrate up-to-date expertise based on standards developed by their medical association and can therefore be identified as having proficiency for the role. Because SCEN doctors are volunteers, they cannot be accused of an economic interest, and because they are a network they also provide mentoring for one another as both learning and self-care functions. The system is so effective in both supporting doctors receiving AD requests and in undertaking the consulting doctor role that using a SCEN doctor is now widely accepted in Netherlands'

facilities as ‘best practice’ to ensure that an attending doctor complies with the legal requirements and also attends to the emotional aspects of providing AD.

The LEIF organisation in Belgium was based on SCEN and operates a similar model, though it does not (now) have government funding nor any significant input or support from the Orde der Artsen.⁵¹⁷ LEIF doctors are available to provide information to the general public as well as health practitioners, which seekers and families consider extremely useful.⁵¹⁸ The service provides attending as well as consulting doctor services, considered highly valuable by Belgian doctors.⁵¹⁹ An evaluation suggested that the SCEN/LEIF model be adopted in all places where AD is legal.⁵²⁰ However the AD provider agencies elsewhere, while admiring the model, are hindered in setting up similar services by the lack of engagement of their respective medical professional bodies. Ideally, a modified SCEN system should be mandated in the legislation and require input from the health practitioner regulatory bodies [§2.XI], to provide not only capacity-building but also consistency across AD assessments (see Part 3).

A related option might be to have a structure for registering health practitioners to provide all aspects of AD services, similar to the registration systems in some jurisdictions for abortion services. A statutory AD registration system would facilitate both public and practitioner confidence in the knowledge that participating doctors are registered by a government agency, based on accredited training and a rigorous accountability regime, and could ensure that doctors are available when needed. However such registration should not be mandatory for health practitioner participation, to avoid preventing a seeker’s family doctor or specialist from participating on a unique or occasional basis. Many research participants questioned whether the services provided by the AD provider agencies ultimately facilitate or hinder seeker and practitioner access. In the US states, AD would barely be available without these agencies, but their continuing availability is ipso facto a disincentive to doctors becoming engaged when seekers almost invariably ask their current

⁵¹⁷ The Orde der Artsen <www.ordederartsen.be>. LEIF’s funding has been primarily from the Belgian RTD, Recht Op Waardig Sterven (RWS).

⁵¹⁸ Participants’ comments; Yanna van Wesemael and others “Role and Involvement of Life End Information Forum Physicians in Euthanasia and Other End-of-Life Care Decisions in Flanders, Belgium” (2009) 44 Health Serv Res 2180.

⁵¹⁹ Yanna van Wesemael and others “Establishing specialized health services for professional consultation in euthanasia: experiences in the Netherlands and Belgium” (2009) 9 BMC Health Serv Res 220.

⁵²⁰ Smets, above n 146; the Québec Select Committee recommended that their statute establish such a system, but that did not occur.

treating doctor first. In Switzerland, the provider agencies are recognised as the ‘go to’ organisations, even though legally it is within any doctor’s remit to provide AD. AD provider agencies’ goal to ensure that AD is available only works if the agencies are well known, respected and readily accessible. In contrast, the US agencies have struggled to recruit doctors due substantially to strenuous opposition that has used the US media effectively. In The Netherlands, the SCEN mandate is deliberately limited to providing consulting doctor services, to place the responsibility on family doctors and specialists to action seekers’ requests, and other jurisdictions saw this as an ideal, but found themselves caught in a self-perpetuating cycle of inadvertently disincentivising more widespread doctor engagement in their quest to ensure that AD is available.

For the same reasons, research participants thought AD provision should not become a medical specialisation as such. Given the apparent effectiveness of the AD provider agencies’ existing doctor training and mentoring systems, those could be readily adapted into a statutory optional registration system, provided funding and an appropriate infrastructure were available (see below). Research participants thought such a system would be valuable but that their (and other) governments might be reluctant to fund it, despite the small usage.

A low cost and effective option might be to have a participating doctor register established by the relevant health authority [**\$2.V**]. The Oregon and Washington provider agencies have ‘hotlists’ of doctors who are willing to provide AD services, adding to that list as more seekers’ regular doctors become willing to participate. Those lists are kept secure to ensure that doctors are not harassed or attacked in any way. Likewise, the US statutes do not require a statement on the death certificate that a death was assisted, so avoid AD opponents identifying participating doctors from publicly discoverable death certificate information. The absence of this requirement has been labelled dishonest by some critics,⁵²¹ but is seen as necessary by participating US doctors.

A key factor affecting the Netherlands’ high AD uptake is the continuing involvement of the family doctor during a person’s end-of-life care. Netherlands family doctors receive significantly more requests for AD than specialists and nursing home doctors, requests to

⁵²¹ BioEdge “Filling out euthanasia death certificates in Quebec” (21 November 2015) <www.bioedge.org>.

family doctors more frequently result in a prescription, and they attend 40 percent of assisted deaths, even if they are not the administering doctor.⁵²² Given these evident advantages of continuity of care for AD access, it would be beneficial to legislate for family doctor involvement in the seeker's decision-making where possible, as does the New Zealand abortion legislation (ss 32(5) and 35) [§2.VII]. Similarly, the Swiss membership system means that members will have met the AD agency doctors at some time before they formally request AD. Research participants believed that ideally the attending doctor in AD would be the seeker's regular doctor, or potentially a nurse (see below), with whom they had an existing relationship, for both emotional and pragmatic reasons.

Many research participants commented on the crucial importance of participating practitioners transparently adhering to the law, to avoid any potential for accusation by opponents of a slippery slope or misuse that might further deter health practitioner participation. Compliance has largely been achieved. For example the Netherlands Regional Review Committees (RRCs)⁵²³ queried only five of 4,829 AD reports in 2013, all on grounds of less than satisfactory adherence to the due care procedures, recommending education rather than reprimand in all instances.⁵²⁴ Annual monitoring reports from the other jurisdictions have reported minimal concerns. Apart from some recent criticism of the governance, management and standards of the Federal Control and Evaluation Commission (FCEC) in Belgium,⁵²⁵ and the report of a Belgian doctor who may be prosecuted,⁵²⁶ in general there has been almost no evidence of inappropriate actions by doctors undertaking AD provision, which has encouraged doctor recruitment as well as uptake by seekers.

4.3.4 An expanded role for nurses

Having nurses more involved could increase capacity significantly for all AD tasks and potentially resolve the barrier of doctor unavailability. Many commentators have discussed a potentially greater role in AD for nurses and nurse practitioners (or physician assistants in the US), given their typically closer relationship with seekers, their evident and inevitable

⁵²² Onwuteaka-Philipsen and others, above n 395.

⁵²³ Regional Euthanasia Review Committees, most commonly referred to as 'RRCs'.

⁵²⁴ Regional Euthanasia Review Committees *Annual Report 2012* (The Hague, July 2013).

⁵²⁵ Participants' comments; BioEdge "Study tour of Auschwitz outrages Jewish organisation (23 May 2014) <www.bioedge.org>; discussed further in Chapter 5.

⁵²⁶ BioEdge "Belgian euthanasia doctor faces criminal charges" (31 October 2015) <www.bioedge.org>. At the time of writing no charges appear to have been laid.

role in AD, their apparent interest in participation,⁵²⁷ and the often neutral stance of their professional bodies.⁵²⁸ It is now accepted Netherlands practice that nurses record AD requests, are consulted in eligibility assessments, provide input into doctors' deliberations and decisions, and are commonly included in the meetings where seekers are advised of the assessment decisions, whatever those are.⁵²⁹ However none of the existing statutes explicitly includes nurses in the statutory immunities and only the Québec statute (s 50) includes them implicitly as "health professionals" in the provision for conscientious refusal. Accordingly, nurses can feel vulnerable to taking on a greater role, despite many wishing to have greater involvement. Nurses interviewed wanted provisions affecting their immunities and rights to be clearly visible in the statutes [§2.V], or, where there is reluctance to amend the statutes, through supplementary regulations or policy guidelines issued by government health authorities. The potential for additional nurse roles in AD is discussed again in Parts 3 and 4.

4.3.5 Infrastructure for AD service provision

Providing an operational infrastructure has been problematic in most jurisdictions because the statutes do not create one, leaving a vacuum in oversight and management of AD implementation. The various AD provider agencies have all established delivery structures in recognition that, at least initially, some infrastructure would be needed to ensure that doctors were actually available to provide AD in compliance with the law. Each of these agencies has developed a database of doctors who are trained and available to be the attending doctor as needed, and typically these relatively few doctors undertake a majority of the AD requests and assessments.

Without structured capacity-building programmes, however, these systems struggle to maintain capacity, especially when demand is growing rapidly.⁵³⁰ While these structures are valuable as an interim measure, to be effective they need both funding and public legitimation. The Netherlands has achieved this through the backing of SCEN and the

⁵²⁷ Participants' comments; De Bal, Gastmans and Dierckx de Casterlè, above n 144; Inghelbrecht, above n 514; Trowell, above n 144; Martin Woods and Joy Bickley Asher "Nurses and the euthanasia debate: reflections from New Zealand" (2015) 62 Int Nurs Rev 13.

⁵²⁸ Herring, above n 51; Trowell, above n 144.

⁵²⁹ Participants' comments; De Bal, Gastmans and Dierckx de Casterlè, above n 144.

⁵³⁰ Participants' comments; BioEdge "Swiss assisted suicide group notches up 34% rise in deaths" (14 March 2015) <www.bioedge.org>.

recently established Levenseindeklinik by the RDMA,⁵³¹ government funding for university-based research to monitor trends in usage and identify any significant issues, and the accepted authority of the RRCs to monitor compliance and refer cases directly to the public prosecutor.⁵³² In Switzerland EXIT has achieved legitimization through decades of exemplary operation, building a membership that now comprises nearly 10 percent of Switzerland's adult population, and ensuring membership of high profile health professionals on its Board.

Research participants were unanimous in their belief that, ideally, the statute would establish a government-funded infrastructure for delivery of AD services [§2.X]. This has not been proposed in any Bill until the recent End of Life Choice Bill in New Zealand,⁵³³ which proposes (s 21) both a registrar to oversee compliance and facilitate doctor availability, and a mandatory 'SCENZ Group' to be the exclusive provider of consultant doctor services.⁵³⁴ However there are significant problems with making that function mandatory (see page 159). Most recently, the P-TEAG Report has recommended a "publicly-funded care coordination system", modelled on effective existing systems for other health care services such as cancer care and organ transplantation, using a 'patient navigator' structure that would assist the seeker through the various required processes, minimising obstacles (Recommendation 4) [§1.VI and §2.X]. The patient navigator role, which has similarities to the physician assistant role now established as a profession in the US,⁵³⁵ has been used in North America for more than a decade, mostly to facilitate cancer screening and treatment. Patient navigators have been found highly effective in supporting both clients and providers, supporting the person seeking treatments with information about options and support for access to avoid systemic obstacles to effective and preferred treatments. Programme evaluations have demonstrated the role's effectiveness with high rates of client retention and satisfaction, high rates of treatment effectiveness and feedback

⁵³¹ The Levenseindeklinik was established by the NVVE to provide an AD assessment service primarily for referrals from declined seekers or doctors wanting specialist assessments where seekers appear to not meet the mental competence eligibility criterion; see Part 3.

⁵³² Participants' comments; Griffiths, Weyers and Adams, above n 3.

⁵³³ End of Life Choice Bill, Member's Bill, 2015 <www.parliament.nz>.

⁵³⁴ 'Support and Consultation for End of Life in New Zealand', s 19.

⁵³⁵ See American Association of Physician Assistants <www.aapa.org>.

from clinicians that the navigators saved valuable clinician time and were better suited to those tasks than were doctors.⁵³⁶

4.3.6 Normalising AD as a ‘standard’ end-of-life treatment option

The advantages of framing AD statutes to incorporate AD within standard end-of-life treatments, as has the Québec statute, were discussed in Part 1. Creating such a framework may encourage palliative care practitioners to acknowledge AD as an actual or potential option for that specialisation, as is beginning to occur in the European jurisdictions.⁵³⁷ It was the experience of research participants, and other researchers, that legalising AD results in improved palliative care provision because end-of-life care providers are “forced to develop further” through participation in AD,⁵³⁸ resulting in:

“Healthcare professionals and patients alike [being] more knowledgeable on end-of-life care [and] better able to distinguish between the six or seven broad choices that can be made regarding end-of-life care; the demands of patients are better acknowledged; and professionals are more aware of what they are doing... standards of care are rising and there is no indication of an alarming increase in euthanasia cases or any significant misuse... [and] the decriminalisation of euthanasia has stimulated more thorough communication around end-of-life care, starting with advance care planning... at the micro level of the individual, the intermediate level of institutions and organisations, and the macro level of public policy (including around financial and ethical issues).⁵³⁹

At present, the statutes require only that the doctor discuss all treatment options when a seeker requests AD. By regulating provision of terminal sedation and CPS, doctors may be discouraged from delivering those options when the seeker has clearly requested AD, because they are required to report regardless of the method of hastening death [§2.I]. AD requests might also be significantly facilitated through statutory requirements that health practitioners who receive a request for *any* end-of-life treatment provide information to the person on *all* legal end-of-life treatment options [§1.III], so that a person considering hastening their death in any way whatsoever, including refusal of treatments, nutrition and/or hydration, would be informed also about AD, terminal sedation and CPS.

⁵³⁶ Karyn Hede “Agencies look to patient navigators to reduce cancer care disparities” (2006) 98(3) J Natl Cancer Inst 157; Kristen J Wells and others “Patient navigation: state of the art or is it science?” (2008) 113 Cancer 1999.

⁵³⁷ Participants’ comments; Bernheim and others, above n 337; Gamondi and others, above n 199; Paul Vanden Berghe and others “Assisted dying - the current situation in Flanders: euthanasia embedded in palliative care” (2013) 20 Eur J Pall Care 266.

⁵³⁸ Vanden Berghe and others, above n 537, at 268.

⁵³⁹ At 268-269.

4.3.7 Specific legislation for AD

The experience in Switzerland highlights both advantages and disadvantages of not having a specific statute. The advantages are that the Swiss Penal Code provision permits, in principle, a broad AD eligibility and also allows it to be provided by others. In reality the need for a legal prescription requires doctor involvement. However due to the irreversible nature of the procedure, continuing opposition from SAMW and the palliative care sector, and a lack of authorised guidelines, a majority of Swiss doctors have been unwilling to participate, leaving the services to a small number of doctors willing to work through the AD provider agencies. Swiss research has shown consistently that more doctors would engage in AD if it were legalised by statute.⁵⁴⁰ To address this problem, EXIT Suisse Romande has lobbied, successfully, for cantonal health regulations in two cantons so far (Vaud and Neuchatel) that set out the procedural requirements without changing the broad eligibility scope.

We have introduced this law first in canton Vaud with two purposes – to permit assisted suicide inside the hospitals and the nursing homes, so people must not leave and go to a hotel to have it, and because the doctors, yes, they want it. Without a law, they feel they are not safe, and they want a, you call it a ‘protocole’, yes? So they can show the patient and their collègues and the directeur and so on, so it is all clear for everyone and they can check on the list every action they must do. Without a law, no one will feel safe. *Director AD provider agency*

Where AD has been legalised by virtue of a court decision only, there is apparent reluctance by doctors to participate. While no statistics are available for those jurisdictions in the absence of monitoring, research participants with contacts in those jurisdictions understood uptake to be low, based on anecdotal reports, and provision of AD remains almost entirely secret, due to doctors’ fear of prosecution by upset relatives or confused public prosecution services.

4.3.8 Costs

There was a consensus amongst research participants that billing for AD services needs to be provided for in the statutes or supplementary regulations to clarify where the costs lie. The US Medicare programme recently began paying for end-of-life consultations with doctors and nurse practitioners,⁵⁴¹ and health insurers are reviewing end-of-life coverage to

⁵⁴⁰ Gamondi and others, above n 199; José Pereira and others “The response of a Swiss university hospital’s palliative care consult team to assisted suicide within the institution” (2008) 22 Palliat Med 659.

⁵⁴¹ Belluck, above n 312.

include all aspects of AD in their policies, but most AD services currently are still provided by doctors who volunteer their services.

The costs of administering an AD law also need to be provided for in the statute, so that any infrastructure systems set up are funded adequately.⁵⁴² In the US states no budget was included in the Bills, to avoid voters voting against the Bills for economic reasons, so that monitoring had to be undertaken within existing health authority budget, constraining collection of relevant data that would have been valuable for evaluative purposes.

4.3.9 Innovation

The development of new statutes needs to look at new technologies - medical, communications, social - to identify ways in which access barriers can be mitigated. For example, responding to a remote/rural request or need for AD assessment might be provided through online face-to-face communications, provided that it was under the direction of a doctor with some registered clinician present [§2.VII] (see further Part 3).

Doctors interviewed stressed the importance of keeping the “red tape” simple, so it is not onerous, commenting that doctors are already burdened by clinical reporting requirements and are more likely to participate in discretionary activity when others (nurses, physician assistants, social workers) can complete some of the paperwork for their sign-off. Today’s technologies allow for pre-formatted, forced-choice, online recording and reporting systems that can remove another barrier to doctor participation and could be provided for explicitly in the statute or regulations.

Regulatory innovation is also possible. For example, a “first of its kind” statute in Washington state requires all registered mental health professionals to receive six hours of suicide prevention training every six years, starting in 2014.⁵⁴³ In principle, regulation for medical and nursing registration could require mandatory training in responding to all requests for hastened death.

Finally, none of the statutes to date has created an explicit ‘right’ of seekers to have their AD request prompt a series of actions by health providers. Although the law is shy to create

⁵⁴² The New Zealand abortion legislation does this (s 42).

⁵⁴³ Matt Adler Suicide Assessment, Treatment and Management Act 2012.

‘rights’ around hastening death generally, taking this step might be a powerful enabler of access.

5 Beyond regulation?

A strategy adopted by the RTDs to enable better seeker and doctor access to AD while avoiding having to revisit the statute has been to lobby for changes to policy. The SCEN and LEIF initiatives are good examples of this approach, where the RTDs sought collaboration with the medical professional bodies to set up AD provider structures within which doctors would feel safe to engage. Likewise, the recent Belgian collaborations between palliative care practitioners and doctors supporting seekers’ AD requests demonstrate how seekers’ requests can be supported without risk of health practitioner gatekeeping.⁵⁴⁴ While building collaborations can facilitate access, it can take years to effect quite small changes, during which period many *prima facie* eligible seekers are denied access, and research participants considered statutory provision a more effective pathway. The omission of some clearly important provisions typically reflects either a deliberately conservative framing of the Bills to promote their passage or the early participation of medical associations and/or colleges in designing the statute, with a clear understanding that those bodies had agreed to take responsibility for producing practice standards, protocols and health regulations to ensure safe practice. For example, the many additional due care and eligibility provisions in the Belgian statute, compared with the Netherlands legislation on which it is based, in part reflect the minimal involvement of the (then) Orde der Geneesheren in framing the Belgian law together with a lesser history of acceptance of AD practices in Belgium. Research participants also generally agreed that a provision within the statute for formative evaluation of early implementation would signal an intention for early amendment of the legislation where indicated from the early implementation experience [§1.XIII]. The P-TEAG Report has recommended this approach specifically in relation to consideration, after a year of implementation experience, of permitting AD by an advance directive prior to diagnosis of a qualifying medical condition (Recommendation 13).

The high uptake in the Benelux countries has been enabled by a high level of rational discussion and debate at public, professional and government levels facilitated by the mass media, the AD provider agencies, researchers and the medical bodies, often in

⁵⁴⁴ Vanden Berghe and others, above n 537.

collaboration.⁵⁴⁵ For example the NVVE has recently launched a programme for secondary schools with factual information about AD and other end-of-life options that encourages young people to consider their own ethical stance through facilitated discussion. In the UK, as part of the campaign to legalise AD, Dignity in Dying helped establish a lobby group called Health Professionals for Assisted Dying,⁵⁴⁶ which now includes high profile practitioners supporting the campaign.

Advance care planning may be the most effective way for the public at large and people at end of life to become well informed about legal AD together with other end-of-life treatment options, provided that the information is evidence-based, non-partisan and delivered by health professionals who are in principle supportive of all legal options. For the latter to occur, better professional education is key. One way to achieve that might be for standards of care around end-of-life health care to mandate disclosure of the practitioner's personal views for or against AD whenever they discuss any end-of-life options with clients, together with an offer for clients to be referred to a professional who does support all legal options. Ideally, that requirement would be included in a statute or in regulations [§1.V]. In addition, including the provisions for making advance directives together with those for AD, CPS and terminal sedation within one statute that addresses end-of-life care options generally could encourage people, in conversation with their health care providers, to consider registering an advance directive and simultaneously become informed about other end-of-life options [§2.I].

Although undergraduate education in AD is sparse currently, research participants believed that it would become incorporated within curricula within the next decade as AD demand increases. Canada's 17 medical schools announced recently that their curricula were being reviewed in anticipation of the forthcoming legalisation of AD nationally.⁵⁴⁷ Requiring health practitioner regulatory bodies to develop practice standards and guidelines for AD is likely to facilitate their inclusion in both undergraduate and professional education curricula, helping to normalise AD as part of end-of-life health care.

⁵⁴⁵ Participants' comments; Meeussen and others, above n 386.

⁵⁴⁶ Health Professionals for Assisted Dying (HPAD) <www.hpad.org.uk>.

⁵⁴⁷ Sharon Kirkey "Canadian medical schools readying doctors to talk to patients about assisted suicide" *The Star Phoenix* (online ed, Saskatoon, 2 April 2015).

Many of the access issues for doctors would be dramatically reduced if there were less vocal and aggressive opposition from religious organisations. Research participants and others identified some attenuation of opposition in the past year, with church leaders publicly supporting AD and research demonstrating high levels of support from people of faith.⁵⁴⁸ Doctors and others working in Catholic hospices across jurisdictions want to see a constructive interface established between the AD providers and the hospices, to find ways to provide better AD access for both seekers and staff.⁵⁴⁹

6 Summary

The greatest barriers to making a viable formal request for AD appear to be a continuing unwillingness of many doctors to either acknowledge an AD request as such and then record and action the request or refer it on in a timely way, the unwillingness of the medical regulatory and professional bodies in some jurisdictions to support doctors to become engaged through providing robust guidelines and training, and a corresponding lack of infrastructure for the provision of AD within which mandatory recording and referral systems are available to ensure that gatekeeping, however unintentional, is minimised. Arguably the only, or at least most effective, way that the necessary structures can be put into place, in the absence of the medical professional bodies taking the initiative, is to legislate for such systems and structures. Part 3 looks at how some of these same barriers affect seekers at the eligibility assessment phase.

D Part 3. Eligibility assessment⁵⁵⁰

1 Eligibility and due care requirements - Commonalities and differences across jurisdictions

The existing statutes all require the person seeking AD demonstrate, to the satisfaction of two doctors, that they:

- Are mentally competent⁵⁵¹ – this is commonly defined in the statutes (and/or other statutes and case law in each jurisdiction) as fully understanding the fatal impact of taking or being administered a lethal medication;

⁵⁴⁸ Inter-Faith Leaders for Dignity in Dying “Religious attitudes to assisted dying” (May 2013) Campaign for Dignity in Dying <www.dignityindying.org.uk>.

⁵⁴⁹ Participants’ comments; Gamondi and others, above n 199.

⁵⁵⁰ The discussion throughout Part 3 again reflects research participants’ interview data, supplemented from the literature as footnoted.

⁵⁵¹ The term ‘competent’ is used throughout this thesis to refer to the mental decision-making competence of the seeker.

- Have a qualifying medical condition;
- Have considered AD alongside other options in a reasoned and informed manner and rejected the other options as inadequate or not acceptable;
- Genuinely want to end their life in the near future;
- Have clearly expressed that wish on multiple occasions (two or more, depending on the statute);
- Have made their decision and requests free of coercion;
- Have independently completed the necessary forms (not legally required in The Netherlands but recommended).

The US statutes also require that the seeker be advised to consider discussing their decision with others.

However eligibility differs radically across jurisdictions. The US jurisdictions require a six month terminal illness prognosis, whereas in the other jurisdictions eligibility focuses on unbearable suffering, as subjectively experienced by the seeker and confirmed by the assessing doctors, together with a clinical judgment that the seeker's medical condition is irreversible and hopeless. Moreover there are ostensibly small but practically significant differences in the eligibility requirements, based on the use of particular terms in the statutes that make each jurisdiction unique in one or more ways. For example, the Belgian and Québec statutes require that the seeker's suffering be 'constant', whereas the Netherlands statute requires only that it be 'lasting'.

2 Patterns in granting AD

The AD eligibility assessment process generally overlaps with the formal requests, since multiple requests are required. Following an initial formal request, the focus of decision-making shifts from the seeker's wish to the issue of eligibility, and from the seeker to the assessing doctors as the decision-makers. Typically the seeker continues to review their wish for AD, though reviewing the timing of their assisted death rather than whether they want AD.⁵⁵²

⁵⁵² Participants' comments; Pasman and others, above n 125; Pestinger and others, above n 319.

Variance across jurisdictions in rates of writing prescriptions suggests barriers at the request and assessment stages. For example the prescription rate relative to requests was only 15 percent in Oregon in 2011, as compared with nearly 50 percent in The Netherlands in 2010,⁵⁵³ even though the Oregon law had been in force longer. There have been few studies of AD grant and decline rates since request rates have increased in recent years and decline rates are not routinely monitored in any jurisdiction. However the studies available show that there are high rates of non-access for reasons other than eligibility. Belgian research in 2011 found that nearly 40 percent of doctors covering a broad range of specialisations including family medicine had received an explicit AD request, with 48 percent of requests granted; however only five percent were explicitly declined, with nearly one quarter (23 percent) of seekers dying during the assessment phase. Some apparent reasons were either differences of view between the two assessing doctors, or, the researchers concluded, the result of avoidable delays, in particular “that the attending physician waited too long to contact a second physician, perhaps to take the time to consider the request, or wanted to avoid the subject”.⁵⁵⁴ A Netherlands study in 2010 found that two thirds of requests were declined or lapsed, in 40 percent of those cases because the person died during the assessment process. Seekers living at home and being attended by their family doctor had a 400 percent greater chance of being granted AD than did those in hospital or a nursing home, and the nursing home residents had the least chance of receiving AD.⁵⁵⁵ These anomalies demonstrate that, even where the seeker may be otherwise eligible, there are significant barriers to achieving AD due to how the procedural requirements are implemented.

This Part examines barriers arising in the assessment process due to the interaction of doctors and other health practitioners with the legal requirements for AD. As in Part 2, the barriers and their interactions are discussed first, with actual and potential mitigation strategies presented subsequently.

⁵⁵³ Lewy, above n 10.

⁵⁵⁴ Yanna van Wesemael and others “Process and Outcomes of Euthanasia Requests Under the Belgian Act on Euthanasia: A Nationwide Survey” (2011) 42 *J Pain Symptom Manage* 721, at 730.

⁵⁵⁵ Onwuteaka-Philipsen and others, above n 395.

3 Barriers in the assessment process

3.1 Unavailability of doctors

The unavailability of doctors remains the main access barrier for seekers in the assessment phase. The reasons described earlier for doctors' reluctance to participate in AD are acutely exacerbated at the assessment phase, because doctors are now undertaking an accountable process and making actual judgments that may result in people having a hastened death, with the doctor as a direct agent of that. Thus doctors willing to record a request may not be willing to undertake the assessment, whether for reasons of ethics, workload, billing, paperwork requirements or anxiety about their level of relevant skill. Doctors willing to assess tend to be clustered in cities, making rural assessment difficult to access. However research participants attributed doctors' unavailability for assessment primarily to two related factors – a lack of knowledge of how to undertake the required processes safely, together with a fear of “a false hit”⁵⁵⁶ and the potential for censure or stigma. As a result, across jurisdictions most doctors willing to action a request refer it on to the AD provider agency, and in Switzerland and The Netherlands that is the generally accepted protocol.

3.2 Interpreting the eligibility and due care criteria

Research has shown that doctors struggle with the AD eligibility criteria across jurisdictions. In The Netherlands, where legal AD has been available for more than 20 years, up to two thirds of participating doctors encountered significant problems in making a decision about one or more of the eligibility requirements,⁵⁵⁷ and nearly half identified significant gaps in their knowledge around the legal/ethical aspects, methods for administration and palliative care options,⁵⁵⁸ possibly due to the relative infrequency for many doctors of receiving AD requests. Some commentators have focused recently on the generally problematic nature of the relationship between the medical and health professions and the law, including the law in relation to end-of-life care, highlighting a range of difficulties that doctors and others have in interpreting permissive law in particular. Meisel, Snyder and Quill drew attention to the range of “myths” that inform doctors' end-of-life practices in the absence of education about the law on those practices, resulting in doctors “overestim[ing] the legal risks of some practices” and declining people's requests for a

⁵⁵⁶ As previously, short quotes reflect research participant data.

⁵⁵⁷ Buiting and others, above n 126.

⁵⁵⁸ Johanna E Hanssen-de Wolf, H Roeline W Pasman and Bregje D Onwuteaka-Philipsen “How do general practitioners assess the criteria for due care for euthanasia in concrete cases?” (2008) 87 Health Policy 316.

hastened death.⁵⁵⁹ Kapp has highlighted the common paucity of practical guidance for health professionals in implementing health law reforms, and the often complicated and time-consuming paperwork required.⁵⁶⁰ US legal theorists have discussed doctors' claims of 'bad law' - laws that require them to act in ways harmful to their clients - based on difficulties in interpreting legal requirements, in particular around permissive (versus proscriptive) laws that override criminal or civil culpability for particular treatments as personal autonomy has become the prevailing ethical principle, creating decision-making contexts that doctors are not trained for.⁵⁶¹ They describe the problems for health practitioners in understanding and complying with statutory provisions that are open to wide interpretation without sufficient professional standards, and the potentially serious outcomes for both clients and doctors where the latter either misinterpret or ignore laws relating to life and death options,⁵⁶² pointing out that the framing and phrasing of statutes renders them cryptic to people without legal expertise unless interpreted. All of these authors have called for better provision of practice standards and protocols for health practitioners implementing health laws generally and end-of-life laws in particular.

As already discussed, across jurisdictions such guidelines are not sufficiently available to practitioners contemplating AD participation or participating infrequently. Research participants emphasised that AD decision-making is complex and multi-factorial, as well as emotional, and without guidelines promoting consistency practitioners can vary significantly in their assessments. Even highly experienced Levenseindekliniek staff commented that they can vary in their judgments of a reasonable prospect of improvement, depending on the individual practitioner's experience. Without assessing practitioners having sufficient expertise in the eligibility and due care requirements, seekers can be seriously disadvantaged.

3.2.1 Medical condition

All of the statutes require that the seeker have a serious medical condition. The Belgian and Québec statutes explicitly include mental or psychological conditions, and although the Netherlands statute does not, their courts have long since upheld mental suffering as

⁵⁵⁹ Meisel, Snyder and Quill, above n 118, at 2500.

⁵⁶⁰ Marshall B Kapp "Beyond medical advance directives: Implementing the POLST (Physician Orders for Life Sustaining Treatment) paradigm in Florida. Florida State University Center for Innovative Collaboration in Medicine & Law, 24 August 2011 <<http://med.fsu.edu>>.

⁵⁶¹ Griffiths, Weyers and Adams, above n 3; Johnson, above n 143.

⁵⁶² Hoffman, above n 143.

included under the legislation (see below). Similarly the European Court of Human Rights in *Haas* agreed that seekers with psychiatric conditions were not excluded from assisted suicide under Swiss law;⁵⁶³ Mr Haas's difficulty was in finding a psychiatrist in Switzerland willing to undertake an assessment. In all jurisdictions seekers with episodic psychological conditions encounter difficulty finding doctors who are willing to process their requests and psychiatrists who are willing to assess them, apparently due to doctors' lack of confidence to make such assessments (see further p 166).⁵⁶⁴

The statutes all require that the condition must be advanced, with no reasonable hope of recovery (variously phrased as 'serious', 'hopeless', 'irreversible') and no other treatment solution acceptable to the seeker. However doctors experience a range of challenges in making diagnoses and prognoses and in accepting seekers' subjective judgments of their suffering and what treatments are acceptable to them.

3.2.2 Terminal illness

International reviews of AD research have identified doctors' difficulties across jurisdictions in interpreting what constitutes 'terminal' illness, especially as medical interventions that extend life are constantly being introduced.⁵⁶⁵ Statutory terminology such as "terminal", "incurable" and "irreversible" has become problematic as medical advances render judgments based on these terms impossible to justify scientifically, so doctors are increasingly reluctant to do so. Even where people's symptomatology is highly similar, receiving a terminal diagnosis (defined as six months to live) can vary significantly based on both consumer and doctor attributes, including age and gender.⁵⁶⁶ Prognosis is harder to determine for heart disease, pulmonary diseases, stroke and disabling diseases such as multiple sclerosis than it is for cancers, resulting in more seekers with cancers being granted AD.⁵⁶⁷ Recognising these problems, a legislator in Oregon introduced a Bill to extend the prognosis period to 12 months, but it was opposed by proponents of AD because doctors believed that would be an even more fraught prognostic task (and also because US residents require a six months prognosis to qualify for hospice).⁵⁶⁸

⁵⁶³ *Haas*, above n 255.

⁵⁶⁴ Participants' comments; Eva Elizabeth Bolt and others "Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living?" (2015) *J Med Ethics*: medethics-2014.

⁵⁶⁵ Gawande, above n 227.

⁵⁶⁶ Aabom and others, above n 124.

⁵⁶⁷ Hedberg and Tolle, above n 124.

⁵⁶⁸ Personal communication, Compassion and Choices National, 23 August 2015.

Prognoses might be better determined through collaboration between the two assessing doctors, which is not proscribed, but many doctors interpret the term ‘independent’ as prohibiting collaboration. Two studies found a significantly higher rate of declines where the assessing doctors did not consult with the seeker’s health care team.⁵⁶⁹ Where prognosis is uncertain, some doctors will act “sympathetically” in these cases and endorse eligibility, while others will not. Doctors can be deterred from participating in assessment when they hear of occasional cases where the seeker lives past the six month prognosis, for fear of looking incompetent to their colleagues. US doctors are highly cautious of stepping outside their zone of expertise for liability reasons.⁵⁷⁰

We have such a litigious society, most doctors don’t want to make the judgment any more, that’s why they deliberately over-estimate, because then you’ve got less chance of being wrong, but for someone wanting aid in dying, well that’s an obstacle... so eventually most [seekers] come our way, and very few of them outlive the prognosis. *AD provider agency doctor*

Many of the statutes include ‘safeguard’ provisions that reflect a compromise agreed to with AD opponents in the legislatures or at large, such as the US statutes’ restriction to terminal illness. Although the Québec statute does not require a terminal illness, in order to get the Bill through the third reading under a new government, an additional clause was included requiring that the seeker be “a la fin de vie” (at end of life). The Collège des Médecins remains unclear how that phrase will be interpreted by doctors and expects that it will eventually be tested in the courts to determine what constitutes ‘end of life’. However it has the potential to deter both seekers from making a request and doctors from granting it. Moreover, since it is inconsistent with the wording recommended subsequently in *Carter*, the P-TEAG developing Canada’s federal legislation is now suggesting to the Québec legislature that it repeal that clause to avoid eligibility inconsistencies federally.⁵⁷¹

3.2.3 Unbearable suffering

The main seeker barriers associated with the requirement of the Benelux laws for evidence of the seeker’s suffering lies in many doctors’ difficulties in accepting, firstly, that such suffering does not have to include physical symptoms but may comprise spiritual or

⁵⁶⁹ Hanssen-de Wolf, Pasman and Onwuteaka-Philipsen, above n 558; Pasman and others, above n 125.

⁵⁷⁰ Johnson, above n 143; Marilyn M Rosenthal, Linda Mulchay and Sally Lloyd-Bostock (eds) *Medical mishaps: Pieces of the puzzle* (Open University Press, Philadelphia, 1999) 141.

⁵⁷¹ “Ontario forms expert panel on assisted dying” *CBC News* (online ed, Toronto, 14 August 2015).

existential suffering alone, and secondly that the judgment of suffering is subjective to the seeker.⁵⁷² Suffering has always been interpreted broadly by Netherlands courts⁵⁷³ and by the RRCs, which have a quasi-judicial status.⁵⁷⁴ Collectively these bodies have ruled that, for the purposes of the statute, mental suffering is sufficient to justify AD eligibility.⁵⁷⁵ Commentators point out that the anticipation of intolerable agony or fear of further suffering is itself suffering,⁵⁷⁶ as was also held in *Schoonheim*.⁵⁷⁷ However doctors are not trained to assess mental or existential suffering, but rather to focus their diagnostic skills on observable, tangible symptoms, and doctors often feel embarrassed and out of their depth when attempting to discuss emotional matters with clients.⁵⁷⁸

Even though courts internationally have ruled that the seeker's subjective experience of suffering cannot be refuted but is "unimpeachable",⁵⁷⁹ cautious doctors can delay or deny granting AD where they are not aware of or do not personally accept those rulings, for example, failing to understand that unbearable existential suffering can be caused, and typically is, by a seeker's total loss of autonomy, dignity, independence and identity rather than fear of pain. Where the seeker's suffering manifests in antagonistic behaviour, doctors sometimes interpret that behaviour as symptomatic of anxiety rather than suffering and prescribe anti-depressants rather than assessing the AD request.⁵⁸⁰ Some research has shown that declines occurred more often where *doctors* perceived a lesser degree of suffering, irrespective of the seeker's subjective experience.⁵⁸¹

... because we [doctors] are used to being the ones who make the decisions, so many doctors will still think, oh, I am not convinced, she still has some happy moments, I don't see that this is unbearable for her yet, I have to wait. So they are not thinking from the patient's point of view, they just look if she has unbearable pain. So we [SCEN] have to help those doctors to understand it is about the spiritual suffering... *SCEN doctor*

⁵⁷² Participants' comments; Pieter Admiraal "Physician-Assisted Suicide: A Doctor's Perspective" in Birnbacher and Dahl, above n 437.

⁵⁷³ *Schoonheim*, Nederlandse Jurisprudentsie 1985, no 106.

⁵⁷⁴ Griffiths, Weyers and Adams, above n 3.

⁵⁷⁵ Regional Review Committees Annual Report 2002; KNMG "The role of the physician in the voluntary termination of life. Position Paper" (KNMG, Amsterdam, June 2011).

⁵⁷⁶ Participants' comments; Pestinger and others, above n 319; Vanden Berghe and others, above n 505. Seven percent of all UK suicides in 2014 were by people with terminal illnesses, see "A Hidden Problem...", above n 272.

⁵⁷⁷ *Schoonheim*, above n 573.

⁵⁷⁸ Groopman, above n 230.

⁵⁷⁹ *Seales*, at [46].

⁵⁸⁰ Participants' comments; Starks and others, above n 281.

⁵⁸¹ Onwuteaka-Philipsen and others, above n 395.

Prognostic uncertainty is also an issue in the Benelux countries where the statutes require that the assessing doctors determine that the suffering and, in Belgium and Luxembourg, the medical condition are “hopeless” or without any prospect of improvement. As with terminality, doctors can struggle to decide individually or collectively that a particular condition is beyond effective treatment, even though the statutes give the seeker the right to decide whether the treatments offered are acceptable to them. Much of the cause of these issues was, in the view of both research participants and other commentators, either a paternalistic unwillingness of some doctors to accept the seeker’s decision-making autonomy,⁵⁸² doctors’ reluctance to accept that the seekers’ suffering is purely subjective, and/or their confusion where suffering fluctuates daily,⁵⁸³ or even hourly,⁵⁸⁴ as seekers work through the grief of dying and try to remain outwardly positive for the sake of family, doctors or even for their own coping.⁵⁸⁵

I have seen the situation where people with end-stage illnesses like pancreatic cancer or liver cancer have been told no you don’t have euthanasia because you don’t have suffering, because the doctors could not see any of the symptoms that they think are the things that show suffering, which would be extreme pain or very hard to breathe or something like this. If the patient doesn’t have these things, the specialists don’t understand that there is another kind of suffering, the existential suffering, they don’t recognise that. *Swiss AD provider agency*

Ironically, the norms of the doctor-patient relationship can result in some seekers, especially women, putting on a “brave face” for the doctor - wearing their best clothes, smiling, chatting - which can lead the doctor to believe that the person is still in good spirits and therefore cannot be suffering unbearably.

Discontinuity in medical care remains a problem at AD assessment. Where the attending doctor has not known the seeker prior to their advanced illness, as occurs in up to three quarters of all assessments,⁵⁸⁶ depending on the jurisdiction, they lack baseline knowledge of the seeker’s personality, lifestyle and relationships, so it is more difficult to assess the unbearability of the suffering and the seeker’s competence.⁵⁸⁷

⁵⁸² Participants’ comments; Buiting and others, above n 126; Gamondi and others, above n 199; Sheahan, above n 133.

⁵⁸³ Sissel Johansen and others “Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit” (2005) 19(6) Palliat Med 454.

⁵⁸⁴ Tolle and others, above n 301.

⁵⁸⁵ Participants’ comments; Gamondi and others, above n 281; Starks and others, above n 281.

⁵⁸⁶ Participants’ estimates; Onwuteaka-Philipsen and others, above n 395; Oregon Public Health Division, above n 303.

⁵⁸⁷ Participants’ comments; Admiraal, above n 572.

Belgian doctors can encounter difficulty determining what constitutes ‘constant’ suffering, especially since the experience of suffering can fluctuate significantly within a day depending on the seeker’s medical and psychosocial situation.⁵⁸⁸ In contrast, ‘lasting’ suffering, as required in the Netherlands statute, is not difficult to identify where the seeker can show suffering over a period of weeks or more. Some commentators have highlighted how the Belgian law, in attempting to clarify the eligibility criteria, has so complicated the Belgian statute that even the courts have struggled to interpret the requirements, resulting in widespread confusion and reluctance to participate amongst some doctors for fear of prosecution,⁵⁸⁹ further reducing doctor availability. Many current medical students at one Belgian university believed that AD eligibility there requires a terminal illness.⁵⁹⁰

There is medical and legal consensus now that palliative care, however good, cannot address all physical pain or refractory symptoms,⁵⁹¹ let alone the spiritual or existential suffering which many commentators believe is at the core of all end-of-life suffering.⁵⁹² Other constant, terrifying and/or otherwise intolerable symptoms that can be ultimately unmanageable, potentially for weeks or even months,⁵⁹³ such as continuous rectal incontinence, overwhelming nausea, unrelenting sensations of choking or drowning that cause a persistent feeling of panic, extensive pressure sores that cannot be healed, and constant high-level anxiety, can be caused by either medical conditions or iatrogenic effects, or both.⁵⁹⁴ Moreover palliative care quality is acknowledged to be variable across regions and even providers, and often channelled more into cancer care than for other conditions,⁵⁹⁵ and potentially unavailable due to doctors’ “opioid phobia” and unwillingness to acknowledge other than physical suffering.⁵⁹⁶ Two thirds of Netherlands doctors surveyed

⁵⁸⁸ Participants’ comments; Johansen and others, above n 583.

⁵⁸⁹ Participants’ comments; Adams and Nys, above n 127.

⁵⁹⁰ Personal communication, Ghent University professor, 2 July 2015.

⁵⁹¹ Assemblée Nationale Québec *Select Committee Dying with Dignity Consultation Document* (May 2010); Seales, above n 34, at [32]-[48]; Vanden Berghe, above n 505.

⁵⁹² Participants’ comments; Gerald Dworkin *Life’s Dominion* Harper Collins, London, 1993; Cardy, above n 58.

⁵⁹³ Nessa Coyle and others “Character of terminal illness in the advanced cancer patient: pain and other symptoms during the last four weeks of life” (1990) 5 J Pain Symptom Manage 83.

⁵⁹⁴ Quill and Battin, above n 278.

⁵⁹⁵ Participants’ comments; Vanden Berghe and others, above n 505; Expert Panel Report, above n 296.

⁵⁹⁶ Admiraal, above n 572; Yasmin Noone “There’s no need to suffer in silence” Australian Ageing Agenda (2 March 2012) <australianageingagenda.com.au>.

acknowledged that “even adequate treatment of pain and terminal care did not make euthanasia redundant”.⁵⁹⁷

3.2.4 Mental competence assessment

Across jurisdictions there are problems with assessing mental competence for assisted dying. Some depressive symptoms are seen in up to half of seekers across jurisdictions and up to one fifth of seekers are declined on that basis, often without first being referred for a competence assessment or to a consulting doctor for a second opinion.⁵⁹⁸ Issues in competence assessment that can create access barriers for seekers include doctors’ inability to accurately distinguish mental illness from ‘demoralization syndrome’, lack of clarity about exactly what competencies are being assessed, lack of training or authorised guidelines for either mental health specialists or other doctors, and unavailability of mental health practitioners to undertake competence assessments. Firstly, doctors commonly acknowledge their lack of ability to distinguish accurately between clinical depression and the symptoms of sadness, listlessness and grief common at end of life.⁵⁹⁹ Ganzini’s research found identical symptomatology being more often interpreted by doctors as a mental illness but by other hospice professionals as a normal reaction to terminal illness.⁶⁰⁰ Seekers’ ability to demonstrate mental competence (and therefore a well-considered decision) can be impeded by grief, sadness, the exhaustion associated with illness, impaired cognitive function associated with loss of function generally or from being heavily medicated for refractory symptoms, rather than from the incipient dementia common when nearing death. Frail, ill people may make requests that appear vague, inarticulate or not sufficiently credible to physicians even though still competent.⁶⁰¹ One study found some doctors declining requests on the basis of a ‘treatable mental disorder’, without first making a referral to a mental health professional.⁶⁰²

⁵⁹⁷ JJ Georges, BD Onwuteaka-Philipsen and G van Der Wal “Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners” (2008) 34(3) J Med Ethics 150, cited in Lewy, above n 10, at 61.

⁵⁹⁸ Ilana Levene and Michael Parker “Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review” (2011) 37 J Med Ethics 205.

⁵⁹⁹ Ganzini and others, above n 123; Groenewoud and others, above n 134.

⁶⁰⁰ Above n 123.

⁶⁰¹ Buiting and others, above n 126; Ganzini, Goy and Dobscha, above n 135.

⁶⁰² Groenewoud and others, above n 134.

Doctors often have no specific training in assessing competence, even where they specialise in end-of-life care,⁶⁰³ relying instead on experience and “intuition”. Family and general medicine doctors distinguish regularly between situational and clinical depression as they dispense anti-depressants, but many are reluctant to make these judgments in end-of-life decision-making generally because of the potentially lethal implications.⁶⁰⁴ Two US psychologists interviewed who had undertaken collectively more than 50 competence assessments noted that they had never been referred a person who was clearly not competent, but rather people whose current cognitive functioning was impaired by grief or medications, concluding that doctors preferred to avoid either litigation or having moral responsibility for enabling a hastened death.

Mostly it's handholding the doctor. They see big risks for themselves and they don't want to put their licence on the line, so they hide behind a specialist assessment. *Psychologist undertaking assessments*

Additional barriers occur where individual providers or institutions implement policy requiring a competence assessment for any seeker who is one of their clients, even though the laws do not require it.⁶⁰⁵

Without clarity in the statute, ‘mental health professional’ is normally interpreted as a psychiatrist or psychologist with generic training, rather than professionals such as hospice social workers and nurses with training in distinguishing between end-of-life symptoms and clinical depression. However few psychiatrists and psychologists are willing to undertake these assessments, which research participants attributed to reasons mirroring doctors’ reluctance - a combination of the lack of appropriately authorised guidelines and training, lack of experience in end-of-life care, continuing stigma, fear of litigation, and fear of making an inaccurate assessment, given the implications.⁶⁰⁶ Though convictions for AD malpractice are rare, they have occurred often enough to feed that fear.⁶⁰⁷

⁶⁰³ Participants’ comments; Suzanne Jarrad “Reclaiming personhood in later life: Towards a new model of decision-making” (Doctoral dissertation, Flinders University, 2015); Kapp, above n 560.

⁶⁰⁴ Ibid.

⁶⁰⁵ Participant comments; Cees Ruijs and others “Depression and explicit requests for euthanasia in end-of-life cancer patients in primary care in the Netherlands: a longitudinal, prospective study” (2011) 28(4) Family Practice 393.

⁶⁰⁶ Despite repeated attempts to contact the presidents of the relevant psychological and psychiatric medical bodies in each of the jurisdictions visited for this research, only one replied, stating that the association did not currently have a clear policy on AD and that establishing one was not a high priority amongst its current activities.

⁶⁰⁷ See Griffiths, Weyers and Adams, above n 3, at 475-476, for a brief summary of the only three known Swiss prosecutions (all in the early 2000s) out of several hundred each year, one where the doctor further

US studies found that the majority of psychiatrists (65-94 percent) were not confident to distinguish accurately between clinical depression and end-of-life sadness and apathy, especially if they had not met the person previously.⁶⁰⁸ Where AD has been legalised, only one psychological association, the Washington State Psychological Association (WSPA) has compiled authorised guidelines for the purposes of the legislation,⁶⁰⁹ and those, while a desirable attempt at guidance, have been criticised as lacking an evidence base for discussing requests for AD as distinct from withdrawal of treatment.⁶¹⁰ The brief coverage of decisional capacity in Orentlicher's 2015 "Clinical Criteria" does not mention that end-of-life medications might interfere with competence. Participating psychologists interviewed knew of no training programmes specifically for AD competence assessments, and there is limited or no professional supervision available even though assessors recognise that as ethically essential. Without structured capacity-building in any jurisdiction, there was no succession plan for assessors availability.⁶¹¹

We're completely starved for guidance, the psych associations don't want a bar of it, it's far too controversial, so we're really abandoned professionally. *Psychologist undertaking assessments*

The case law is clear that mental competence assessment must be specific to the particular medical decision,⁶¹² and on the importance of not confusing "the question of mental capacity with the nature of the decision made by the patient, however grave the consequences".⁶¹³ However the assessors interviewed were unclear about standards for either seeker competence or assessor confidence, or what the law indicated in this regard. No accepted, evidence-based or standardised tests have been developed for assessing mental competence for AD. Without such guidance, the few professionals undertaking these assessments relied on generic mental capacity assessments while acknowledging that these are probably not

hastened the deaths of two people who had not died "several hours after ingesting the lethal barbiturate", and two others where the doctors failed to obtain sufficient assessment from psychiatrists before prescribing lethal medications. All resulted in swift prosecutions.

⁶⁰⁸ L Curry and others "Physician-assisted suicide in Connecticut: physicians' attitudes and experiences" (2000) 64(7) Connecticut medicine 403; Levene and Parker, above n 598.

⁶⁰⁹ Washington State Psychological Association "The Washington Death With Dignity Act: WSPA Guidelines For Mental Health Professionals" (2010) <www.endoflifewa.org>.

⁶¹⁰ Personal communication, WSPA member.

⁶¹¹ WSPA ran a well-attended conference in 2010 for interested mental health professionals, but that did not result in any additional AD participation; participant comment.

⁶¹² *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112 (UK HL).

⁶¹³ *Re B (Adult: refusal of medical treatment)* [2002] All ER 449 at 474.

suitable, or simply applied their own notions of what constitutes an appropriate approach,⁶¹⁴ leaving them ethically and professionally unsafe and vulnerable to complaints or litigation.

Limited competence assessor availability can cause sometimes crucial delays for seekers. The little research on seekers' experience of competence assessment suggests that it can be bruising. The following description of an assessment is taken from a study with families of people who received AD:

We had to go to a psychiatrist and she [seeker] had an awful time getting through this because she had to do all these word games and everything. And it was so sad. When she was through, she looked at the psychiatrist, and she said, "Well, did I pass?"... It was hard. It was very strained. ... And they were asking all these questions and probing and prodding through her brain. And she was trying to give the right answer so she could do what she wanted to do... I swear the psychiatrist almost lost it. She almost started crying. I mean, she was puddling up [because it seemed to her that] Mother's life was so sad—that her idea of winning and achieving was so she could take her life.⁶¹⁵

Assessors also lack guidelines for how to respond to the anger often demonstrated by frustrated seekers referred for what they perceive, often reasonably, as a spurious assessment. Similar issues occur commonly where people are assessed around requests for withdrawal of treatments.⁶¹⁶

They see it as an extra hoop that they're being made to jump through just to prove their sanity, and some people are very very insulted by that, and very upset, so first you have to deal with their antagonism. It [assessment] can end up taking quite a while, and mostly you realise from the get-go that they're probably entirely competent, but you can't just give them a big tick right away, you have to be able to show the docs and everyone involved that you've undertaken a proper assessment – whatever *that* is. *Psychologist undertaking assessments*

Practitioners in the US who are undertaking these assessments on behalf of health insurers feel that they have to make "conservative" assessments, to avoid any suggestion from AD opponents that the insurers are promoting AD for economic reasons.

Uncertainty around the boundaries on the competence assessment role can create barriers for seekers. Although the mental health literature emphasises the ethical importance of distinguishing between assessing and therapeutic roles to avoid role conflicts of interest,⁶¹⁷

⁶¹⁴ De Campos, above n 136.

⁶¹⁵ Starks and others, above n 298, at 121.

⁶¹⁶ Jarrad, above n 603.

⁶¹⁷ James L Werth, Mary M Lewis and Jessica M Richmond "Psychologists' Involvement with Terminally Ill Individuals Who are Making End-of-Life Decisions" (2009) 9(1) J Forensic Psychol Pract 82.

assessors interviewed saw it as unethical to *not* discuss the seeker's reasons for seeking AD as part of the assessment. In their view, not only was this the best way to assess the person's mental competence, but it was their ethical responsibility to provide seekers with advice about and/or access to treatments which might help them to become competent, such as prescription of an anti-depressant, even though strictly speaking this was outside of the legal mandate under the statute. A related issue is whether the appropriate person to be undertaking the competence assessment should be the seeker's existing mental health professional, or an independent practitioner, or possibly even these two people in consultation. The Washington guidelines recommend that the person undertaking the assessment not be the person's existing therapist, to avoid a role conflict.⁶¹⁸ However research participants believed that the seeker's existing therapist, if any, would be in the best position to provide relevant background information for assessing not only competence but also whether the person's wish is informed and free from undue influence. For example, where seekers are heavily medicated there may be no good baseline for assessing competence without prior acquaintance. It seems inconsistent that the laws recognise the importance of having two professional opinions to verify medical eligibility, but do not apply the same principle to mental eligibility.

Assessor capability is also an issue, with commentators noting that "before assuming such roles, psychologists need to make sure they are professionally (including culturally) competent, aware of their biases, and knowledgeable about cognitive and biopsychosociospiritual issues near the end of life".⁶¹⁹

In the Benelux countries and Switzerland, where a history of mental illness, including incipient dementia, does not *per se* disqualify seekers, competence assessment also remains problematic. Some Netherlands doctors are still confused generally about the concept of life fatigue and regard it as evidence of mental illness,⁶²⁰ even though the RDMA has clarified that it is not, *per se*.⁶²¹ Doctors' competence judgments may be inconsistent, for example, some viewing suicide attempts as an indicator of the client's seriousness about wanting to die while others viewed them as evidence of lacking mental competence, as has occurred

⁶¹⁸ WSPA Guidelines, above n 609.

⁶¹⁹ Werth, Lewis and Richmond, above n 617, at 89.

⁶²⁰ Bolt and others, above n 564.

⁶²¹ KNMG Position Paper, above n 575.

also where people refuse lifesaving treatments.⁶²² Doctors unaware of the ability of people with episodic and well-medicated psychiatric conditions to make competent decisions during their well phases can make competence judgments that inadvertently breach seekers' basic autonomy.⁶²³ The issue has begun to be addressed in recent years as supporters have considered that their respective societies have been ready to consider the issues. In each of the European jurisdictions, accessibility for this category of seekers has been guided by the relevant tribunals, which have variously ruled that additional care is needed in assessing competence and generally required that additional psychiatric assessment be undertaken.⁶²⁴ However across jurisdictions seekers continue to experience difficulty finding psychiatrists and psychologists willing to undertake AD assessments.⁶²⁵

3.3 Implementing the due care requirements

3.3.1 Waiting period

Several studies across jurisdictions have shown that from 30-40 percent of seekers die before their request can be processed fully,⁶²⁶ due often to timing requirements or delays. RRC Annual Reports have commented consistently on this problem.⁶²⁷ Where delays occur many seekers resort to other methods to die that add to their suffering, such as refusing treatments, food and fluids and in some instances suiciding in violent ways.⁶²⁸

US doctors interviewed agreed that the required 15 day waiting period was excessive, arbitrary and obstructive, failing to take into account the variable progression of terminal illnesses. The additional 2-day wait requirement in the US statutes was also seen as counterproductive, sometimes resulting in avoidable delays and stress where seekers had to redo both a verbal and written request because they were made out of order. Doctors assumed that the required waits were intended for both seeker and doctors to be convinced of the seeker's wish to die, to protect potentially vulnerable people from requesting AD precipitately. However US doctors interviewed saw one week as sufficient time for repeated visits and conversations to be clear about whether the seeker's wish was consistent, well-

⁶²² Mark D Sullivan and Stuart J Youngner "Depression, competence, and the right to refuse lifesaving medical treatment" (1994) 151 Am J Psychiatry 971.

⁶²³ Groenewoud and others, above n 134.

⁶²⁴ Haas, above n 255; KNMG Position Paper, above n 575.

⁶²⁵ Participants' comments; Bolt and others, above n 564.

⁶²⁶ See Onwuteaka-Philipsen and others, above n 395.

⁶²⁷ Griffiths, Weyers and Adams, above n 3 at 97.

⁶²⁸ Participants' comments; Snijdwind and others, above n 342.

informed and without pressure. If seekers were able to receive AD support from their family doctors or specialists, rather than having to resort to the AD provider agency, essential discussion and preparation could take place well before the formal request.

The purpose [15 day wait] was to give the person a goodly time to reflect and be truly certain, but I guess also to give the doctor time to check and recheck so *you* can be truly sure. Often we [AD provider agency doctor] have never met the person before, so we don't know whether they have a history of impulsivity or whatever, but heck, I've never assessed anyone who I thought had decided on physician-assisted dying on a whim! It's completely their last resort, when they are just *done*. And they can always change their mind later, and lots do. So it's [15 days] really just a sad obstacle for people who do come to us a tad late. *US AD provider agency doctor, 20 years AD experience*

They [seekers] cling onto that date [15 days away]. Actually they remember it as two weeks and they're all ready with that form [written request] a day early. And it's a *very* long vigil for the family. *Participating US doctor*

In contrast, the Benelux model, where the timing of the repeat requests is based on the progression of the seeker's condition and suffering, was experienced by research participants across jurisdictions as ideal in principle, rationally based and mostly effective at also accommodating urgent requests. Although it was anticipated that the Netherlands RRCs might form an opinion on what constituted a 'reasonably spaced interval', in fact those Committees have not found any need to do so, indicating that this framing of the wait period is appropriate.⁶²⁹

Of course it is always best if you know the patient for a long time and know about their wish too for a long time. If he [patient] suddenly says one day, 'oh I'm ready to die now, please give me the medicine', then it can be hard, because you [doctor] have to prepare yourself. It is not a normal procedure. ... Some patients do understand that it is difficult also for the doctor, and very complex, but often they are very weak and not thinking about what effect it can have on the doctor, because they just trust you to do the best for them. Actually all those days [assessment process] are very emotional, so that is why we [AD provider agency] always take some free time after that, to talk with each other [debrief]. *Participating Netherlands doctor*

3.3.2 Undue influence

All statutes require that the assessing doctors check for pressure on seekers to request AD, and all research participants saw that safeguard as important. However there is no equivalent check on whether seekers are being pressured to *not* have AD, including pressure from the doctors themselves or others in the health care team. There is no requirement for health practitioners to declare their own position on AD or a potential conflict of role or interest. Many research participants believed that, at the assessment phase, pressure against

⁶²⁹ Griffiths, Weyers and Adams, above n 3.

having AD came most often from health professionals, including doctors, nurses, social workers and chaplains, often providing unsolicited personal opinions. Pressure may be as subtle as a doctor advising the seeker to discuss their wish with family but not also advising them that doing so is not mandatory. Palliative care doctors' strong focus on resolving family opposition, rather than accepting the seeker's wish, can also be viewed as undue influence.⁶³⁰ Several studies have shown that seekers can be intimidated out of AD requests, or have them significantly delayed or obstructed, by palliative care professionals who are firmly opposed to AD.⁶³¹ Despite high decline rates in the US, doctors are not required to state their reasons, so it remains unclear to what extent it might include doctors' personal opposition to AD.⁶³²

Moreover doctors cannot be present at all family and health care team contacts with the seeker, are unlikely to have had training at detecting subtle coercion, including their own, and without such training cannot be relied on to be impartial in the process. Studies have found that some doctors declined requests more often if concern about 'being a burden to others' was even *one* of the reasons given by the seeker.⁶³³ Accordingly the requirements around undue influence, however essential and well-intended, may be largely ineffective in the absence of guidelines and/or training for identifying coercion and conflicts of interest.

3.3.3 Understanding the attending and consulting doctor roles

All statutes require a second opinion through a consulting doctor assessment (although perversely the Belgian statute allows the attending doctor to ignore that opinion; s §2). However where clarifying guidelines and training are lacking, doctors are often confused about the role of the consulting doctor – for example, is it meant to be a replication of the attending doctor's assessment, or a confirmation that the first doctor's assessment was rigorous? – and the statutes do not clarify that question. The statutes require the consulting doctor to be 'independent' of the attending doctor, but without defining independence. While doctors might take guidance from general principles (eg seeking a second opinion in other medical decision-making contexts), research participants preferred the statutes to define independence, largely to protect seekers from inadvertent collusion by doctors either strongly opposed to or strongly in favour of AD. A significant issue with the attending

⁶³⁰ Participants' comments; Gamondi and others, above n 199.

⁶³¹ Participants' comments; Gamondi and others, above n 199; Lewy, above n 10, at 57; Starks, above n 281.

⁶³² Loggers and others, above n 137; Sheahan, above n 133.

⁶³³ Ganzini and others, above n 123.

doctor role is the requirement that this doctor write the prescription, which deters doctors not wishing to be the effective agent of the death. With an ingestion system, doctors can avoid feeling instrumental by arguing that “the patient can always change their mind, so I’m not writing a death warrant, just a licence”, whereas doctors administering a lethal injection cannot reinterpret their role in that way.

3.3.4 When the assessing doctors disagree

In the absence of mechanisms for consistency in interpretation of the laws, achieving an accurate or even relevant assessment can be the luck of the draw for seekers depending on each assessing doctor’s subjective understanding of the requirements. Significant numbers of seekers have their requests either delayed or declined because the two assessing doctors disagree on one or more eligibility or due care requirements,⁶³⁴ including what amounts to ‘unbearable’ suffering.⁶³⁵ Research participants commented that such disagreements can result in unpleasant conflicts amongst doctors within a provider facility, service or sector that may adversely affect the seeker’s wellbeing as well as practitioners’ relationships while it is being played out.

One time got quite ugly when I couldn’t agree with the first doctor’s prognosis. There just wasn’t enough evidence, no biopsy data, nothing to go on, just a best guess really. She [seeker/facility resident] got very angry, the other doctor got angry because I wouldn’t support her prognosis and she thought I was showing her up, Compassion and Choices got very antagonistic, it was all just horrible. But, you know, it’s not just rubber-stamping, it’s my reputation and integrity on the line with my peers and my employers and my whole staff. You have to use the evidence, not just make a stab. I’m a doctor. *Participating US doctor*

Under the Belgian law, where the consulting doctor’s opinion is not binding, attending doctors have been known to change their mind at the final request and decline AD even where the consulting doctor approved it.⁶³⁶ Disagreements can result in the seeker dying due to an ensuing delay or decline, without any opportunity for a third opinion or an appeal.⁶³⁷ Thus the selection of doctors is a critical factor in assessment, with a far greater chance of being granted AD if at least one of the doctors has prior AD experience,⁶³⁸ though seekers may well be unaware of that factor.

⁶³⁴ Pasman and others, above n 125; Rietjens and others, above n 125.

⁶³⁵ Ibid.

⁶³⁶ Sheahan, above n 133.

⁶³⁷ Participants’ comments; Pasman and others, above n 125; Rietjens and others, above n 125.

⁶³⁸ Participants’ comments; Snijdewind and others, above n 342.

3.4 Lack of an appeals or complaints process

The lack of an appeals or complaints process may be a significant gap in the existing statutes, given the serious impact of being declined or delayed, which has resulted in many seekers taking desperate alternative action, such as starving themselves or even suiciding actively, essentially defeating their quest for a death free of agony.⁶³⁹ Lord Goff said in *Airedale National Health Service Trust v Bland* that the law's solution to declines in relation to seeking withdrawal of life support was to find another doctor with a different balance of values.⁶⁴⁰ However that suggestion referred to able family members seeking action, not dying and exhausted people, and to a context where there was no statute specifying required procedures. While (or perhaps because) the statutes are silent on whether declined seekers can either reapply or ask for a further assessment, no research participant knew of that occurring nor had ever thought to suggest it to a declined seeker, even assuming it were not too late.

There are several factors that indicate that an appeals and complaints process may be both appropriate and necessary, based on natural and procedural justice principles. First, even though up to 40 percent of seekers die while their requests are being processed, the statutes place no maximum time requirement on commencing or completing assessments. Nor do they intimate any possibility for seekers to have further assessments. They include no requirement for follow-up on a declined request other than informing the seeker of that. There are no provisions in the statutes for informing the person of the reasons for the decline, orally or in writing, nor for seeker referral for counselling in that context, nor for advising them when or under what circumstances they may renew their request. Although all statutes require the assessment certificates or similar and other associated documentation to be provided to a designated authority for review following an assisted death, none of the statutes requires that the assessment certificates or report be filed with the health authority prior to the death, and there is no requirement to file assessment process documentation with a review body if the seeker is declined.

The P-TEAG Report recommends against establishing complaints or appeals structures in the statute (Recommendations 24-25), on the grounds that the Canadian health systems have

⁶³⁹ For example, see BioEdge “Dutch doctor in hot water for refusing to approve euthanasia” (26 September 2015) <www.bioedge.org>.

⁶⁴⁰ *Airedale National Health Service Trust v Bland* [1993] AC 789 (HL).

existing structures sufficient for those purposes. However not all jurisdictions may have effective structures for complaints or appeals,⁶⁴¹ and even if they do, the existing statutes do not require seekers or families to be informed of those vehicles, and it cannot be assumed they will already be aware of them. The New Zealand's Health and Disability Commissioner Act 1994 (Part IV) provides for complaints to be made by any person about a health practitioner's conduct affecting a health consumer, but the processes set out in the Act are likely to take at least weeks, and possibly months, so are inadequate for the AD context.

Many declined seekers continue to want AD, but even where doctors are aware of that they commonly decline to discuss the seeker's psychological reactions or refer them for support.⁶⁴² Hospice personnel interviewed commented that declined requests are sometimes followed up by an unsolicited visit from the chaplain to people who had firmly declined that offer. Many doctors interviewed related the sense of profound abandonment and hopelessness that some seekers experience when doctors respond less than honestly to their requests. Ironically, a concern voiced often by AD opponents is that legalising it will erode trust between doctors and clients, who will think the doctors do not care enough to keep them alive, when in practice the converse occurs.⁶⁴³

As for procedural gaps, there is no requirement in the statutes that an assessing doctor have any particular competencies or experience in AD assessments, even though training should reasonably be expected for such a critical medical procedure, there are no qualifying criteria in the statutes for either the attending or consulting doctor other than registration, and with the exception of The Netherlands, there is no guidance for what constitutes an 'independent' opinion. Crucially, there are no requirements for assessing doctors to declare a role conflict, conflict of interest or their level of opposition to or sympathy for AD. Ultimately, seekers are highly vulnerable to the availability, personal beliefs and attributes and variable expertise of the doctors undertaking the assessments.⁶⁴⁴ Given the evidence of

⁶⁴¹ For example, New Zealand does not have a specific structure for reviewing mental competence appeals.

⁶⁴² H Pasman and others "What happens after a request for euthanasia is refused? Qualitative interviews with patients, relatives and physicians" (2013) 92 Patient Educ Couns 313.

⁶⁴³ Participants' comments; Battin and others, above 35; H Pasman and others, above n 642.

⁶⁴⁴ Participants' comments; Anthony Back and others "Clinician-Patient Interactions About Requests for Physician-Assisted Suicide: A Patient and Family View" (2002) 162 Arch Intern Med 1257; Gamondi and others, n 199.

gatekeeping of requests by doctors and others, whatever the motives or reasons, a system for complaints and/or appeals should be available.

4 What has enabled an effective assessment process, and what more is needed?

The main barriers to an effective assessment process appear to be:⁶⁴⁵ unavailability of willing and competent doctors; inconsistent or inaccurate interpretation of the eligibility and due care requirements in the absence of clear practice standards; assessment timing and delays; and insufficient information, advocacy and options for complaints or appeals for seekers. Each of these issues has been partially mitigated by actions taken primarily by the AD provider agencies, but other strategies are needed to address them effectively.

As for Parts 1 and 2, key statutory enablers needed to support effective and timely AD assessment are summarised in **Table 2** (p 199). These are focused mostly on providing infrastructure supports and robust guidance mechanisms to facilitate health practitioner participation.

4.1 Availability of willing and competent doctors

Doctors' willingness and capability to undertake AD assessments are separate but related factors because perceived lack of capability contributes to unwillingness. To undertake fair and accurate assessments, doctors need to have several core competencies reflecting the eligibility and due care requirements, and the effective pathways to those competencies are written guidelines, training and experience. To date the AD provider agencies have taken the initiative and responsibility for providing those supports (albeit with strong support in The Netherlands from the RDMA and the RRCs, see below), with varying success. The annual reports for the RRCs have provided safe direction for Netherlands doctors (and for those in Belgium due to the similarity of the statutes), by reporting (anonymously) on the tiny proportion of instances each year where doctors may not have attended sufficiently to the due care requirements, clarifying their errors. The AD providers in all jurisdictions have achieved some success in encouraging family doctor participation, though usually not beyond their existing clients, but little success in engaging palliative care doctors or other

⁶⁴⁵ The term 'effective' refers here to an assessment undertaken in a timely manner and in compliance with the provisions of the law, regardless of the ultimate decision; see Xanthaki, above n 109.

specialists. The recent Belgian collaboration with the palliative care professional bodies has greatly improved referral of requests, but not participation in assessment.

In both recruitment and capacity-building, the SCEN organisation was seen by research participants as exemplary. The evident value of the SCEN system is that doctors engaging in AD assessment, whether on a first or subsequent occasion, have expert guidance available to interpret the legal requirements, provide logistical and emotional support and answer any uncertainties. A supported experience free of errors and anxieties encourages continuing participation by doctors and nurses. Appreciating this service, many Netherlands hospitals and aged care facilities have established policy requiring a SCEN doctor in the consulting role to ensure that all processes satisfy the RRCs. The RDMA explicitly recommends using a SCEN doctor in all instances.⁶⁴⁶ Some end-of-life care units in Swiss and Belgian hospitals are developing decision-making protocols for doctors and providing mentoring similar to the SCEN system.⁶⁴⁷ To support mentoring, responsibility needs to be specifically allocated in the statute to the health practitioner regulatory bodies for the development of authorised evidence-based AD assessment standards and guidelines and accredited training at both undergraduate and continuing education levels [§1.XI].

However the experience of research participants was that it had taken decades to build doctor engagement in this way. Early capability- and capacity-building could be facilitated via a statutory infrastructure for recruiting and training doctors. As suggested in Part 2, many research participants saw establishing a SCEN system by statute as an ideal solution to doctor availability by providing a structure that ensures safe, professional, timely assessments by registered doctors that are known to adhere to the provisions of the law [§2.XI]. However such a system should not be mandatory (as proposed in the 2015 EOLC Bill), as that would exclude doctors who are willing to undertake the consulting role on an occasional basis or for their own clients, impede collegial recruitment, and might also deter doctors averse to mandatory systems. Rather, any such system established by statute should be under the oversight of the relevant government health authority, whose role was seen by doctors interviewed as crucial to provide credibility and confidence to such a structure. Such a structure could register both willing and unwilling doctors, with notification of that listing annually to give doctors the opportunity to modify their listing status at any time.

⁶⁴⁶ KNMG Position Paper, above n 575.

⁶⁴⁷ Participants' comments; Pereira and others, above n 540.

The statute might also require availability of sufficient assessors, both doctors and mental health professionals, with the necessary competencies and a sympathy in principle for AD [§2.V]. For example, the New Zealand abortion law delegates responsibility to the health authority to ensure a sufficient supply across the regions of “certifying consultants” (s 30, 30(2) and 30(4)) who are “competent” (s 21(1)(b)), not opposed in principle to abortion (s 20(5)), and registered annually (s 30(6)), which requires them demonstrating the relevant competencies.

To facilitate access to assessment for seekers in remote locations or too ill to attend a clinic, outreach systems are needed. Mobile ‘clinics’ that go to the seeker, like the Levenseindeklinik, address those barriers and also result in better contextual information to inform the assessment. AD assessments could be undertaken by videocommunications link, provided always that they were under the direction of a doctor and a clinician were present with the seeker [§2.VII], avoiding assessment delays and addressing rural access problems. ‘Telehealth’ and ‘telemedicine’ assessment and consultation has been found effective for many medical conditions, is generally accepted by health insurers in the US and UK,⁶⁴⁸ and is being used increasingly in New Zealand for a wide range of health consultations.⁶⁴⁹ A 2015 American Medical Association position paper encourages its use in primary care settings where a registered clinician of some kind is available on site.⁶⁵⁰ Given Canada’s size and the absence of any doctor in some remote locations, the P-TEAG Report recommends explicit statutory provision for this option or alternatively for bringing seekers to an assessing doctor at government expense, as currently for other medical services (Recommendation 23). In the Australian geographic context, a spokesperson for the Australian and New Zealand Royal College of Psychiatrists (ANZRCP) recently suggested that “...a face-to-face assessment would always be preferable, but... using video assessment would be the minimum standard that could be expected...”⁶⁵¹

⁶⁴⁸ Michael McCarthy “US physician group calls for expanded role for telemedicine in medical practice” (2015) 351 BMJ h4799.

⁶⁴⁹ Ministry of Health “Telehealth enhances rural healthcare” (18 June 2015) <www.health.govt.nz>.

⁶⁵⁰ Hilary Daniel and Lois Snyder Sulmasy “Policy recommendations to guide the use of telemedicine in primary care settings: An American College of Physicians position paper” (2015) 163(10) *Ann Intern Med* 787; Ateev Mehrotra and others “A comparison of care at e-visits and physician office visits for sinusitis and urinary tract infection” (2013) 173(1) *JAMA Intern Med* 72.

⁶⁵¹ Dr Roderick McKay, Australian and New Zealand Royal College of Psychiatrists (Proof Committee Hansard [Australia], 15 October 2014) 2.

Many commentators have mooted that, for both capacity and capability reasons, nurse practitioners and nurses might be authorised to undertake the functions currently delegated to doctors only.⁶⁵² Many studies have demonstrated the value of nurses' AD participation:⁶⁵³ nurses typically have more contact with seekers than other health practitioners across a range of everyday contexts, so are likely to have a better understanding of the seeker's emotional life; they have a vital role in managing AD negotiations involving families; they were commonly seen as more approachable than doctors and having better communication skills for dealing with the high levels of emotionality involved in discussing AD, due to training that focuses on a more holistic approach to health care provision;⁶⁵⁴ and nursing professional bodies tend to hold less absolute opposition to AD.⁶⁵⁵ Research participants believed that nurses working in end-of-life care would operate highly effectively in all AD functions because their roles would not change significantly, given their experience in other end-of-life decision-making and health care, such as withdrawal and withholding of life-prolonging treatments. Levensideklinik nurses have a major role already, undertaking the initial eligibility assessment as well as assisting AD administration. As a minimum, AD statutes could specify that AD assessments take into account the views of the health care team [§2.VII].

Research participants saw strong arguments for also authorising nurse practitioners to undertake all aspects of AD provision except medical diagnosis and prognosis and mental competence assessments [§3.XIII]. The NZMA recently made a similar suggestion, on the grounds that, in its view, AD is not an ethically appropriate role for doctors.⁶⁵⁶ Any statutory role for nurses needs thorough consideration by nursing and medical regulating bodies and colleges before being written into legislation, to ensure that all implications for practice and impacts on seekers and health practitioners generally are fully canvassed. After lengthy deliberation, the P-TEAG has recommended that nurse practitioners be given the same AD authorisations as doctors to assess, prescribe and administer, and that registered nurses be authorised to prescribe and administer AD under the direction of a doctor where no doctor

⁶⁵² Participants' comments and following footnotes 653-654.

⁶⁵³ Participants' comments; Bernadette Dierckx de Casterlè and others "Nurses' views on their involvement in euthanasia: a qualitative study in Flanders (Belgium)" (2006) 32 J Med Ethics 187; Griffiths, Weyers and Adams, above n 3; Trowell, above 144; Woods and Asher, above 527.

⁶⁵⁴ These points are discussed in detail in the External Panel Report, above n 296, at 82-84.

⁶⁵⁵ Herring, above n 51.

⁶⁵⁶ Cliff Taylor "Caring or killing? GPs speak out in ongoing euthanasia debate" *NZ Doctor* (online ed, Wellington, 8 August 2015).

or nurse practitioner is available (Recommendation 8) and the Expert Panel Report appears to support that approach.

To avoid perceived paperwork requirements deterring doctor participation, regulations could specify accessible online recording and reporting systems [§1.VI], as already occurs with many aspects of medical practice, and having assessment documentation lodged with the health authority that has AD oversight [§1.VI].

4.2 Interpreting the eligibility and due care requirements

4.2.1 Terminal illness requirement

Doctors working with the US AD provider agencies believed that, short of changing the eligibility criteria (which should nonetheless be an option), having doctors available willing to make confident diagnostic and prognostic judgments was the only effective way to address other doctors' unwillingness to do so. Matching the areas of expertise of assessing doctors to the particular medical condition of the seeker was an obvious way to support accurate diagnosis and prognosis, and some statutes have suggested doing so by defining the consulting doctor as "qualified by specialty or experience" (s 127.800 §1.01(4)). However that can only be achieved if specialists are willing to become involved in AD, at least as the consulting doctor, or participating doctors' experience is acknowledged in the profession. The Swiss system of requesting the seeker's current attending doctor, whether specialist or family doctor, to provide a diagnostic report only, without participating in assessment, was a largely effective compromise that most non-participating doctors felt comfortable to undertake. The availability of good practice guidelines, including standards for decisional confidence, together with accredited training might well encourage more family doctors and specialists to participate and could be valuable more generally for health practitioners working in end-of-life care settings.

4.2.2 Expanding eligibility

Although the eligibility requirement of a terminal illness was an intended barrier in the US statutes, this section briefly reviews its appropriateness, given the difficulties in determining prognosis as outlined earlier. The terminal illness requirement was determined by those drafting the Oregon statute, and subsequently the other US states, to "create a ledge in the slippery slope" for voters fearful of the latter, not because it was seen as the most appropriate eligibility criterion. Removing that requirement would make AD available to

people in equally unbearable (to them) conditions, in particular genetic ‘wasting’ illnesses and neurological disorders that cause profound suffering, notably motor neurone disease.

Recent years have seen the interpretation of eligibility expanded in the European jurisdictions, as was always anticipated in these countries.⁶⁵⁷ The Netherlands law was purposely worded to provide broad eligibility, and that was confirmed by the Netherlands Supreme Court in the *Brongersma* case,⁶⁵⁸ which held variously that under the statute ‘disease’ could include a psychiatric condition, provided that the other eligibility conditions were met. *Brongersma* also held that ‘life fatigue’⁶⁵⁹ was not an acceptable reason for receiving AD, but the RDMA and RRCs have regularly updated or affirmed policy direction that has been relied on by Netherlands (and Belgian) doctors to provide AD on grounds of life fatigue, provided there is also evidence of a medical condition and unbearable and hopeless suffering.⁶⁶⁰ In Switzerland, EXIT Suisse Romande expanded eligibility in 2013, in response to democratic membership vote, to include multiple irreversible degenerative medical conditions that are aging-related and it is now considering extending eligibility to encompass life fatigue, given apparent demand and the prevalence of life fatigue as an aspect of suffering. In several countries there have been proposals that people over 75 or 80 be given a legal right to ‘rational suicide’, and some RTDs have policy supporting that option.⁶⁶¹

Since early legalisation in Oregon and The Netherlands, there has been significant movement towards accepting AD within the disability sector, which now appears to have two distinct but potentially reconcilable perspectives.⁶⁶² On the one hand, opponents remain concerned that legalising AD will result in pressure, subtle or otherwise, for people with disabilities to request AD out of a sense of obligation to not be a ‘burden on society’; this view was voiced repeatedly in the 2014 House of Lords debate on Lord Falconer’s Bill.⁶⁶³ In contrast, a growing lobby is demanding that, where AD is legalised, it is discriminatory for it not to be fully available to people with profoundly disabling conditions that make

⁶⁵⁷ Participants’ comments; Griffiths, Weyers and Adams, above n 3; KNMG Position Paper, above n 575.

⁶⁵⁸ *Sutorius/Brongersma* Nederlandse Jurisprudentie 2003, no 167.

⁶⁵⁹ Also referred to commonly as the ‘completed life’; Chambaere and others, above n 119.

⁶⁶⁰ KNMG Position Paper, above n 575.

⁶⁶¹ Participants’ comments; “Holland proposes giving over-70s the right to die if they ‘consider their lives complete’” *Daily Mail* (online ed, London, 10 March 2010); Society for Old Age Rational Suicide <www.soars.org.uk>.

⁶⁶² Drum and others, above n 304.

⁶⁶³ Hansard (18 July 2014) 755 UKHL.

remaining alive intolerable to them.⁶⁶⁴ The Disability Advisory Council of Dying with Dignity Canada recently stated that “any measures taken to protect the individuals with disabilities [should] not create barriers to physician assisted dying” for people who are otherwise eligible.⁶⁶⁵

Internationally, a trend is apparent for Bills that prefer the European model of broader eligibility based on suffering rather than terminal illness, with Bills in New Zealand, several Australian states and Canada all adopting that model.⁶⁶⁶ The recent UK Bills are the exceptions. The ethical arguments for focusing eligibility on suffering have been increasing in recent years as more ethicists view the legal fictions developed by the courts to justify withholding treatments where they are deemed futile, in particular the ‘double effect’ distinctions amongst motive, intention, causation and foresight, as specious, “incoherent and morally irrelevant”,⁶⁶⁷ and generally unsatisfactory,⁶⁶⁸ not least because they allow AD to be provided under the radar, without any accountability for doctors’ clinical conduct,⁶⁶⁹ and therefore no robust way to assess its frequency.⁶⁷⁰ There is also evidence that doctors surveyed on illegal AD provision, even anonymously, frequently do not answer honestly.⁶⁷¹ These commentators note that “doctors who administer high doses of a pain reliever do not always find it easy to interpret their own motives”,⁶⁷² which is seen as the primary reason for the high levels of under-reporting of AD in Wallonia, and recommend statutory regulation clarifying what is and is not permissible. Some doctors working in intensive care units were keen to see regulation also for futile therapy and withdrawal of treatment generally, noting that, in Belgium at least, treatment withdrawal or withholding occurs 10 times more often than AD but without accountability for whether such withdrawal is intended to hasten death.⁶⁷³ Accordingly there is a strong argument for regulating terminal

⁶⁶⁴ Hendry and others, above n 62; Herring, above n 51; Sumner, above n 10; Kathryn L Tucker, Megan N Harper and Paul A Spiers “The Sky Is Not Falling: Disability and Aid-In-Dying” in Timothy H Lillie and James L Werth (eds) *End-of-Life Issues and Persons with Disabilities* (PRO-ED, Austin (TX), 2007) 135.

⁶⁶⁵ Cited in the External Panel Report, above n 296, at 96.

⁶⁶⁶ Samantha Halliday “Comparative reflections upon the Assisted Dying Bill 2013. A plea for a more European approach” (2013) 13 *Med Law Int* 135; Ross, above n 345. Note that Canada’s federal legislation was ultimately less broad than recommended by the *Carter* judgment and subsequent advisory committees.

⁶⁶⁷ Jackson, above n 75, at 912.

⁶⁶⁸ Williams, above n 42.

⁶⁶⁹ Johnson, above n 143.

⁶⁷⁰ Jackson, above n 75.

⁶⁷¹ Alan F Merry and others “Doctors’ willingness to give honest answers about end-of-life practices: a cross-sectional study” (2013) 3 *BMJ Open* e002598.

⁶⁷² Lewy, above n 10, at 61.

⁶⁷³ Participants’ comments; Jean-Louis Vincent and others “‘Piece’ of mind: End of life in the intensive care unit Statement of the Belgian Society of Intensive Care Medicine” (2014) 29 *J Crit Care* 174.

sedation and CPS [§2.I], and potentially all hastened death options, including refusal of life-prolonging treatments, to provide health practitioner accountability for all end-of-life responses. In general, commentators welcome the “undoubtedly increased ... trend towards proceduralism and legalism in end-of-life care” where that clarifies accountabilities and supports intelligent participation, not least because it raises the due care threshold for all other kinds of EOL options so that it becomes “clear to professionals that all end-of-life interventions have their own indications and are not interchangeable”.⁶⁷⁴

AD proponents highlight evidence of the absence of any ‘slippery slope’ in Europe to support eligibility focused on suffering rather than requiring terminal illness. Many researchers and ethicists alike view the Netherlands and Belgian expansion of approval for AD in recent years to seekers with mental health conditions, multiple conditions related to old age and life fatigue as a reflection not of any ‘slippery slope’ laxness on the part of doctors, but of societal acceptance, changes in population demographics and the maturing of the original intent of the laws.⁶⁷⁵ Moreover, expanding eligibility in The Netherlands has apparently resulted in tighter application of the procedural requirements.⁶⁷⁶ Given the now extensive evidence refuting the slippery slope hypothesis, it is hard to find a rational argument for retaining terminal illness as a condition of eligibility. Only US research participants could not envisage AD becoming accessible to people other than the terminally ill in the foreseeable future, though most supported such a change in principle.

Of course we’d love to see it [AD] available to people with non-terminal conditions, we get requests regularly from people with terrible suffering because of neurological conditions, their doctors even support it sometimes, and it’s heartbreaking to have to tell them no. But that’d be a hard sell here [US], unless there was a major drive from the disability sector, and that’s not happening any time soon. *Participating doctor*

A possible option for relaxing the terminal illness requirement in unfederated jurisdictions might be to follow Québec’s approach and require evidence of a medical condition plus unbearable suffering and the seeker being “at end of life”, leaving it to the courts to determine the range of factors that indicate end of life. For the avoidance of doubts that might create barriers, the Tasmanian Bill defines a medical condition for the purposes of

⁶⁷⁴ Vanden Berghe and others, above n 505, at 270.

⁶⁷⁵ Participants comments; Snijdwind and others, above n 342.

⁶⁷⁶ Griffiths, Weyers and Adams, above n 3; Regional Euthanasia Review Committees *Annual Report 2012* (The Hague, July 2013).

AD eligibility as caused by “illness, disease or injury” (section 11), while the draft Canadian legislation defines it as including “illness, disease or disability”.⁶⁷⁷

4.2.3 Unbearable suffering

The challenges in accepting the seeker’s experience of suffering have been addressed successfully in SCEN and LEIF in two main ways – through training and mentoring, and by excluding from registration doctors who cannot accept the subjectivity and essentially existential/spiritual nature of suffering. Those protections for seekers could also be achieved through statutory requirements that participating doctors be both trained and supportive in principle of all legal end-of-life care options [§2.V]. Commentators have deemed it unwise, and probably impossible, for the statutes to define ‘unbearable’ in any meaningful way, given the subjectivity of the experience,⁶⁷⁸ but some believed that the statutes should use stronger phrasing to clarify the unimpeachability of the seeker’s subjective experience [§3.VII]. Some also commented that ‘constant’ suffering should be replaced by ‘enduring’ suffering, since the experience of suffering fluctuates significantly in dying people, affecting seekers’ decision-making.⁶⁷⁹ Since doctors cannot be in the seeker’s skin, accepting the subjectivity of suffering remains difficult for some, even though health professionals now routinely accept their clients’ subjective ratings of physical pain. Acceptance of the person’s suffering was identified by Netherlands participants as a defining factor in the effectiveness of the Levensidekliniek’s work, where even the 75 percent of seekers who are declined for the second time are usually accepting of that outcome because their suffering has been acknowledged,⁶⁸⁰ and often also because their suffering, which is typically psychological for these particular seekers, is then addressed in ways that make it now bearable for them. Starks suggests that doctors working in end-of-life care generally need better training in understanding the complexity of suffering and its relationship to pain and the end-of-life context, both for assessing AD eligibility and to provide appropriate treatment options for all.⁶⁸¹ Doing so requires that doctors be willing to

⁶⁷⁷ Downie, above n 44 at 4; note, the draft legislation does not include section numbers.

⁶⁷⁸ Participants’ comments; KNMG Position Paper, above n 575.

⁶⁷⁹ Johansen and others, above n 583; Adams and Nys, above n 127; see also the declaratory order in *Carter* at [1393].

⁶⁸⁰ Participants’ comments; Snijdewind and others, above n 342.

⁶⁸¹ Starks and others, above n 281.

meet the seeker as an autonomous person and be a facilitator of decision-making, rather than driving it.⁶⁸²

4.2.4 Mental competence assessment

With up to one fifth of seekers across jurisdictions being declined for perceived depression,⁶⁸³ responding appropriately to requests from seekers with apparent psychiatric symptoms requires better strategies. Following the 1994 CAL Report and the Netherlands Supreme Court decision in *Chabot* that the seeker's competence should not be presumed lacking on the grounds of a psychiatric condition,⁶⁸⁴ the RDMA developed guidelines for assessing competence in such cases. Seekers with a history of mental illness can be well enough to make competent decisions and “may have a *realistic* estimation that hope is illusory and the prospect of relief of suffering is imaginary”.⁶⁸⁵ Increasingly, based on strong philosophical reasoning as well as medical evidence of the safety of cautious AD decision-making, arguments are being made, supporting the views of many research participants, that “[j]urisdictions that are considering, or that have, decriminalised assisted dying are discriminating unfairly against patients suffering from treatment-resistant depression if they exclude such patients from the class of citizens entitled to receive assistance in dying”.⁶⁸⁶

In The Netherlands and Belgium, the Levenseindekliniek and ULteam services were established respectively by the NVVE and LEIF in 2011-2012 to provide AD assessment services,⁶⁸⁷ and administration where approved, to seekers whose doctors have declined them. Their referrals are primarily of people with apparent mental health conditions or who are seeking AD for reasons of “life fatigue” or other reasons where the doctor was uncertain about eligibility or had ethical objections or anxieties about complying with the law. The services are staffed by multidisciplinary teams comprising end-of-life care doctors,

⁶⁸² Participants' comments; R Jeffery Kohlwes and others “Physicians' responses to patients' requests for physician-assisted suicide” (2001) 161(5) Arch Int Med 657.

⁶⁸³ Levene and Parker, above n 598.

⁶⁸⁴ *Chabot*, Nederlandse Jurisprudentie 1994, no 656; Royal Dutch Medical Association “Report of the Commission on the Acceptability of Termination of Life” (1994).

⁶⁸⁵ Ron Berghmans, Guy Widdershoven and Ineke Widdershoven-Heerding “Physician-assisted suicide in psychiatry and loss of hope” (2013) 36(5) Int J Law Psychiat 436 at 442; emphasis added.

⁶⁸⁶ Udo Schüklenk and Suzanne van de Vathorst “Treatment-resistant major depressive disorder and assisted dying” (2015) 41(8) J Med Ethics 577 at 577; see also Dominic Wilkinson “Safeguarding choice at the end of life” (2015) 41(8) J Med Ethics 575.

⁶⁸⁷ For an outline of the services provided by each organisation, see Snijdewind and others, above n 342 (Levenseindekliniek), and Lieve Thienpont and others “Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study” (2015) 5 BMJ Open e007454 (ULteam).

psychiatrists, oncologists, ethicists and nurses who have specialist training and knowledge in end-of-life care and differential diagnosis of endemic versus situational or episodic mental illnesses. Through similar engagement processes to those used by SCEN and LEIF, their specialist expertise can be drawn on by any doctors or other health practitioners involved in AD assessments, and their expertise has been acknowledged recently by the Netherlands courts.⁶⁸⁸ Because these services are now funded as registered health providers for insurance purposes, they are vigilant about operating strictly within the terms of their respective statutes, giving confidence to the public and health professions that they are providing the services legally and professionally. The Levenseindekliniek personnel interviewed saw it as a “laboratory exploring the flexibility and potential scope” of the Netherlands law. From using these services, more psychiatrists and doctors have become willing and confident to undertake assessments for seekers with mental health conditions, including early stage dementia, with positive seeker outcomes. For example, the numbers of competent seekers with early dementia who were granted AD doubled between 2012 (42) and 2013 (97), almost all of these endorsed by the RRCs,⁶⁸⁹ and that increase was viewed as a trend. Research participants noted that an important benefit of these services for seekers is that many of them finally receive a level of effective psychiatric care that they have not managed to access previously, resulting in them withdrawing their requests for AD. Similarly, valuable insights are being gained in the sector around suicide ideation amongst people with mental health conditions that can help prevent suicide.

In the US, earlier calls for mandatory competence assessments have largely been retracted. Commentators now acknowledge that, with mentoring and relevant experience, doctors can undertake this task safely in the AD context,⁶⁹⁰ and the British Columbia Civil Liberties Association has expressed a view that any such “barriers erected to qualifying individuals accessing physician-assisted dying” might be challenged as unconstitutional in Canada.⁶⁹¹ Some have also suggested that, without relevant experience and training in working with people at end-of-life, mental health professionals may actually have lesser ability to

⁶⁸⁸ BioEdge “Court tussle over right to euthanase Dutch woman with dementia” (7 August 2015) <www.bioedge.org>.

⁶⁸⁹ Regional Euthanasia Review Committees *Annual Report 2013* (The Hague, August 2014).

⁶⁹⁰ See discussion in the External Panel Report, above n 296, at 80-82.

⁶⁹¹ Cited in the External Panel Report, above n 296, at 96. Several other submissions were received by the External Panel (see pp 96-97) emphasising that access to AD must not be controlled by a court or tribunal, as has been proposed in the UK, citing the ruling in *R v Morgenthau* [1988] 1 SCR 30 that found the use of such a process by hospital committees unconstitutional in Canada.

undertake accurate competence assessments than specialist end-of-life care health practitioners.⁶⁹²

Some basic legal principles should guide regulation. Firstly, at least those seekers with no history of mental illness should be entitled to a presumption of competence, as applies under health regulations generally [§1.II],⁶⁹³ and not be subject to additional scrutiny simply because the statutes require confirmation of competence. Where there is a continuous history of mental illness, the principle of rigorous scrutiny of competence established by case law would still apply.⁶⁹⁴ However the onus should be on the assessing health practitioners to show good evidence of incompetence, as was held in the Canadian decision in *Malette v Shulman*, where the court prioritised autonomy over sanctity of life and saw that principle as reflected in an onus on the assessing doctor to demonstrate evidence inconsistent with the person's competence.⁶⁹⁵

In addition, procedural justice principles arguably require that seekers be fully involved in the procedures surrounding their assessments, including a right to receive all relevant documentation and to be advised of their rights to appeal, complain and/or be informed about any option either to reapply for AD if they are declined [§3.II and §3.VII], or to have further treatments that may facilitate developing the competence required for AD requests. Since declines occur disproportionately with seekers who have experienced psychiatric conditions, it is especially important to ensure that declines at both request and assessment are managed sympathetically and effectively so that declined seekers are not abandoned with the refusal [§3.VII]. To avoid seekers being referred for mental competence assessments as an avoidance strategy by doctors, the statute could require doctors wishing to make such a referral to do so within a specified time limit from the first request *and* to provide a description of the symptoms prompting the referral in writing to both the seeker and the mental health practitioner [§3.VIII], as is accepted practice for specialist referrals generally.

Research participants suggested a range of ways in which competence assessment by both assessing doctors and specialists could be made more effective for all involved, each of

⁶⁹² Participants' comments; Ganzini and others, above 123.

⁶⁹³ For example, Right 7(2) and (3), New Zealand Code of Rights.

⁶⁹⁴ Eg *Chabot*, above n 684.

⁶⁹⁵ *Malette v Shulman et al* [1990] 72 OR (2d) 417.

which could, in principle, be provided for in the statute or regulations. A statutory requirement for ‘competent’ consulting doctors and mental health professionals would prompt a further delegation of responsibility for medical bodies to ensure the provision of accredited training and expertly developed, evidence-based guidelines and protocols. As gatekeepers, these professionals need clear guidelines about the purposes of the competence assessments and when they should not be needed, to avoid adding unnecessarily to seekers’ stress.⁶⁹⁶ A protocol for competence assessment might suggest an intermediate step via a discussion between an uncertain doctor and an appropriately trained specialist assessor, to discuss the doctor’s reasons for uncertainty. This approach was already being used by some participating psychologists to “weed out the ones [cases] that won’t meet the criteria for other reasons”. The competence assessors interviewed saw their role as a type of triage, to help seekers to find a legal pathway to achieve AD where they are otherwise eligible, as has occurred for many years with refusal cases.⁶⁹⁷ Some assessors used a quasi-therapeutic process involving the competence assessor, the attending doctor and other members of the health care team to determine a path ahead where the seeker lacks competence due only to currently inadequate or inappropriate medical treatments. Several research participants highlighted a need for hospital teams to collaborate more effectively in responding to AD requests, as occurs in the Levenseindekliniek and has been recommended by health practitioners based on experience and evidence of outcomes.⁶⁹⁸

The most people we [Levenseindekliniek] see are standing out in the cold because their doctor is too afraid to do anything for them. We try to have that doctor stay with the patient, so they can see that what they think must be a psychiatric symptom is not so, it can be the patient’s way that they react to their situation. Of course sometimes the person is really very unwell [psychologically], so then we must see if they have the right treatment for that condition. A big problem is that the doctors who send us these patients are afraid of too many things. They don’t want to say no to their patient who is desperate but also they don’t want to give the euthanasia himself, and they don’t want to make mistakes. So that is our job, to help them both [patient and doctor]. ... Another big problem is that people are getting very old now, 90 or over 100, and doctors are not trained how to talk with people who are so very old and how to understand what their life can be like at that age. When they can’t make the person better, they don’t know what to do next. *Levenseindekliniek personnel*

Given the lack of mental health practitioners with end-of-life expertise, the relative infrequency with which competence assessments are needed and the potential impact on an

⁶⁹⁶ Jerome Sobel “Panel on Dementia” (panel discussion at the World Federation of Right to Die Societies Conference, Chicago Illinois, 17-21 September 2014).

⁶⁹⁷ Curnow, above n 430; Sullivan and Youngner, above n 622.

⁶⁹⁸ Marianne K Dees and others “Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives and treating physicians in the Netherlands” (2013) 27 *Palliat Med* 27.

otherwise eligible seeker, a registration system for specialist competence assessors may be desirable with formal certification for the role, based on end-of-life care experience and training specifically for AD competence assessment. Development of guidelines, protocols and training should be the delegated responsibility of the health authority in collaboration with the relevant psychiatry and psychology regulating bodies [§1.XI], and that guidance should include a clear understanding of the legal requirements, knowledge of relevant religious and other cultural belief systems significant to the particular jurisdiction, and due respect for the particular spiritual situation of seekers. Several research participants also believed that other end-of-life professionals, in particular social workers and nurses, could, with the same training, be authorised by the statutes to undertake specialist competence assessments [§1.XIII].

4.2.5 Avoiding delays

The most effective strategies perceived by research participants to mitigate delays obstructive to AD were to: minimise and rationalise any mandatory waiting period; facilitate early actioning of initial requests, for example by imposing maximum statutory time frames on referrals and assessments; establish a statutory breach of and penalties for obstructing an assessment; enable continuity of care so that the AD attending doctor already knows the seeker's condition; and implement good advance care planning. US doctors interviewed approved the Benelux approach for its rational basis and sympathy to genuinely urgent situations, in preference to a fixed required time, and because it places responsibility on the health care team to monitor the seeker's progression, allows for normal fluctuation in the experience of suffering and makes the seeker the driver in decision-making. That conclusion was reached also by the P-TEAG Report and the External Panel Report. Several palliative care doctors commented that people at end of life can have very sudden and dramatic downturns in their condition that simply do not allow for either early warning or an extended wait.

Given the often crucial importance of a quick response to seeker access, maximum time frames, subject to extension with seeker approval, could be specified in the statutes to prompt actioning requests and commencing assessments.⁶⁹⁹ The New Zealand abortion law (s 33(6)) specifies a 14 day time limit on undertaking the assessment, after which the doctor

⁶⁹⁹ The Netherlands Regional Euthanasia Review Committee *Annual Report 2002* recommended that the assessment period never amount to several weeks.

must report immediately to the health authority explaining the delay. Any argument that an AD seeker's need does not have a physiological time frame, as does pregnancy termination, ignores that person's subjective suffering and right to an assessment. To support adherence with timing requirements, the statutes could provide for a breach of the statute where any person wilfully or negligently fails to comply with them or otherwise frustrates the expressed wish of a seeker, together with a priority response by a designated person in the health authority for addressing complaints [§2.X]. In a bold move, Orentlicher and colleagues have intimated recently that US doctors might vary from the 15-day waiting requirement, noting that:⁷⁰⁰

... the committee believes recommending a mandatory 15-day waiting period exposes some patients to unnecessary and intolerable pain and suffering, and is not required in all cases. *This can be left to physician discretion.*

4.2.6 Undue influence

Research participants saw the requirement to check for coercion on seekers as vital, and the case law on refusal of treatment supports the need to protect against “the vitiating effect of outside influence”.⁷⁰¹ However that protection needs to be explicitly applied by the statutes to prevent pressure on a seeker from any person to have or to *not* have AD. Training is needed for health practitioners to identify their own biases and the potential for those to place pressure on seekers, however well-intended, to not have AD, and statutory provisions for opposing or ambivalent health practitioners to declare a conflict of interest and refer on would support that [§1.V]. Subtle or indirect coercion of seekers by health practitioners might also be prevented by regulating CPS and terminal sedation, and by requiring a response to any requests for hastened death in any form, including treatment refusals [§1.III].

To ensure that seekers' decisions and requests are properly “informed” or “well-considered”, as required by all of the statutes, the Tasmanian Bill (section 12(3)) details explicitly the categories of information that must be given to seekers by the attending doctor prior to undertaking an assessment. Those include comprehensive information about the assessment processes, eligibility and due care requirements, the various options and requirements for AD administration and any potential complications with each, all provided

⁷⁰⁰ Orentliche, Pope and Rich, above n 451, Supplementary Materials, at 4; emphasis added.

⁷⁰¹ *In re T* [1992] 4 All ER 649 at 652; see also *Re B (Adult: refusal of medical treatment)* [2002] 2 All ER 449.

in a language that the seeker understands. This approach places the onus firmly on the attending doctor to know the requirements thoroughly and to communicate them to the seeker and answer questions [§1.III].

In addition, health practitioners need training to avoid presuming influence on mentally competent seekers. For example, until recently agencies and doctors providing AD have been very reluctant to accept concurrent requests from both parties in a couple out of a presumption that one person must be putting pressure on the other to die with them. Recognising the paternalism in that presumption, EXIT has resolved this issue by requiring each of the couple to have completely separate request and assessment processes – allocating separate volunteers to each person, requiring separate medical certificates assessed on their merits, and, to protect the agency, requiring a notary confirmation that the due care requirements have been undertaken entirely separately – and incorporating those requirements into EXIT’s written policy.⁷⁰² Where AD is specifically legislated, similar policy could be expressed in regulations.

4.2.7 Attending and consulting doctor roles

The most effective strategy to date to clarify and distinguish the two attending and consulting doctor roles is the SCEN structure. The RRC Annual Report 2012 included substantial clarification of what kinds of relationship might not qualify as independent and then described how independence could be achieved. ‘Independent’ relationships might be specified in the statute or regulations [§3.VII], and/or in implementation guidelines.

However a core problem with the dual assessor role is the ever-present potential for doctors assessing independently to arrive at discrepant conclusions due to differences in knowledge and experience, exacerbated by application of different standards. Without an appeals system or at least the option of further assessments, a seeker may be declined simply because of one assessor’s lack of relevant experience or esoteric views of what constitutes a terminal stage or unbearable suffering. One solution is the SCEN model of training and registration of assessors, designed to facilitate consistency in assessment standards.⁷⁰³ However the current assessment systems might be made more effective by statutory option

⁷⁰² Jerome Sobel “Working with Couples” (presentation to World Federation of Right to Die Societies Conference, Chicago Illinois, 17-21 September 2014).

⁷⁰³ KNMG Position Paper, above n 575, at 30.

or recommendation for a team-based collaborative process involving open consultation,⁷⁰⁴ as suggested in the P-TEAG Report (Recommendations 7-8) and Expert Panel Report. Research shows that doctors make more confident AD assessments when they involve more information sources, including colleagues,⁷⁰⁵ and decline rates are higher when doctors do not consult with others.⁷⁰⁶ An effective consultative process might comprise a series of appropriately timed discussions involving the two assessing doctors and others in the health care team, together with the seeker, an advocate of their choice, and where appropriate their family doctor (who might also qualify as the ‘independent’ doctor).⁷⁰⁷ The process might optionally be facilitated by an independent person with AD expertise, to arrive eventually at a shared decision around eligibility and best options for the individual seeker. Such an approach would not only be more consistent with personal autonomy and client-centred care but would also reflect the process that health care teams commonly use now for medical decision-making, including other end-of-life decisions. Reflecting this philosophy, the NZMA Code of Ethics notes that “Some ethicists are beginning to argue for a fifth [bioethics] principle, namely, the duty of doctors in some circumstances to recognise the need to work in collaborative groups, sharing their skills, experience and judgement with others”.⁷⁰⁸

4.3 Appeals and complaints

The absence of statutory provisions for complaints or appeals in most statutes to date appears to be a significant oversight, given the vulnerability and relative powerlessness of seekers,⁷⁰⁹ the absence of explicit provisions permitting third or subsequent assessments, and the common absence of authorised practice standards, accredited guidelines or mandatory training of any kind for health practitioners providing AD services. Given that the AD laws provide specifically for medical assistance and delegate the responsibility to doctors, sufficient regulation needs to be in place to provide for *effective* assessment processes. Where assessment is clearly not effective, there is a strong argument based on natural and procedural justice principles for having both complaints and appeals processes

⁷⁰⁴ Participants’ comments; Admiraal, above n 572; Van Bruchem-van de Scheur and others, above n 514.

⁷⁰⁵ Participants’ comments; Dees and others, above n 698.

⁷⁰⁶ Bregje D Onwuteaka-Philipsen, Gerrit van der Wal and Lode Wigersma “Consultation and Discussion with Other Physicians in Cases of Requests for Euthanasia and Assisted Suicide Refused by Family Physicians” (2000) 9 *Cam Q Healthc Ethics* 381.

⁷⁰⁷ For example New Zealand’s abortion law (s 35) provides that consultations should include the client’s own doctor where appropriate.

⁷⁰⁸ New Zealand Medical Association “NZMA Code of Ethics” (May 2014) <www.nzma.org.nz> 2.

⁷⁰⁹ Curnow, above n 430.

available to seekers and others advocating for them, and they have been considered by people drafting Bills more recently.⁷¹⁰ The Québec statute (s 48) provides for complaints by “any person” in relation to the various provisions of the law, including AD assessments and requests, and for priority attention to such complaints, but it does not clarify the mechanism/s available. While the Levenseindekliniek and ULteam services constitute de facto appeal structures, a formal complaints and appeals structure would be more effective in affirming the rights of seekers to natural and procedural justice. The P-TEAG Report proposes, reasonably, that the existing complaints and appeals processes available in each Canadian province and territory are sufficient (Recommendation 20), but falls short of recommending that seekers must be informed of those rights.

Complaints mechanisms, including a requirement for expedited processing, should be available in particular for situations where health practitioners or providers do not comply with or respond within reasonable time frames, fail to provide sufficient information about diagnosis or prognosis, fail to refer, or behave in a manner that is otherwise obstructive to an effective AD assessment [**§3.III**]. There should also be requirements in the statutes that seekers be physically handed copies of all assessment certificates and reports, including reports that result in a decline, with a full opportunity to discuss the contents with the assessor [**§3.VII** and **§3.VIII**]. Ideally these documents should also be filed with the health authority so that there is a record independent of the seeker’s medical record that can be accessed readily.

In relation to appeals, given apparently common discrepancy amongst doctors over diagnoses, prognoses and judgments of suffering and the normal fluctuation of people’s symptoms and suffering in the advanced stages of illness, there should be at least allowance for a second opinion on a declined mental competence assessment and/or a repeat assessment opportunity where the person has a history of episodic mental illness, together with an opportunity to request a third or subsequent assessment where the two assessing doctors disagree on any eligibility grounds [**§3.VII**]. The statutes need to provide for seekers to be informed of these options in response to their first recorded request [**§1.VI**]. An appeals system could be facilitated through a statutory body such as an existing health commissioner or ombudsman or one established by the statute, and should ensure that

⁷¹⁰ Personal communications with RTD personnel and legal academics in the UK, Scotland, Canada and Australia, July-December 2015.

access is free and provides advocacy support.⁷¹¹ To permit seeker complaints and appeals, the statutes may need to place limits on health practitioners' immunities from civil liability. Legal drafting allows for such limitations by inserting exemption clauses and provisions.

4.4 Guidelines, education, training and mentoring

While a range of guidelines for doctors has been produced over the past 20 years by interested medical academics and self-appointed working groups,⁷¹² only those in The Netherlands have been endorsed by the medical association and are, in the view of research participants, easily accessible and digestible to doctors at large. Various evidence-based guidelines produced by the NVVE and RDMA in collaboration are available online and in English,⁷¹³ and improvements to guidelines for assessment are included each year in the RRC Annual Reports, together with detailed case studies that illustrate how to manage ethically and logistically challenging situations. Commentators across jurisdictions continue to call for authorised guidelines, competence and consent assessment tools and accredited training, and that developing these be the responsibility of the health practitioner regulatory bodies.⁷¹⁴

A major benefit of the SCEN system is that, through advice and mentoring, it provides “before-the-fact control” of AD,⁷¹⁵ where highly trained consultants provide what is in essence quality control of the attending doctor's activity, reducing risks and barriers all round. Since engaging its services is not mandatory, doctors seek SCEN help because they want to learn from the mentoring doctor and continue participation, knowing they are likely to receive another request at some time. The RRCs consider SCEN participation in an assisted death as an indicator, *prima facie*, that the doctor's conduct will have complied with the law, which further encourages doctors to use SCEN services.⁷¹⁶ In principle there

⁷¹¹ As does the current complaints system in New Zealand; see Health and Disability Commissioner “Making a complaint” <<http://www.hdc.org.nz>>.

⁷¹² See for example Bosshard and others, above n 94; Chris Gastmans, Fernand van Neste and Paul Schotsmans “Facing requests for euthanasia: a clinical practice guideline” (2004) 30 J Med Ethics 212; The Task Force to Improve the Care of Terminally-Ill Oregonians “The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals” (2008) <www.ohsu.edu>.

⁷¹³ “Dealing with requests for assisted suicide by patients with a psychiatric disorder” Netherlands Regional Euthanasia Review Committees *Annual Report 2012* (The Hague, August 2013).

⁷¹⁴ Participants' comments; Deschepper and others, above n 450; Hudson and others, above n 288; P-TEAG Report Recommendations 19-20.

⁷¹⁵ Griffiths, Weyers and Adams, above n 3, at 139; the LEIF system does this also though to a lesser extent due to the different level of training provided to LEIF doctors, see Van Wesemael and others, above n 519.

⁷¹⁶ Griffiths, Weyers and Adams, above n 3.

seems little reason why the consulting doctor role could not be undertaken by other health professionals and provision for anticipating that scope included in a statute [§1.XIII].⁷¹⁷

The information made available to date about AD eligibility and procedural requirements has been targeted either at doctors (produced variously by SCEN, LEIF, and self-appointed working groups) or at seekers (produced by the AD provider agencies), when arguably both groups need the same basic information provided in easy-to-understand media and made credible through government endorsement. The now widespread use by both professional learners and the general public of online media for learning make the webinar, already used widely, a suitable medium for making readily and freely available on health authority websites both accurate evidence-based information, for all audiences, and training specifically for health practitioners. EXIT Suisse Romande has already produced a DVD that has had good uptake, despite a cost, because the medium is easily digestible and the information can be viewed repeatedly. Webinars are already used widely by health authorities and tertiary education providers worldwide as an effective, user-friendly and cost-effective training and public education tool.⁷¹⁸ Excellent toolkits have already been produced with guidance from medical and nursing schools for health practitioners and the public to understand the legal and other requirements for use of advance directives that could be used as a model for online information.⁷¹⁹

5 Beyond regulation?

Endorsement of legalisation by the medical regulatory bodies is a key enabler, because it diffuses many of the underlying barriers for access by doctors and therefore many of those for seekers. Where participation by medical associations has occurred readily - The Netherlands and Québec - key factors in facilitating that engagement have been the efforts of individual drivers, both legislators and medical association leaders, who have recognised the crucial importance of that collaboration, based significantly in both jurisdictions on the medical bodies being driven by members' views.

At the end, most doctors are shy to do this [AD participation] still because [medical association] tells us not to, so even though I have done it for many years, I still stay quiet

⁷¹⁷ See for example the P-TEAG Report, above n 277, Recommendations 8 and 23.

⁷¹⁸ Kristine M Zaragoza-Anderson "Online webinars for continuing medical education: an effective method of live distance learning" 2(8) Int J Instructional Tech Distance Learning 7.

⁷¹⁹ Compassion in Dying "Making and Implementing Advance Decisions: A Toolkit for Healthcare Professionals" (September 2015) <www.compassionindying.org.uk>.

about it, because I have to look after my reputation as a professor, and most of my colleagues are either against it, or like me they stay quiet. We [medical profession] need to have open discussion for that to change. *Academic and doctor*

Many commentators have identified a need for more open discussion of AD – the ethical issues, the role/s in AD of the various health and associated professions involved, and the role of palliative care in the context of increasing public demand to have non-medicalised death and avoid the prolonging of insupportable lives that current generations no longer feel obliged to ensure. Across the developed world, advance care planning is now seen as a major facilitator in respecting people’s autonomy at end of life.⁷²⁰

6 Summary

As decision-making shifts at the assessment phase to the health professionals, the barriers relate more to the systemic factors deterring their participation. Again, while determined efforts by the AD provider agencies can eventually overcome most of those barriers, given sufficient funding and *if* the medical professional bodies are engaged, the more effective solution will be to legislate to avoid those barriers. Part 4 looks at the barriers to achieving AD once the seeker has met the eligibility requirements.

E Part 4. Administering, reporting and accountability ⁷²¹

The administration of AD, whether the death is self-administered or delivered by a doctor, is the poignant achievement of the seeker’s wish and all parties involved experience deep and complex emotional impacts, as with dying generally. To comply with the laws, all jurisdictions have requirements relating to the acts of administration and to reporting and accountability. Reporting and accountability are discussed here briefly because administration and reporting occur contiguously and the requirements of either can constitute barriers to doctor participation.

1 Administration methods

The two features on which the AD statutes differ most are those relating to the eligibility criteria and the permissible methods of administration. The US states have all opted for a self-administered ingestion approach, primarily to ensure voter support for their Bills and

⁷²⁰ Arianne Brinkman-Stoppelenburg, Judith AC Rietjens and Agnes van der Heide “The effects of advance care planning on end-of-life care: A systematic review” (2014) 28 Pall Med 1000.

⁷²¹ As in previous Parts, the discussion that follows reflects the interview data unless otherwise referenced. Short quotes reflect interview data unless otherwise indicated in references.

avoid deterring doctors from participating in AD altogether. Anecdotally, US doctors found lethal injection both repellent, due to publicity around Dr Kevorkian's questionably altruistic killing of many terminally ill people,⁷²² and frightening, due to a lack of existing skills, standards or training and the evident unwillingness of the medical professional bodies to facilitate building capability. They were also reluctant to be the immediate agent of death.⁷²³ However the term 'ingestion' was deliberately not defined in the US statutes so that at least multiple options for ingestion would be available, for example by gastric tube or anally. The Swiss providers, who essentially self-regulate, also opted for ingestion only, for essentially the same reasons.

The US statutes have strict provisions for dispensing the drugs,⁷²⁴ since the seeker may receive those months before using them. In the US and Switzerland, the liquid medication must be held and drunk without any external assistance, purportedly as evidence of no coercion, though pressure is arguably more likely to be psychological; in The Netherlands statute that independent administration was not required because seekers choosing ingestion always have the fallback option of doctor-administered injection.

The Netherlands deliberately opted to make both self-administered ingestion (Article 294) and injection (Article 293) available, primarily to avoid potential complications for the seeker with ingestion, secondly because injection and ingestion can each be either inappropriate or inaccessible to some people at end of life, and also to allow for individual seekers' and doctors' preferences. The Netherlands had a long history of providing AD 'under the radar', administering it by injection to avoid detection, so that the practice was established and widely accepted.⁷²⁵ Although Belgium and Luxembourg did not have the same history, they saw the pragmatic advantages of adopting the Netherlands law. Debate in Belgian medical circles resulted in a decision to not legislate for ingestion, to avoid administration problems. However the phrasing in the statute has been interpreted broadly so that ingestion is used, relatively rarely, where the seeker prefers or where injection and IV are contraindicated logistically, and so far the FCEC has not challenged that practice.

⁷²² Hoffmann, above n 143.

⁷²³ Participants' comments; George Eighmey "Testimony Before Vermont Legislative Committee" (Montpelier, 12 April 2013).

⁷²⁴ Section 127.815 §3.01(1)(l) in the Oregon Act.

⁷²⁵ Participants' comments; Griffiths, Weyers and Adams, above n 3.

2 Barriers to effective administration

2.1 Administration method

Choice of administration method is important for both emotional and logistical reasons. Each of the methods may be unavailable to a particular seeker due to their physical condition at end of life. Emaciation can make finding a vein either extremely painful or impossible, drinking may be impossible where the swallow reflex is lost, and regurgitation may occur where the digestive system is malfunctioning. Seekers, family members or the attending doctor respectively may be repelled by the notion of lethal injection for a range of emotional reasons related to its associations with execution and abuses.⁷²⁶ Nonetheless injection remains the majority preference of seekers and doctors - 92 percent in The Netherlands and 98 percent in Belgium - where both options are available.⁷²⁷

2.1.1 Self-administration

In the US jurisdictions, problems have occurred in around seven percent of deaths overall, all apparently due to self-administration by ingestion.⁷²⁸ The reasons are several: personal constraints can become exacerbated at later stages, for example the onset of dementia since receiving the drugs or loss of ability to hold a cup; because the trigger for eligibility is a six months prognosis, where seekers apply early, the medication is often provided to them weeks or even months before it is used, during which time receptivity to the standardised dose of drugs may change; the guidelines given to people about ingestion are limited, not specifying in any detail what might impede ingestion or absorption; seekers and family with no medical training may not understand the instructions well; the volunteers are not usually medically trained, and typically no health professional attends the death to advise on administration or deal with problems such as gagging, vomiting (even where an anti-emetic is prescribed) or inability to swallow; and seekers' families can feel uncomfortable about asking the volunteer to stay on if death does not occur quickly. The most common problem appears to be regurgitation of the medication that can result in asphyxiation, needing an urgent medical response; even without asphyxiation, the seeker is left with no backup dose to effect the death.

⁷²⁶ Participants' comments; Georges, Onwuteaka-Philipsen and van der Wal, above n 597; Sumner, above n 10.

⁷²⁷ Gamondi and others, above n 281. The reasons still need to be explored through qualitative research; see discussion Chapter 5.

⁷²⁸ Hedberg and Tolle, above n 124.

It's [regurgitation] very loud, very violent and very traumatic for both the family and the patient, and it's exactly what they were trying to avoid. I've only seen it once myself, but I really felt for the families who don't have someone [doctor] with them. *Participating doctor*

Where there is no option of injection or IV, some people end their lives earlier than they would like to because of anxiety that they will lose the capability to ingest.

However research participants described many unreported instances of deaths delayed by up to 26 hours, resulting in major trauma for family and sometimes also for volunteers or health practitioners,⁷²⁹ due to the absence of authorised and accessible guidelines, protocols or responsible agencies for managing an assisted death. People have been known to take up to 104 hours to die.⁷³⁰ The following case example illustrates the key issues.

A consulting doctor was contacted suddenly very late on a Saturday night by distraught family whose comatose father had not died several hours after taking the medication and was now showing symptoms of severe respiratory distress. The panicked family were reluctant to call emergency services, assuming their father would be resuscitated. In the absence of guidelines authorised by a professional association or statutory agency (or in fact anyone, in that particular instance), there was a total lack of clarity as to the appropriate actions to resolve the situation, the legal liability of the doctor or family members, appropriate action for emergency services, should they be called, or what further medical intervention might be legal. As the consulting doctor only and having met the seeker only twice, the doctor had no mandate to provide any treatment whatsoever; moreover, there was no delegated agency or authority from which she could seek advice in the situation without risking frustrating the dying person's approved wish for AD, which the doctor perceived as her moral (and perhaps legal) obligation to uphold. Without authorised guidelines or protocols for this situation, the doctor remained with the family for 16 hours until he died.

It was like no one, *no one*, had considered the reality of when something doesn't go to plan. There were no advices available for them [family] or me, no number to call, no agency monitoring when it was going to happen [the death], no information for emergency services or whatever, no nothing. He wasn't my patient before then, so I had no authority to do anything at all. I shouldn't have even been called, but they were desperate and my name was the only one that anyone in the family could remember in that state. So I had nothing to guide me other than my own conscience... I've never felt

⁷²⁹ Participants' comments; Starks and others, above n 298.

⁷³⁰ Oregon Public Health Division, above n 303.

so lonely in my whole professional life. And even now, there's no one I can talk to about this without creating a monster for myself and the family. You're the first person I've ever told about that night. ... It was the worst experience of my entire life.

As stories like the above inevitably circulate amongst the profession, US doctors can be deterred from AD engagement.

2.1.2 Lack of formal guidelines and protocols for self-administration

The guidelines provided to seekers for self-ingestion are, understandably, designed for laypeople, not doctors, and are not comprehensive. The US AD provider agencies are not available outside of working hours, and anyway might not be able to assist due to legal uncertainty. The guidelines available to doctors in Oregon and Washington states were compiled by self-appointed working groups in the late 1990s before actual experience of implementing the laws, so they focus on policy and ethics, with very little 'how to' information, and they were not well known to research participants. Moreover the sections on AD administration largely comprise cautions around medical intervention, suggestions that seekers have a written advance directive, even though that cannot legally instruct AD, and repeated recommendations for the compilation of better guidelines. Not surprisingly, US doctors are reluctant to attend deaths while their legal liability in such situations remains unclear, as are Swiss doctors.

In the absence of authorised protocols for managing problems with ingestion, it is unclear whether the family is criminally liable if they fail to call emergency services, and if they do so, there are no clear guidelines for what those services should do in that situation. It is also unclear if the seeker can access an urgent second dose of the drugs based on their initial assessment, or must start afresh, and there is no central register of the assessments. In the case described above, the doctor's key concern was the absence of legal and medical guidelines for participating doctors and families setting out their legal options and responsibilities and authorising appropriate procedures and supports when the death is not straightforward. Because the Oregon law prohibits any action by another person to accelerate the death of the person who has ingested the medication, strictly speaking a doctor attending is not able to provide further intervention except to resuscitate or palliate the person, creating a further barrier even at this late stage. Were the statute to be amended, some research participants wanted this provision modified so that backup medication can be

provided in this circumstance. Without the prescribing (or another) doctor being required to attend and supervise the death, and in the absence of protocols for managing such issues, problems will remain a distinct possibility with ingestion.

2.1.3 No medical professional attending the death

Hospice and hospital policy in the US and Switzerland very often prevents employees from attending the deaths of patients even where doctors and nurses have helped them to access AD, and AD provider agency doctors are reluctant to attend for fear of both legal liability and professional stigma. Where no doctor or other health professional is present, there is a significant risk of no one being available to manage situations where complications impede the procedure. The US and Swiss volunteers, while well trained for a support role to navigate access, do not have medical training and are often present immediately before but not at the death, at the seeker's discretion.

Without authorised protocols around legal responsibilities and liabilities, most US and Swiss doctors interviewed who were willing to write a prescription were not willing to attend the death of a person, unless they were invited by that person *and* could specify that they were attending in their private capacity, not as a doctor. Even where invited, most declined, to avoid compromising situations, but many were unhappy about that decision which felt both unkind and unprofessional. The result in the US jurisdictions and Switzerland was a self-perpetuating conspiracy of silence in most instances, with doctors not completely unwilling to attend but not offering to, and seekers shy to ask.⁷³¹ In the absence of robust information about how many seekers might want their doctor, or a doctor, to attend, it is unclear what seekers' preference is. Currently none of the US health authorities or medical professional bodies have made moves to address these issues, though that could potentially occur in California where the medical association changed its policy to support legal AD shortly before legalisation there.

In contrast, Netherlands and Belgian doctors interviewed were clear that, even for administration by ingestion, their preference was to be present, both as emotional and logistical support and because they already were or had become close to the seeker through the inevitably intimate request and assessment process.

⁷³¹ Participants' comments; Gamondi and others, above n 281.

2.2 Administration by willing and competent doctors

Because administering a lethal injection removes any potential for the doctor to distance themselves from the death, and undertaking that task confidently and without error is vital not only logistically but also to the dignity of the dying experience for all present, that function is challenging morally as well as technically. Consequently fewer doctors are willing to undertake the attending than the consulting doctor role. Despite more than two decades of legal AD and the availability of SCEN support, around one sixth of Netherlands doctors who had participated in AD reported a lack of knowledge or experience for administering AD affecting their engagement.⁷³² Without training for implementing AD within the medical curriculum (always with an option of conscientious objection), research participants across jurisdictions thought those statistics may remain constant. Moreover, without a critical mass of doctors participating in AD, those who do so remain a marginal minority that others can be reluctant to join, and without robust structures for professional support, including supervision and debriefing, many continue to avoid participation for safety reasons alone. Despite over half of US doctors nationally supporting AD,⁷³³ only a tiny minority have become engaged even in progressive states where it is legal;⁷³⁴ this marginal status lays them open to criticism and perpetuates the unwillingness of other doctors to join their ranks.⁷³⁵

Legal commentators have also noted that, for the safety of all concerned, it is essential to have clear practice standards for appropriate drugs and doses. Without those, not only will many doctors feel unsafe to participate, but it is also not possible for a review committee or, potentially, a tribunal, to determine whether a doctor has been criminally negligent,⁷³⁶ which Hoffmann argues has contributed to the reluctance of US medical review bodies to prosecute doctors where there is evidence of inappropriate opioid use.⁷³⁷

⁷³² Hanssen de Wolf, Pasman and Onwuteaka-Philipsen, above n 558.

⁷³³ Kane, above n 446.

⁷³⁴ Stevens, above n 131.

⁷³⁵ George Eighmey “Testimony Before Vermont Legislative Committee” (Montpelier, 12 April 2013).

⁷³⁶ James A Filkins “‘With no evil intent’: The criminal prosecution of physicians for medical negligence” (2001) 22 J Legal Med 467.

⁷³⁷ Hoffmann, above n 143.

2.3 Timing

Determining the timing of an assisted death is difficult for many seekers as their symptoms and spiritual health fluctuate.⁷³⁸ Seekers do not want to rush their death, as every remaining good moment becomes precious, but once they are ready to die, doing so can become urgent. Where death will be doctor-administered, a confirmed plan is important. Seekers commonly arrange farewell gatherings, often inviting health practitioners. In contrast, late requesters commonly schedule their death for the earliest date allowed by the legislation. Any seeker uncertainty about the right time to end their life can make short notice availability difficult for doctors. If doctor attendance is ideal, then advance planning becomes crucial.

2.4 Availability of a suitable venue

Most people want to die at home, where possible, and that is common for ingestion in the US and Switzerland. However many people are too sick or already living in end-of-life facilities when they wish to die, and a majority of those facilities refuse to allow AD on their premises, for moral (usually religious) reasons or fear of damage to their public reputation. Even if a doctor is willing to administer an assisted death in a non-participating facility, the seeker is normally required to leave. Health practitioners interviewed described that requirement as unnecessary and “cruel” for both seekers and families, requiring transporting a literally dying person, often in a critical medical condition, from the facility bed to another place. Seekers in rest homes no longer have another home, there may be few suitable options for people in facilities long distances from their home or relatives’ homes, and for many good reasons, otherwise supportive family and friends may not want an assisted death in their home. These restrictions can sometimes deter seekers from finally exercising the approval they have for AD, just to avoid compromising family or friends. In Europe some churches have allowed people with no other good option to end their lives on church premises.

In the US states, however, assisted deaths remain largely unavailable in end-of-life facilities as so many are run by faith-based organisations. The US statutes require the attending doctor to advise the seeker to have another person present when they take the medication and to not do so in a “public place” (section 127.815 §3.01(1)(g)), but not all seekers have a

⁷³⁸ Participants’ comments; Pestinger and others, above 319; Starks and others, above n 281.

place to go once discharged from a health facility. Some people have had assisted deaths in hotel rooms, raising further ethical issues around whether legally that purpose should be declared in advance, then running the risk of being refused the accommodation. A few people, without or avoiding family, have self-administered the medication alone in a motel room, to be found by the cleaning staff.

The onus of finding a suitable place to die should not be on the dying person and requiring them to do so or discharging a dying person from an end-of-life facility, even at their request, is arguably a breach of the bioethics principles of beneficence and non-maleficence (eg non-abandonment).⁷³⁹

2.5 Family roles

Research participants identified a significant gap in guidance for families supporting a seeker, especially where ingestion is used. While family are rarely oppositional at the administration stage, their role in “midwifing” the death can be difficult for families and add stress to the seeker’s dying experience, creating a barrier to the death intended.⁷⁴⁰ However the main access issue for families at administration is a potential problem with ingestion that they will have to manage. Family trauma can last for months or even years where families with insufficient guidance have made decisions over administration complications that resulted in the seekers not dying as wished.⁷⁴¹

Although the AD provider agency volunteers play a valuable role, their mandate does not extend to counselling, and accessible materials for family still appear to be lacking. Although comprehensive guidelines exist in developed countries for supporting family caregivers of people at end of life generally, research participants noted the lack of guidelines or support material for families.

⁷³⁹ Quill and Battin, above n 278,

⁷⁴⁰ Starks and others, above n 298.

⁷⁴¹ Back and others, above n 644; Kimsma, above n 380.

3 What has enabled effective AD administration, and what more is needed?

3.1 Administering AD effectively

Research participants identified three key features of effective AD administration: achievement of a calm death for the seeker and their attending family and/or friends; the delivery of a medical procedure in compliance with the law and according to prescribed standards that results in death without technical problems; and an experience for the participating health practitioners that has no significant or lasting negative impacts, legal or other. Enabling these features requires administration methods that are evidence-based and problem-free, doctors who are not only willing and competent but also well supported, a safe physical and emotional context for administration, and good preparation for all involved parties. These factors were seen as most likely to occur where there is a sound infrastructure facilitating them.

3.1.1 Administration methods

The Netherlands (Article 1(b)) and Québec (s 30) laws deliberately permitted “administration” by either injection or ingestion to provide seeker and doctor choice by negotiation. Belgium decided not to allow ingestion, in recognition both that ingestion can create administration barriers that injection avoids.⁷⁴² Doctors interviewed agreed that the safest and most reliable administration method used currently is injection, because it requires the presence of a health practitioner and is swift and virtually failsafe provided that the drugs are administered in the correct dosages and order. For these reasons, it is the preferred method of both doctors and seekers where both options are available.⁷⁴³

Many participating doctors and others now believe that the best administration method is intravenous line triggered by the seeker, because it is clearly autonomous, is accessible across all disabilities,⁷⁴⁴ avoids the acute last second pain of injection or the protracted stress of emptying and mixing 90 capsules of medication in water, is emotionally gentler on all parties, and is already used effectively in some facilities in Switzerland and The Netherlands.⁷⁴⁵ Increasingly the Swiss agencies providing AD to non-residents are using this

⁷⁴² Groenewoud and others, above n 134.

⁷⁴³ Participants’ comments; Gamondi and others, above n 281.

⁷⁴⁴ Eg by nodding or blinking; see the video referred to in footnote 52.

⁷⁴⁵ Participants’ comments; Griffiths, Weyers and Adams, above n 3.

method and filming it as evidence of voluntariness, and the Swiss police have so far accepted that method as appropriate. In the only Swiss court case where a doctor was prosecuted for turning on the drip when the patient was ultimately incapable, the court found the doctor not guilty of killing the patient, but recommended independent witnessing of IV deaths,⁷⁴⁶ for example by confidential, consented filming. However no statute yet has included this method explicitly as an option. European doctors interviewed believed that AD by injection and/or IV line be allowed wherever AD is legalised [§4.IX], as the safest practice for AD administration, or that the ingestion medication regime be investigated more rigorously to determine the most effective drugs and dosages, since some seekers may always prefer ingestion for their own reasons. Where there is an option, the choice of administration method should ideally be made by the doctor and seeker together having fully discussed the pros and cons of all options, with an opportunity to have that discussion again should the seeker's circumstances change [§4.IX]. Where there is no intravenous option, it is vital that seekers and families be fully advised of potential problems at administration and how to respond to them, including emergency contacts for the attending doctor and a requirement that that person be informed of the proposed time of administration [§4.IX].

The authors of the Québec statute purposely left the administration method unstated with the understanding that the Collège des Médecins would determine best practice and set out protocols for both CPS and AD (s 32). Learning from the Netherlands experience, the Collège decided, in consultation with members, that the drugs will be administered by IV line, or by injection if medically indicated or preferred by the seeker. It has developed comprehensive administration 'kits' that include medications for all methods, an optional sedative before the barbiturates, backup doses, sufficient equipment and medications for emerging contingencies, and clear guidelines for situations where medications administered initially appear not to take effect as expected. To avoid problems, the guidelines are prepared by the dispensing pharmacist, based on guidelines from the Collège des Médecins, and individualised to each seeker's medical condition.⁷⁴⁷ Unused medications must be returned promptly. Comprehensive, bilingual password-protected guidelines for doctors, based on intensive research of the overseas experience, are provided on the College's

⁷⁴⁶ Verwaltungsgericht des Kantons Zürich, Entscheid der 3. Kammer VB Nr 99.00145 1999; cited in Griffiths, Weyers and Adams, above n 3, at 473.

⁷⁴⁷ Dyer, above n 465. The relevant website materials are password-protected and only accessible to members of the Collège des Médecins.

website. These kinds of procedural good practice might be recommended in supplementary regulations. The External Panel Report also suggests that training is important for pharmacists.⁷⁴⁸

Claims that AD by IV is difficult to administer in people's homes are addressed by technologies now available that make IV portable. In the US, seekers have been vulnerable to arranging their death earlier than they want to, to avoid losing that option due to becoming unable to hold the glass alone, for example due to a stroke or extreme weakness. Mandating the presence of the prescribing doctor and/or the filming of the procedure to demonstrate seeker voluntariness to a review committee are solutions to that barrier [§4.IX], especially now that filming by digital camera or mobile phone are widely available.

To address some doctors' reluctance to attend assisted deaths at their clients' invitation, the immunities could be restructured to clarify where doctors are not attending in a formal capacity [§4.IX], and the prescription could be endorsed by the health authority through a system registering each approved assisted death on receipt of assessment certificates, reducing the sense that the attending doctor alone is the agent of that death [§2.X]. The latter system would have the added advantage of avoiding late barriers for seekers by being available to arrange a replacement doctor where a doctor, for whatever reason, changes their mind belatedly about administering the medication. That situation occurred recently in The Netherlands, resulting in trauma to all parties with the woman suiciding and her family suing the doctor.⁷⁴⁹

The statutes or regulations need to include clear provisions for management of administration problems to ensure that barriers are minimised, the seeker does achieve an assisted death, albeit with additional intervention, and that occurs without compromising the voluntariness of the death [§4.IX].⁷⁵⁰

⁷⁴⁸ At 85.

⁷⁴⁹ BioEdge, above n 639.

⁷⁵⁰ Lewis and Black, above n 395.

3.1.2 Doctor attendance at self-administered deaths

Research participants were almost unanimous that doctor attendance at an assisted death by ingestion, if not in the room then close by or available quickly by mobile phone contact, was essential until death occurs, not only to avoid or address technical problems that might impede death, but also for ethical reasons, especially given the seeker's discretion over the timing and other circumstances.⁷⁵¹ Leaving administration support to a volunteer, however well trained and experienced, was seen as an abrogation of a prescribing doctor's responsibility to supervise administration of a lethal dose either personally or by delegation to another appropriately trained health professional. The main objections by doctors to supervising an assisted death by ingestion seemed to be either concerns about their legal liability or the time potentially required until the person dies. Some doctors interviewed commented that, given how relatively infrequently most doctors are likely to be called on for this task, the latter objection seems unworthy of the profession, but that the issue could be addressed by permitting delegation to another registered health practitioner [§4.IX]. Legal liability could be addressed through clearer statutory provisions for attendance by health practitioners as private individuals [§2.V].

In contrast, the P-TEAG Report recommends against requiring doctor presence at ingestions, on grounds that significant problems at ingestion are “extremely rare”,⁷⁵² guidelines should be provided for responding to those, and seekers should be informed of them and then be free to determine who attends their death. However since significant problems occur in around seven percent of ingestions, causing potentially major and lasting trauma to all parties involved and sometimes defeating the gentle death wished by the seeker, it seems ethically essential, at the least, that the prescribing doctor or a delegated health practitioner should be on call to manage such a possibility [§2.V]. Negative family experiences could also result in their opposition to the wishes of future seekers.

It's just not OK to leave them all [seeker and family] to it, and it's not fair on the volunteers, that's [problem-solving impeded deaths] not part of their role or their training. There has to be a doctor available for the 'just in case' situations, that's *our* job, and the medical associations should be standing up and demanding that. We need that leadership from our associations. Where are the grown-ups here? *Participating US doctor*

⁷⁵¹ Participants' comments; Pereira and others, above n 540.

⁷⁵² At 41.

Orentlicher and colleagues suggest that having an advance directive available can help a doctor to determine their response if a seeker does not die quickly, but that suggestion overlooks the legal barriers to further intervention by a doctor with no legal mandate beyond assessment.

3.1.3 Willing, competent and supported doctors and other health practitioners

The Netherlands systems for administering AD were widely acknowledged by research participants as best practice so far. Their effectiveness lies in several wraparound factors that collectively provide an infrastructure for assisted deaths: the comprehensive training given to SCEN doctors and requirement for continuing education for re-registration; the presence in most instances of a SCEN doctor, to avoid anxiety and errors; the attention to debriefing for participating health practitioners; and the availability of the detailed *Standaard Euthanatica* guidelines for safe and effective doctor administration, including practice standards, protocols, legal professional entitlements, responsibilities and immunities, which were developed over years by the RDMA together with the pharmacists' professional body and are updated regularly.⁷⁵³

To further support and encourage health practitioner engagement in hospitals, administration of AD in Netherlands public facilities now typically involves a small team of people on each occasion,⁷⁵⁴ normally including a SCEN doctor, where team members share the responsibilities, act as witnesses to one another's actions and debrief comprehensively after the assisted death [§4.IX]. SCEN doctors have the discretion to administer the injection where the attending doctor prefers not to,⁷⁵⁵ though the preference is to support the attending doctor to do so. A major benefit of this team approach is that the agency of the death is diffused, since several professionals are contributing to the outcome. It also shares responsibility for supporting family present.

A goal of the AD provider agencies is to engage as many primary care doctors as possible in providing AD services - family practitioners, oncologists, palliative care doctors - both so that seekers can work with their immediate attending doctors rather than a stranger, and to

⁷⁵³ See most recently KNMG/KNMP *Richtlijn Uitvoering euthanasie en hulp bij zelfdoding* (Amsterdam, 1 August 2012).

⁷⁵⁴ Though not all necessarily staying to witness the death itself, at the seeker's discretion.

⁷⁵⁵ Regional Euthanasia Review Committees *Annual Report 2011* (The Hague, July 2012).

avoid the burden of administering AD falling on just a few willing doctors. Thus it will remain important that the laws and regulations are framed to support ongoing engagement of new doctors and other health practitioners. There are several options not available currently in any statute. Practitioners willing to administer AD could be registered with the health authority [§2.V].⁷⁵⁶ Many commentators have proposed extending the AD administration role to include specialising nurse practitioners, and potentially physician assistants and registered nurses, provided that they have accredited training in that role and/or undertake it under the direction of a doctor [§4.XIII].⁷⁵⁷ Not only would this expansion of authorisation improve AD access in rural and remote locations and avoid seekers having to travel away from home, it would also reduce the emotional load on doctors participating currently through the AD provider agencies. Statutory provision for that designation would reinforce a team approach to AD and share the tasks and knowledge across the professions, building practitioner capacity for AD roles. Nurses interviewed across jurisdictions believed that nurses working in end-of-life care would operate highly effectively in all AD service provision because their roles would not change significantly, given their experience in other end-of-life decision-making and health care, such as withdrawal and withholding of life-prolonging treatments. Across jurisdiction nurses are already administering AD on doctors' directions, though typically without the doctor present, even though not permitted by the legislation.⁷⁵⁸ If nurses are to be involved in administration, they need the same immunities and protections as doctors [§2.V]. To further encourage doctor participation and accountability, the Israeli Bill proposes that doctors receive authorisation from the health authority to write the prescription, so that agency for AD comes ultimately from the health authority [§4.IX].⁷⁵⁹

The guidance from the Netherlands RRCs also recommends debriefing by the participating health practitioners following an assisted death, partly as self-care and to identify any further learning needed by the team, but also to enhance the likelihood of continuing

⁷⁵⁶ The SCEN register does not identify whether individual members are willing to deliver the injection in all instances, as that function is not normally part of the SCEN consulting doctor role, though it is available in some instances, so it might reasonably be assumed that they will.

⁷⁵⁷ See discussion pp 129 and 160.

⁷⁵⁸ Inghelbrecht and others, above n 514; Smets and others "The medical practice of euthanasia in Belgium and The Netherlands: Legal notification, control and evaluation procedures" (2009) 90 Health Policy 181. Nurses are also reported to have delivered AD illegally in New Zealand, see Malpas, Mitchell and Koschwanez, above n 87, and Malpas, Wilson and Oliver, above n 87.

⁷⁵⁹ WFRtDS Newsletter "Israel supports assisted dying legislation" (July 2014) <www.worldrtd.net>.

participation.⁷⁶⁰ Some facilities also allow participating staff to take time off following an assisted death, and experienced doctors may suggest counselling if a participating colleague shows any lasting upset. While these measures might not need regulating, they could be recommended in authorised guidelines.

I tell my colleagues I'm far more worried about a death that's miserable and painful than I am about a death that's preceded by a party. But everyone reacts differently, because it brings back your personal experiences. *Participating doctor*

3.1.4 Safe venue

Research participants commented that it is ethically inappropriate to put the onus on a dying person to make sure they have a safe place to die; rather, the statutes need to provide for that. Across jurisdictions end-of-life facility policies are changing gradually to allow people to die in their usual bed. The Centre Hospitalier Universitaire Vaudois (CHUV) teaching hospital in Switzerland began permitting AD on site in 2014, following intensive staff debate,⁷⁶¹ and AD within Netherlands and Belgian hospitals is regular practice. More recent statutes and Bills have provided some exemplars for statutory provisions enabling AD within facilities: the new Swiss canton laws had the explicit goal of enabling on-site AD in health facilities; the Québec law requires a non-participating end-of-life service provider to refer a client seeking AD to a suitable and participating facility (s 30); the P-TEAG recommendations go a step further, requiring a non-participating facility to provide a “safe and timely” seeker transfer to a participating facility for AD administration *and* to permit an assisted death on site if a safe and timely transfer is no longer possible (Recommendations 37-38) [§4.IX].

3.1.5 Dispensing the drugs

Dispensing of the medications can become a barrier if the drugs are dispensed directly to the seeker and there are insufficient administration guidelines. Also of concern to US doctors was the absence of statutory provision or other guidelines for disposal of unused drugs, which occurs in up to 40 percent of cases.⁷⁶² The Benelux countries have avoided the latter problem by dispensing the drugs only immediately before they are to be used, regardless of the method chosen,⁷⁶³ and research participants were keen for safety reasons to

⁷⁶⁰ Regional Euthanasia Review Committees *Annual Report 2013* (The Hague, July 2014).

⁷⁶¹ Pereira and others, above n 540.

⁷⁶² Oregon Public Health Division, above n 303.

⁷⁶³ KNMG Position Paper, above n 575.

have that regime required by statute, together with a provision requiring early return of unused drugs and equipment [§4.IX]. Doctors interviewed also liked the suggestion that doctors' assessment certificates be registered with a health authority registrar and the prescription and dispensing of medications endorsed by that registrar only when the attending doctor advises an intention for them to be used within a particular period, say, two weeks, with an option to extend [§4.IX]. Such a system would ensure greater security of the drugs against misuse and put to rest any opponents' claims that the systems are unsafe.

3.1.6 Support for families

Research participants stressed the need for families to have good preparation for their role in AD to avoid acute or lasting emotional stress. The SCEN and LEIF services are highly effective facilitators of support for families. LEIF's telephone information services and brochures are available to the general public and in 2014 alone more than 30,000 copies of the LEIF handout, which includes information for families, was sent out to seekers and families. Several doctors interviewed believed that preparing families for the death itself can only be provided sufficiently in one or more comprehensive conversations where a doctor and/or nurse describes the step-by-step administration process and the impacts, physical and emotional, on both the seeker and others present, and then allow for questions and answers, which commonly focus on relieving families' anxieties about the unknown.

They also commented on the importance of providing material in handout form to the seeker and family at the seeker's initial request, so that people can read it repeatedly [§1.III]. Family and doctors need clear guidelines about their legal responsibilities, management strategies should any problems occur, and what may be required of them should the authorities decide to investigate the death [§4.IX], as happens on occasions.⁷⁶⁴

3.2 Role of pharmacists

Pharmacists also have largely been ignored in the statutes, yet their participation is essential for dispensing the drugs without delays that might defeat administration of AD or at least cause major stress to seeker and doctor alike. If a facility dispensary declines to dispense required medications, the process can be delayed, potentially until it is too late, if the drugs

⁷⁶⁴ Starks, above n 298.

are not arranged well in advance, which is not always possible in instances of urgent need. Moreover seekers can experience major stress trying to find a willing pharmacist.

The limited research on pharmacists' views and willingness to participate reveals barriers. An informal television survey in The Netherlands found that even recently "[a]lmost half of all doctors at assisted suicide clinics have been confronted with pharmacists who do not want to help with euthanasia requests".⁷⁶⁵ A UK study found that a third of pharmacists would be unwilling to dispense a lethal dose for legal AD.⁷⁶⁶ Anecdotally, pharmacists' objections are several:⁷⁶⁷ objections to AD on religious or philosophical grounds, either to AD generally or its availability beyond people with terminal illness; concern for their business reputation; a perceived professional obligation, given the implications of dispensing a lethal dose, to investigate the provenance of the prescription and/or the appropriateness of the drugs and doses prescribed, even though that role is not delegated to them by statute; concern that lethal drugs are dispensed into the hands of private individuals; and/or fear of litigation. These objections may be caused by a lack of education, information and engagement for pharmacists, but they are all reasonable.

In The Netherlands, the pharmacy association (KNMP)⁷⁶⁸ has been engaged from the time of legalising in establishing guidelines for pharmacists, but that does not appear to have occurred in other jurisdictions. The American Society of Health-System Pharmacists (ASHP) provides only ethical guidance, not information on medications or administration, and in Oregon "neither the Board of Pharmacy nor the pharmacists' body in Oregon was willing to make recommendations on drugs for assisted suicide because of the fear of litigation".⁷⁶⁹

Statutory provisions like those in the Québec statute (Division III) are needed delegating responsibility to the pharmacists regulating body for providing guidelines for the profession on the legal requirements, appropriate drugs and doses for each administration method, conscientious refusal and timely referral to a participating 24-hour pharmacist [§4.IX].

⁷⁶⁵ Maxime Zech "Pharmacists may refuse euthanasia drugs to docs" (online ed, NL Times, Amsterdam, 16 April 2014).

⁷⁶⁶ Elizabeth A Hackett and Sally-Anne Francis "'Death was a blessing' – should it ever be pharmaceutically hastened? British pharmacists' views" (2003) 25(6) *Pharmacy World and Science* 288; Meek, above n 150.

⁷⁶⁷ Participants' comments; and see footnotes 150 and 765-766 above.

⁷⁶⁸ Koninklijke Nederlandse Maatschappij Pharmacie.

⁷⁶⁹ Meek, above n 150, at 615.

Provisions are also needed for keeping dispensed drugs secure and for early return of unused drugs and equipment [§4.IX].

4 AD by advance directive

Advance directives allow for mentally competent people to make a legal directive authorising and declining specified medical interventions in the event that they become mentally incompetent. AD through an advance directive is discussed only briefly here, variously because it is currently available only under the Benelux laws (Article 2(2) of the Netherlands statute), it is acknowledged as problematic for several reasons, and due also to the word limits for this thesis.

Barriers experienced most commonly to legal AD by advance directive have been twofold: problems with demonstrating, to the doctor's satisfaction, either sufficient evidence of 'unbearable suffering', since the seeker is no longer mentally competent to report that credibly; and the "documented instability of the wishes expressed in advance directives".⁷⁷⁰ These same issues apply to use of advance directives in relation to withdrawal or withholding of treatments.⁷⁷¹ The Belgian statute (section 4) addressed the former problem by waiving the requirement to demonstrate unbearable suffering, deeming (though without strong scientific evidence) people incapable of experiencing unbearable suffering once they are comatose. As a partial solution to the latter, the forms for advance directives have required more detail on specified medical states and options wished or declined, to minimise dispute or confusion in interpreting them, and some include agency for personal care power of attorney in the same document,⁷⁷² to provide multiple witnesses to the person's wishes. As another solution, the P-TEAG Report proposes that people wanting to request AD via an advance directive complete a "patient declaration form" in which "the criteria for intolerable suffering [are] set out by the patient in advance".⁷⁷³ However it may not be possible for a seeker to know in advance what their symptom trajectory is, or what might constitute 'intolerable' suffering for them, given that what is intolerable fluctuates in competent people day by day (see Part 3).

⁷⁷⁰ Cameron Stewart "Advance directive: Disputes and dilemmas" in Ian Freckelton and Kerry Petersen (eds) *Disputes and Dilemmas in Health Law* (The Federation Press, Annandale, 2006) 38.

⁷⁷¹ Participants' comments; Sarah Walker "Autonomy or Preservation of Life-Advance Directives and Patients with Dementia" (2011) 17 UCL Jurisprudence Rev 100.

⁷⁷² See for example the Queensland form for advance directive and power of attorney <www.justice.qld.gov.au>.

⁷⁷³ Recommendation 13, at 32.

Advance directives have other unresolved problems,⁷⁷⁴ including time-limited validity in some jurisdictions, the legal permissibility of a verbal advance directive in some jurisdictions,⁷⁷⁵ a general lack of awareness of them amongst the public and considerable “institutional resistance” to them amongst health practitioners.⁷⁷⁶ These various barriers are being addressed gradually in The Netherlands and Belgium through strategies including training for doctors in making the judgments required, identifying robust clinical indicators to help make those judgments, clarification of the legal status of advance directives, and engaging the person’s regular doctor in decision-making. Other strategies suggested by research participants to improve availability and regulation of legal AD by advance directive available were: requiring advance directives to be written and registered; evidence-based training in undertaking eligibility assessments; not requiring advance directives to be updated more often than 10-yearly; monitoring the rates of requests, deaths and declines of AD by advance directive to determine population demand [§1.XIII]; and omitting provision for AD by advance directive from initial legislation unless the issues have been fully addressed in anticipation of legalisation. Given some evidence that the wish for AD is a common reason for making advance directives,⁷⁷⁷ the P-TEAG Report recommends that the new Canadian legislation includes provision for AD by a “patient declaration form” even before the person is experiencing enduring intolerable suffering (Recommendations 11-12) and for considering, within one year of the statute coming into force, “whether patient declaration forms completed prior to the diagnosis of a grievous and irremediable medical condition might also be considered valid” (Recommendation 13).

5 Regulating for effective reporting and accountability⁷⁷⁸

Doctor accountability is relevant to access because it affects both the willingness of doctors to engage in AD and public perception of the safety of AD generally. Research participants believed that strong accountability regimes are needed to ensure continuing confidence in AD amongst the public and health professionals and diffuse the potential for ongoing opposition if reporting compliance is poor. In most jurisdictions reporting compliance is

⁷⁷⁴ Lindy Willmott, Benjamin P White and Benjamin P Mathews “Law autonomy and advance directives” (2010) 18(2) J Law Med 366.

⁷⁷⁵ Eg in New Zealand; see also Meisel, Snyder and Quill, above n 118, on the fragility of doctors’ responses to verbal advance directives.

⁷⁷⁶ Stewart, above n 770, at 48.

⁷⁷⁷ Participants’ comments; Hertogh, above n 149.

⁷⁷⁸ Accountability mechanisms are discussed only briefly here due to word limits.

high, but the requirements and accountability systems vary greatly, with relatively minimal reporting and independent review in the US and Switzerland, compared with detailed reporting the independent oversight by statutory review committees in The Netherlands and Belgium.⁷⁷⁹

Effective reporting and accountability appears to have three key features: statutory structures and systems that encourage responsible reporting; independent review of AD delivery; and a culture of reporting amongst participating doctors. The accountability structures established by the Netherlands legislation were seen by a majority of research participants as exemplary. Ideally the statutes would provide for a review committee whose membership includes medical, legal and bioethics expertise plus community representation and which reports to the health authority [§4.XIII], rather than only to the profession, so that the review function will have public credibility. The composition and terms of participation of the committee should include a clear requirement for declaring conflicts of interest. Ideally the review committees should review every AD report, not just a sample, provide every doctor with feedback, and publish a report annually, similar to Netherlands RRCs, for continuous learning by participating practitioners. As with personnel undertaking any AD infrastructure functions, people recruited to the accountability bodies must be supportive in principle of all end-of-life options and declare any conflicts of interest. An AD service infrastructure provided by the relevant health authority could provide prompts to doctors to send in reports as required [§4.XII]. Research participants recommended 20 working days to provide those reports to allow for workloads, ensure good information and avoid deterring participation [§4.XII].

Finally, accountability needs to have ‘teeth’, with statutes including penalties for breaches of compliance [§1.XII]. Those drafting the laws to date have been reluctant to include penalties for fear of deterring doctor participation, but without them the laws are vulnerable to slippery slope criticism,⁷⁸⁰ and many research participants saw them as vital to public confidence in safe AD practice, a view supported in the External Panel Report.⁷⁸¹ The

⁷⁷⁹ A detailed description of the Netherlands reporting and accountability systems is provided in Griffiths, Weyers and Adams, above n 3.

⁷⁸⁰ See for example BioEdge “Belgian euthanasia doctor faces criminal charges” (31 October 2015) <www.bioedge.org>.

⁷⁸¹ Above n 296, at 120.

Netherlands RRCs have now developed clear policy around the factors that will or will not attract sanction, making an understanding of safe participation even clearer for doctors.⁷⁸²

5.1 Cause of death

Despite some debate around the ethics of recording an assisted death as having been caused by the underlying illnesses rather than by a lethal dose,⁷⁸³ many participating doctors saw that measure as essential to prevent harassment of doctors or families by AD opponents.⁷⁸⁴ As a solution to the dilemma, the P-TEAG Report proposes that cause of the death be recorded as the medical condition and the *manner* of death recorded as assisted (Recommendation 30) [§4.IX], though that may not address the issue of potential harassment of doctors.

6 Summary

The seeker's wish in having AD is not an early death, but a gentle one with as little stress as possible for them and their family. The administration is the point at which many doctors are most anxious, yet it is important that they demonstrate calm competence. Statutory provisions for mandating training or supervision for the administering doctor, whoever that might be, and for ensuring adequate preparation for all parties and ready access to the medications seem the sensible way to mitigate against last minute barriers. Robust accountability systems need to be established by statute to build both public and professional confidence in AD as an appropriate end-of-life medical treatment.

⁷⁸² Regional Review Committee *Annual Report 2007* (The Hague, August 2008).

⁷⁸³ Wesley J Smith "Doctors Lie on Death Certificates" *National Review* (online ed, 4 September 2015).

⁷⁸⁴ For a full discussion of these issues, see the External Panel Report, above n 396, at 117-118.

F Table of suggestions for statutory provisions

Suggested provisions are set out and numbered according to the Part of this chapter in which each type of enabler was first proposed. They are organised as such provisions would normally be in a statute. A demonstration of how these various provisions might be set out in a statute is provided in my submission to the New Zealand Parliamentary Health Committee on Assisted Dying, Appendix 1.⁷⁸⁵

Table 2: Suggested statutory provisions for facilitating effective and equitable access to AD	
A. Enabler	B. Suggested statutory or regulatory provisions
I. Regulation of end-of-life services generally	
§1.I Positioning AD as a ‘service’	<ul style="list-style-type: none"> Consistent reference in statutes and regulations to AD ‘services’
§2.I AD as a standard end-of-life option	<ul style="list-style-type: none"> Regulate for AD, CPS, terminal sedation and advance directives (and ideally for refusal, withdrawal and withholding of treatments, including nutrition and hydration) within the same statute, and distinguish clearly amongst them in the interpretation section/s
II. Rights of seekers	
§1.II A ‘right’ to end-of-life care	<ul style="list-style-type: none"> Establish a health consumer ‘right’ to quality end-of-life care, subject to available resources
§1.II Seeker autonomy in decision-making	<ul style="list-style-type: none"> Provisions that clarify: <ul style="list-style-type: none"> ✧ Health consumers’ rights to make their own end-of-life treatment choices ✧ Health practitioners’ obligations to respect and act on seekers’ expressed choices and decisions ✧ That consumers may express their choices to health practitioners in any way that makes them clear ✧ For the purposes of the Act, ‘health practitioner’ includes any professional working in an end-of-life care service, including but not limited to doctors, nurses, psychologists, pharmacists, social workers, counsellors and chaplains (as defined by their respective regulating statutes)

⁷⁸⁵ Pam Oliver “Submission to the Parliamentary Health Committee on Assisted Dying – Legislating for safe provision of legal assisted dying” (29 January 2016) <<http://www.parliament.nz/en-nz/pb/sc/documents/evidence?Criteria.Keyword=Maryan&Criteria.Parliament=1&Criteria.Author=Health%20Committee&Criteria.PageNumber=1>>; upload to the website pending at 1 March 2016. The ‘demonstration model’ cannot be included in this thesis due to restrictions on word limit. I wish to acknowledge input into the draft ‘demonstration model’ statute from the approximately 20 people, representing a broad range of sector experience in New Zealand and elsewhere, whose expertise I drew on to review the initial draft of that document. Particular thanks go to Professor Jocelyn Downie who provided valuable comments on two subsequent drafts of the ‘demonstration model’ statute.

§1.II Presumed seeker competence	<ul style="list-style-type: none"> • Presumption of seeker competence unless proved otherwise applies in end-of-life contexts
§1.II Rights of seekers to refuse counselling or pastoral care	<ul style="list-style-type: none"> • Rights of seekers to refuse treatments, including religious or other counselling, and to decline advising family of their choices and decisions
§3.II Complaints, appeals and further requests	<ul style="list-style-type: none"> • Specific provision for a seeker to make a complaint in relation to any function under the statute • Seekers must be advised of their rights to complain, appeal and/or have further eligibility assessments, including further mental competence assessments
III. Information provision to seekers, families and users of end-of-life services	
§1.III Effective dissemination of information on hastened death options to the general public and people at end of life	<ul style="list-style-type: none"> • Responsibility delegated to relevant government health authorities for ensuring that comprehensive, easy-to-understand, up-to-date, evidence-based information on all legal hastened death options is: <ul style="list-style-type: none"> ✧ Produced in consultation with appropriate health regulatory and professional bodies and other informed sources ✧ Available on the health authorities' websites and in brochure form ✧ Offered in brochure form free of charge to end-of-life care providers for dissemination to health consumers and staff ✧ Inclusive of the eligibility and due care requirements, request processes and required forms ✧ Available in languages relevant to significant linguistic minorities ✧ Inclusive of information for families on consumer privacy and rights
§1.III Provision of accurate and comprehensive information to seekers	<ul style="list-style-type: none"> • Participating doctors⁷⁸⁶ must provide timely, accurate and comprehensive information, including information in a written form, to a person seeking information about <i>any</i> end-of-life treatment option, including requests for CPS, terminal sedation and refusal, withdrawal or withholding of medical treatments and/or nutrition and hydration, on: <ul style="list-style-type: none"> ✧ Diagnosis, prognosis and symptom trajectory ✧ <i>All</i> end-of-life treatment options including AD and terminal sedation ✧ The medical procedures involved and advantages and disadvantages of each end-of-life treatment option ✧ The procedures for accessing AD, including eligibility, due care requirements, complaints and appeals ✧ Cost-free availability of AD

⁷⁸⁶ Where the term 'doctor' is used in this Table, that includes any health practitioner who may have statutory delegation to undertake the tasks described.

	<ul style="list-style-type: none"> • Health practitioners may initiate discussion of AD as an end-of-life treatment option • Inclusion of the provision of information as one of the ‘activities’ subject to a time requirement
§2.III Communicating end-of-life care providers’ policy on AD	<ul style="list-style-type: none"> • Every end-of-life care provider must have clear policy on what end-of-life services they do and do not provide in their facilities and programmes that is: <ul style="list-style-type: none"> ✧ Consistent with the statute and with the policy of the health authority ✧ Made known to all personnel, actual and prospective, working in their services ✧ Made available in an accessible form that can be retained by all users of their services, actual and prospective, and by service users’ families ✧ Made available on the provider’s website ✧ Reported on annually to the designated health authority
IV. Protecting against coercion and undue influence on seekers	
§1.IV Protections from undue influence by family or others	<ul style="list-style-type: none"> • Doctors must advise seekers that talking with family, counsellors or others about their wish for AD is not mandatory • Doctors may not consult with family or others without recording a consent from the seeker specific to talk with named individuals on each occasion
§1.IV Sanctions for attempts to coerce against or otherwise frustrate a competent seeker’s wish or request for a hastened death	<ul style="list-style-type: none"> • Wilful attempt by a health practitioner to frustrate a competent seeker’s request or decision-making in relation to a hastened death is a breach of the statute • Penalties set out for such breaches may include sanctions that are educative
V. Health practitioner and provider participation and non-participation	
§1.V Conscientious refusal allowed only to individual health practitioners, not whole agencies	<ul style="list-style-type: none"> • Only individual health practitioners can refuse to participate in AD, except that no health practitioner can refuse to record an AD request • Provider organisations where a majority of health practitioner staff register a conscientious refusal must establish a referral arrangement for seeker requests to a designated person or organisation

<p>§1.V Opposition to AD declared as a conflict of interest</p>	<ul style="list-style-type: none"> • Where a health practitioner who opposes or is ambivalent about AD receives a request for AD or for information about AD, they must within 24 hours declare a conflict of interest and the implications of that to the seeker, record that advice with the designated authority and/or refer the seeker to a designated person or authority willing to action the seeker's requests, and thereafter desist from further engagement with the seeker on that topic • A registered refusal must be followed up by the designated authority within 24 hours to allocate a willing doctor, who must be a doctor supportive in principle of all of legal end-of-life options, to action the seeker's request
<p>§2.V Establish a register of participating and non-participating doctors</p>	<ul style="list-style-type: none"> • A designated health authority must establish a register of doctors wishing and not wishing to participate in AD • Doctors wishing and not wishing to participate may register their name and contact details at any time • Doctors registering as a participating doctor must be supportive in principle of all legal end-of-life care options • Doctors registering a general or particular refusal will be registered as a non-participating doctor and invited annually to confirm or modify that registration • Doctors who file an AD assessment certificate will be registered as a participating doctor and invited annually to confirm or modify that registration • The register/s may not be accessed by parties other than the registrar and other approved parties, including bodies with designated responsibility for reviewing the operation of the legislation • The registrar may release the details of a participating doctor with their prior consent to a health provider for specified purposes
<p>§2.V Ensuring assessor capacity⁷⁸⁷</p>	<ul style="list-style-type: none"> • The designated health authority must: <ul style="list-style-type: none"> ✧ Ensure sufficient registered AD assessors available and accessible across all regions ✧ Review capacity regularly to ensure sufficient assessor availability

⁷⁸⁷ The term 'capacity' refers here to service capacity.

§2.V Immunities for participating ‘health practitioners’ visible in the statute	<ul style="list-style-type: none"> • Visible statutory provisions for immunity for participating ‘health practitioners’, where participation is in good faith <i>and</i> without negligence, from (i) criminal and civil liability, and (ii) censure, discipline and/or loss of rights, privileges or opportunities in relation to employment and professional memberships • Civil immunities do not apply where a health practitioner’s action constitutes a breach of the statute itself • Health practitioners attending an assisted death in their private capacity have immunity from professional liability
§2.V Prevention of coercion against AD	<ul style="list-style-type: none"> • Attempt by any person to coerce a health practitioner or health provider to participate or not participate in AD is a breach of the statute • Penalties established for such breaches include possible suspension or removal of practising or operating licence, as appropriate to the severity of the breach
VI. AD decision-making and requests	
§1.VI Clarifying what constitutes an AD ‘request’ for the purposes of the law and who may accept and record a request	<ul style="list-style-type: none"> • A ‘request’ defined to include either an explicit request for AD or a request that implies or may be inferred as a wish for AD • All ‘requests’ must be recorded on the person’s medical record as a ‘request’ for the purposes of the law • An AD request may be recorded by any health practitioner • A health practitioner who is not a doctor (or person authorised to action the request) and receives an AD request must <i>first</i> record it and then refer it to the person’s doctor within 24 hours • Once a request is recorded, the seeker must be offered the option of a ‘patient advocate’
§1.VI Recording the <i>first</i> request on the required form	<ul style="list-style-type: none"> • A seeker’s first request must, within 24 hours, be recorded on the required form and on the seeker’s medical record and registered online with a health authority
§1.VI Free AD services	<ul style="list-style-type: none"> • The health authority must cover the essential costs of AD consultation and administration services, whether the request for AD is approved or declined
§2.VI Alternative recording of requests	<ul style="list-style-type: none"> • Where for any reason a seeker is not capable of expressing their AD request orally or in writing, alternative mechanisms must be made available to meet the statutory request requirements, which may include sign language, a witnessed proxy signature, expression of the seeker’s wish through a mechanism used regularly by the seeker to communicate their wishes, and/or digital filming of the request.
§2.VI Availability of interpreters	<ul style="list-style-type: none"> • An interpreter must be made available where the seeker and the attending doctor are not both proficient in a shared language • The interpreter may not be a member of the person’s family or a person who is opposed to AD or who might place undue influence on the person

§2.VI Effective referral systems where health practitioners refuse participation	<ul style="list-style-type: none"> • All end-of-life care providers must have an effective system for ensuring timely availability of or referral to a doctor willing to action a request for AD information or for AD • The onus is on the designated health authority, not the seeker, to make available a doctor willing to respond to a request
§2.VI Establishing a register for recording all AD, CPS and terminal sedation requests, decisions and reports	<ul style="list-style-type: none"> • Establishment of a register by the designated health authority for filing all AD, CPS and terminal sedation requests, assessment certificates and decisions, AD reports, and advance directives
§2.VI Time limits on processing statutory AD requirements	<ul style="list-style-type: none"> • Specified statutory time limits on: <ul style="list-style-type: none"> ✧ Recording, declining and referring AD requests – 24 hours ✧ Commencing the eligibility assessment – 24 hours from recording the initial request or receiving a referral to undertake an assessment ✧ Referring the seeker for a mental competence assessment – 24 hours from commencing the eligibility assessment ✧ Completing the eligibility or mental competence assessment – 48 hours from commencing the assessment, unless a longer time is agreed to by the seeker and is in the best interests of an effective assessment • Time limits may be extended with the informed consent of the seeker
VII. Eligibility assessments	
§2.VII Collaborative assessment process	<ul style="list-style-type: none"> • Recommendation that the assessment process involve relevant members of the seeker's current health care team and where possible their regular/family doctor
§2.VII Remote request and assessment process	<ul style="list-style-type: none"> • Provision for remote requests and assessments by video communications link under the direction of a doctor and with a registered clinician present with the seeker
§3.VII Clarification of what constitutes 'suffering'	<ul style="list-style-type: none"> • Relevant statutory provisions to clarify that suffering and the level of intolerability are both subjective seeker judgments

§3.VII Provision of accurate and comprehensive information about eligibility and due care requirements	<ul style="list-style-type: none"> • Prior to commencing an eligibility assessment, the attending doctor must provide the seeker with: <ul style="list-style-type: none"> ✧ Accurate information, in a brochure or handout, about the eligibility criteria and the due care requirements for AD assessment ✧ An opportunity to clarify those requirements in a discussion with the doctor ✧ An opportunity to invite their regular doctor and/or an advocate to participate in the assessment process ✧ Information about the seeker's options for complaints, appeals and additional assessments
§3.VII Management of declines	<ul style="list-style-type: none"> • Where a seeker's request is declined, the attending doctor or their delegate must advise the seeker of that decision face-to-face and inform them of other treatment options, including counselling
§3.VII Definition of 'independent' consulting doctor	<ul style="list-style-type: none"> • 'Independent' defined as a doctor who is not part of the seeker's current health care team
§3.VII Additional assessments	<ul style="list-style-type: none"> • A seeker may request additional assessment/s where either an eligibility or mental competence assessment has declined eligibility
§3.VII Registering assessment certificates	<ul style="list-style-type: none"> • All assessment certificates to be registered with the designated health authority and a copy given to the seeker • The final assessment decision must be confirmed in a letter to the seeker from the registrar that also outlines (i) procedures for notifying intention to exercise the right to AD and (ii) the seeker's rights in relation to complaints, appeals and additional assessment/s where an assessment has declined eligibility
VIII. Mental competence assessment	
§3.VIII Prioritising mental competence referral	<ul style="list-style-type: none"> • A doctor referring a person for a mental competence assessment must: <ul style="list-style-type: none"> ✧ Do so within 24 hours of identifying indicators of seeker incompetence ✧ Describe the perceived symptoms in writing to the seeker and mental health practitioner
§3.VIII Time limits on mental competence assessment	<ul style="list-style-type: none"> • A professional undertaking a mental competence assessment must: <ul style="list-style-type: none"> ✧ Commence that within 24 hours of the referral ✧ Complete the assessment within 48 hours, unless otherwise agreed by the seeker and in the interests of an effective assessment ✧ Provide their report in writing simultaneously to the seeker and the attending doctor, where possible in a joint face-to-face consultation • Where necessary by virtue of distance or assessor availability, an assessment may be undertaken by audiovisual communications

§3.VIII Competence assessment scope and mandate	<ul style="list-style-type: none"> • A mental competence assessment is intended to determine competence but may include a therapeutic component where that aspect may facilitate an accurate assessment • Where additional or modified therapy is indicated for the purposes of facilitating seeker competence, that recommendation must be communicated to the seeker and the attending doctor
§3.VIII Mental competence assessor competencies	<ul style="list-style-type: none"> • A mental competence assessor must have relevant experience in end-of-life competence assessment
IX. Administration of AD	
§4.IX Availability of sufficient AD administration options to afford access to people with disabilities	<ul style="list-style-type: none"> • Statutory provision for a sufficient range of administration options, including injection and self-administration via IV line, feasible for people with the range of physical disabilities
§4.IX Administration method to be decided by the seeker and attending doctor in collaboration	<ul style="list-style-type: none"> • The attending doctor must advise the seeker on the advantages and disadvantages of each administration method at initial assessment and again 24 hours prior to administration and then prescribe medication/s relevant to the seeker's choice
§4.IX Health practitioner attendance at self-administration	<ul style="list-style-type: none"> • All deaths by self-administration must be attended, optionally in an adjacent space, by the attending doctor or an appropriately trained health practitioner who must remain immediately available to the seeker until death occurs
§4.IX Replacement health practitioner available for administration	<ul style="list-style-type: none"> • The attending doctor must arrange for a qualifying health practitioner to be available for the circumstance where the attending doctor is unable to attend the death
§4.IX Authorised guidelines for responding to administration problems	<ul style="list-style-type: none"> • Responsibility delegated to the relevant health practitioner regulatory bodies, in collaboration with the health authority, to produce written guidelines for attending health practitioners, family and emergency services for the appropriate response where problems occur with administration, including the legal and other responsibilities of each party • The health practitioner attending the death must make such guidelines available to the seeker and family immediately prior to administration

§4.IX Safe venue	<ul style="list-style-type: none"> • A refusing provider facility must arrange a safe and timely transfer of a seeker to a participating facility for AD administration • Where a safe and timely transfer is no longer possible, the facility where the seeker is present must permit the AD on site in a sympathetic environment • End-of-life care facilities must provide a private room for the final days of any service user choosing a hastened death
§4.IX Lethal prescription to be authorised and held secure	<ul style="list-style-type: none"> • The attending doctor must advise the registrar of the intended time of an assisted death no more than 2 weeks in advance • The registrar will endorse dispensement of the prescription • The attending doctor must keep the drugs secure until such time as they are used
§4.IX Pharmacist availability	<ul style="list-style-type: none"> • The registrar must ensure that access to a pharmacist willing to dispense the required medications is available across the jurisdiction at all times
§4.IX Return of unused drugs and equipment	<ul style="list-style-type: none"> • Any unused drugs or equipment must be returned to the dispensing pharmacy by the attending doctor within 48 hours of the actual or intended death
§4.IX Assisted death may be videorecorded	<ul style="list-style-type: none"> • The attending doctor may arrange, with the seeker's consent, for the administration of the drugs and the confirmation of the seeker's voluntary wish to be digitally videorecorded and submit that recording with the report on the death as evidence of the doctor's compliance with the statute
§4.IX Death certificate	<ul style="list-style-type: none"> • AD will be recorded as the 'manner' of death on the death certificate
§4.IX Debriefing for health practitioners	<ul style="list-style-type: none"> • Opportunity provided by the health authority for any health practitioner attending an assisted death in a professional capacity to have a free counselling or debriefing session with an appropriate professional
X. Infrastructure for AD service provision	
§2.X Establishment by the national or regional health authority of a registrar for managing end-of-life services	<ul style="list-style-type: none"> • Statutory responsibility must be delegated to the relevant national or regional health authority to establish, within 6 months of the statute being passed into law, an end-of-life registrar service to provide infrastructure for provision of AD services as set out in the statute • The registrar must be a registered doctor • The registrar and staff working within the end-of-life registrar service may not conscientiously refuse to undertake the statutory tasks of the registrar and must be in principle supportive of all legal end-of-life treatment options • The health authority must allocate a budget sufficient to cover delivery infrastructure costs
§2.X Functions of registrar	<ul style="list-style-type: none"> • The functions of the registrar are to:

	<ul style="list-style-type: none"> ✧ Keep registers for <i>and</i> facilitate: <ul style="list-style-type: none"> ○ Participating health practitioners ○ Non-participating health practitioners and providers ○ Conscientious refusals ○ Seeker referrals ○ AD seeker assessments and decisions ○ AD administration ○ Reports on assisted deaths, including unsuccessful, modified and cancelled arrangements ○ Seeker transfers of care ✧ Facilitate a priority response to any complaint under the statute ✧ Authorise dispensement of AD prescriptions ✧ Refer AD administration reports to a review committee ✧ Maintain the health authority's website for AD information ✧ Publish the review committee's annual reports on the website ✧ Produce data annually on AD application, assessment and administration activity
§2.X Availability of a seeker advocate	<ul style="list-style-type: none"> • Establishment of a publicly-funded 'patient advocate' structure
XI. Education and training for health practitioners	
§1.XI Development of evidence-based guidelines, education and training for end-of-life care professionals on all tasks involved in providing AD services constructively and sympathetically with seekers and families	<ul style="list-style-type: none"> • Responsibility must be delegated to designated medical, nursing, pharmacy, psychology, psychiatry and social services regulating authorities for: <ul style="list-style-type: none"> ✧ (i) developing, within 6 months of the statute being passed into law, up-to-date, evidence-based guidelines on all key health practitioner tasks involved in providing AD, including: understanding the legal requirements; AD information provision; responding to AD and information requests; eligibility assessment; administration of AD; standards, practice guidelines and protocols ✧ (ii) making such guidelines available on their respective websites ✧ (iii) updating guidelines at relevant intervals ✧ (iv) consulting with relevant professional associations and tertiary education providers to develop and deliver sufficient and appropriate undergraduate and continuing education programmes for core AD provision competencies • Health practitioners may conscientiously refuse to undertaking training except for training in responding to AD requests in compliance with the law

§2.XI Ensuring doctor capability	<ul style="list-style-type: none"> • The designated health authority must establish a voluntary registration system for participating health practitioners that includes a training regime for acquiring and maintaining core competencies for undertaking AD assessments (that is, similar to the SCEN system) • For every AD eligibility assessment either the attending doctor or the consulting doctor must be registered for AD assessment
§2.XI Training for end-of-life care professionals on responding appropriately to requests for hastened death	<ul style="list-style-type: none"> • All health professionals working in end-of-life care must receive training in responding to requests for hastened death at time of employment and then three-yearly
XII. Reporting, compliance and accountabilities	
§1.XII Penalties for attempts to frustrate a seeker's competent wish or request for a hastened death ⁷⁸⁸	<ul style="list-style-type: none"> • Wilful attempt or negligence by any person that delays or otherwise frustrates a competent seeker's declared wish for a hastened death is a breach of the statute • Complaints processes, remedies and penalties are established to address breaches of the statute • Penalty options include both punitive and educative sanctions that may be applied individually or in combination as appropriate to the breach
§4.XII Reporting	<ul style="list-style-type: none"> • The attending doctor must report on a completed, attempted or scheduled assisted death within 20 working days of the actual or scheduled date
§4.XII Timely reporting on assisted deaths	<ul style="list-style-type: none"> • Doctors administering or attending an assisted death must report on that within 20 working days using the required online form • The registrar prompts the doctor to report 20 working days following authorisation of the prescription • Wilful failure to report on an actual or intended assisted death is a breach of the statute
§4.XII Reporting a perceived breach	<ul style="list-style-type: none"> • Any person knowing of an actual or suspected breach of the statute must report that to the registrar
XIII. Monitoring, evaluation and amendment of the statute and regulations	
§1.XIII Statutory recognition that all innovative law reform will need timely revision	<ul style="list-style-type: none"> • The designated Minister will have responsibility for commissioning a formative evaluation of the implementation of the legislation, to be reported on within 12 months of the Act coming into force and make recommendations for amendment as needed to facilitate the intent of the law reform, the focus to

⁷⁸⁸ This term is used to refer collectively to any measures that are intended by the seeker to hasten death, including AD, terminal sedation, refusal of treatments and withdrawal of nutrition and hydration.

	<p>include but not be limited to:</p> <ul style="list-style-type: none"> ✧ Identifying areas where the legislation is not effective in operation, in particular access issues ✧ The appropriateness of permitting AD by advance directive ✧ Potential for nurse practitioners and registered nurses to undertake various AD functions under certain conditions ✧ Whether mental competence assessments might be undertaken by health professionals other than psychologists and psychiatrists ✧ Rates of health practitioner refusal to participate ✧ Adequacy of the referral systems where health practitioners or providers do not participate ✧ Adequacy of publicly available information on AD ✧ Adequacy of the AD service infrastructure generally ✧ Any other apparent access issues for either seekers or health practitioners ✧ Recommendations for amendments to AD or other end-of-life practice, policy or regulation
<p>§4.XIII Composition, functions and processes of Review Committee</p>	<ul style="list-style-type: none"> • A Review Committee must be appointed by the designated Minister to: <ul style="list-style-type: none"> ✧ Operate independently of the medical professional bodies ✧ Comprise as many lawyers and bioethicists as health professionals ✧ Include a community representative ✧ Exclude from membership any person participating currently in providing AD, not supportive in principle of all legal end-of-life treatment options and/or with any other actual or potential conflict of interest ✧ Be chaired by a lawyer ✧ Review all AD administration reports ✧ Have discretion to contract out some of its executive functions ✧ Report directly to the national or regional health authority ✧ Report annually on its findings in relation to implementation of AD, including suggestions for good implementation by health practitioners and potential improvements to AD legislation, policy or practice ✧ Retain the same membership for 3 years unless there is good reason for a member's participation to be terminated

Chapter 5. So what's been learned and how can it be used?

A Summary – The root of the access problem

This research involved data collection over nearly two years, using a qualitative mixed method approach within an evaluation paradigm. Data were obtained from three main sources: in-depth interviews, including some repeat interviews with the same participants as the dynamic AD context changed internationally; material from key informants additional to those interviewed, to obtain items of supplementary information from particular organisations; and a comprehensive review of documented materials from academic and other research in law, medicine and the social sciences, books, government and other agency publications, various papers and submissions, the mass media, newsletters, blogs, and other relevant internet materials (eg Facebook postings).

I believe the evidence is clear – there are multiple barriers to AD access for both seekers and health practitioners who wish to participate in AD. Those barriers almost always sheet back to systemic causes at the institutional level that are filtered down in complex, interactive patterns to become barriers for individuals and groups.

In addition to, and because of, continuing active and passive opposition to AD where it has been legalised, the existing statutes and Bills to date have focused largely on restricting rather than facilitating access for seekers and have generally omitted to provide sufficient access enablers and protections against gatekeeping.⁷⁸⁹ Despite evident problems, proponents have held back from attempting to amend the legislation to avoid any possibility for repeal.

The following sections summarise the apparent trends in actual and likely uptake of AD where it is legal, identify some 'critical enablers' of effective and equitable AD access, discuss what needs to be taken into account to make AD laws that work for those wanting access, and then present a possible paradigm for AD law-making based on decision-making as a core concept. I also discuss the importance of evaluating AD law reform and draw some implications for potential AD law in New Zealand. Finally I make some comments on

⁷⁸⁹ Participants' comments; Orentlicher, Pope and Rich, above n 451.

useful areas for future research, my research methodology and some issues in undertaking solo research on AD.

B Looking at the trends - Consumer-driven law reform

Across jurisdictions, although the proportion of assisted to all deaths still remains low (from 1-4 percent), the demand for AD is increasing rapidly and doctor availability is challenged. For example, Oregon data for 2015 show some dramatic shifts in uptake. The rate of increase in prescriptions over the previous year was 41 percent, compared with a 28 percent increase in 2014 and an average annual increase of only 12 percent from 1998-2013. The number of recipients with only public health insurance appears to have accounted for some of the increase, trending upwards significantly to over 60 percent in the past two years compared with only 38 percent on average annually before then. However doctor engagement shows that writing prescriptions is still being undertaken disproportionately by Compassion and Choices doctors, with 27 of 218 prescriptions written by just one doctor in 2015.⁷⁹⁰ The capacity issue is not, of course the time taken to write a prescription but the time and emotional burden on doctors of the extensive discussions and assessments required to demonstrate the due care requirements, bearing in mind that for every person being granted AD another two are being declined⁷⁹¹ but still require full assessments. The AD provider agencies in Switzerland and Belgium have also acknowledged that they could soon encounter supply difficulties in having sufficient doctors to undertake the required assessments given very rapid increases in requests in the past two years.⁷⁹² So engagement and in particular retention of doctors is vital.

Support for AD is evidently affected by generation. Polls show consistently that support is higher amongst baby-boomers than older generations; in the US, AD support increased amongst 18-34 year olds by nearly 20 percent in 2015, to 81 percent.⁷⁹³ The users of AD to date have been predominantly over-70s, from generations more accepting of medical paternalism,⁷⁹⁴ and they have often encountered significant opposition, or at least reluctance,

⁷⁹⁰ Oregon Public Health Division, above n 303.

⁷⁹¹ See references, above n 395.

⁷⁹² Participant comments; BioEdge, above n 530; BioEdge “Swiss suicide tourism doubles in four years” (23 August 2014) <www.bioedge.org>; European Institute of Bioethics “Belgian euthanasia increased by 89% in four years” (15 September 2014) <www.ieb-eib.org>.

⁷⁹³ “Attempts to legalize euthanasia/assisted-suicide in the United States” Patients Rights Council (31 October 2015) <www.patientsrightscouncil.org>.

⁷⁹⁴ Gawande, above n 227; Timothy E Quill and Howard Brody “Physician Recommendations and Patient Autonomy: Finding a Balance between Physician Power and Patient Choice” (1996) 125 *Ann Int Med* 763.

from families. Trends in health consumerism, however, show new generations - baby-boomers and beyond - are highly autonomous, assertive and educated consumers who negotiate, rather than receive, health services and are unlikely to accept paternalistic laws or implementation systems. If the predictions of many commentators and survey data on public support for AD are accurate, and the trends data in the US and Europe are robust indicators, the baby-boomers will seek AD in large numbers, but doctor availability will trail behind the demand. In that scenario, given the anticipated numbers of people who will be using end-of-life services in another 15-20 years, and even though legalising AD results in improvements in palliative care,⁷⁹⁵ better AD infrastructure will be needed to manage demand. Moreover, in the countries with current campaigns for legalising AD - New Zealand, the UK, several Australian states - and in Canada where it is now legal⁷⁹⁶ and demand can be expected to rise quickly, the RTDs do not wish to provide AD services, so supply will have to be provided through normal primary health care channels.

There will be a point, some time soon, when I won't want to do it any more, or not as much, but most people [doctors] only want to do it for their own patients, if that, and they prefer to keep very quiet indeed about it, so we're stuck in a place with no simple solution – doctors don't want to get involved until there's a critical mass [of doctors], so how do we start to make that happen? *Participating US doctor*

C Addressing access barriers – 'Critical enablers'

1 What are 'critical enablers'?

The term 'critical enablers' is very familiar to evaluators. Enablers are the factors that contribute to the success of an intervention, and critical enablers are the *sine qua non* of that success. The P-TEAG Report is the first document to use this term in the context of AD law, and it defines critical enablers as those features of the legislation that will facilitate "effective and equitable access to physician-assisted dying".⁷⁹⁷

All functions involved in implementing legal AD are underpinned by societal values, translated into legislation and then converted into actions by organisations and health practitioners. From a TJ perspective, the focus needs to be on access that is both fair and reasonable while also safe from abuse. At a societal level, legislating for AD is motivated

⁷⁹⁵ Kenneth Chambaere and Jan L Bernheim "Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience" (2015) J Med Ethics, 3 February 2015; Vanden Berghe and others, above n 505.

⁷⁹⁶ Albeit requiring a court application pending legislation; see *Carter No 2*, above n 49.

⁷⁹⁷ At 3.

by values of dignity, compassion, hope, personal autonomy, and in particular freedom from oppression. The latter concept, which is framed as a legal right in many human rights statutes, has multiple applications in legal AD – freedom from the oppressiveness of truly appalling physical and psychological symptoms, and also from oppressive life-prolonging treatment, but equally freedom from pressure on people, overt or subtle, whether by individuals, groups or institutions, either to seek or to not seek AD. It is the task of AD laws to find the balance amongst these inevitably discrepant values and principles, to provide both safeguards and enablers. Such is the role of human rights statutes generally, so the law is not without experience in achieving the balance needed.

2 What are the ‘critical’ enablers of legal AD?

The critical enablers of AD will almost certainly differ across jurisdictions, depending on health systems, cultures, demographics and other factors unique to each place. For example, several of the enablers identified by the P-TEAG Report, such as using telemedicine, extending authorisation to nurses, transporting seekers to an assessing practitioner, reflect Canada’s particular geography.

This research has identified some key categories of critical enablers, summarised in **Table 2**, that I believe are all essential to ‘effective and equitable’ seeker and health practitioner access. Each of those enablers, I believe, needs to be explicitly facilitated by statutory provisions that target the institutional and organisational levels, because that is where gatekeeping, however well-intended, begins.

3 Are some enablers essential?

The evidence in Chapter 4 suggests that some enablers are essential to equitable seeker access and effective health practitioner access. In my view they are (in no particular order): free AD (see p 95); a publicly-funded and government-controlled infrastructure; structures for capacity-building to ensure sufficient competent providers; effective systems for conscientious refusal that require a referral to a willing provider; robust accountability systems that build and maintain public and health practitioner confidence in safe AD; and a requirement for provision of full information to seekers, including information about their rights to complaints, further assessments and/or appeals.

In addition to the enablers outlined in Chapter 4, some additional thoughts are presented here about enabling health practitioner participation, without which legal AD cannot occur at present.⁷⁹⁸

3.1 Publicly-funded and government-controlled service

A publicly-funded system for AD, with a government-controlled infrastructure including a central register of participating (and non-participating) health practitioners, is likely to provide confidence to practitioners that they are operating within the law, will be paid for their services and will be protected by the confidentiality provisions of the register. These features immediately resolve some capacity issues. However it is also essential that the statute make government responsible for ensuring sufficient competent provider capacity, as in New Zealand's abortion legislation, so that participating practitioners are not operating as a minority and potentially stigmatised group. Infrastructure supports for doctor participation are pivotal to continuing seeker access, because AD participation tends to be self-perpetuating once doctors become involved *with* appropriate support. Doctors and nurses interviewed said that providing AD services never became easy, but having engaged once in a constructive context and seen the value to the seeker, the great majority - 95 percent of those surveyed in The Netherlands⁷⁹⁹ - were willing to do it again.

I'll never forget - when I brought him the cup, he kissed my hand. That was it [decision to continue participation]. *Participating US doctor*

I remember every person, and their family, every face, how they looked to each other, what they say to each other. I will always remember them. *Netherlands hospital nurse*

That uptake by both seekers and doctors is greatest in The Netherlands is clearly due to a combination of enablers: the active collaboration of the RDMA (medical association) with the RRCs (accountability/review bodies) and the NVVE (AD provider agency) to progressively develop structures that support both doctor participation (SCEN; the RDMA Position Papers) and seeker access (Levenseindekliniek). A key impact of the SCEN system and its formal endorsement by the RDMA has been a high level of capacity-building for AD provision. Its several advantages are building public confidence that doctors are trained and registered, having a pool of willing and available doctors, and avoiding or minimising

⁷⁹⁸ It will be interesting to see what emerges in The Netherlands following the *Heringa* ruling, see p 49. Similarly, the Swiss continue to describe their model as largely citizen-facilitated, because it is provided almost entirely by not-for-profit agencies, even though each assisted death requires a legal prescription.

⁷⁹⁹ Participants' comments; Ilinka Haverkate and others "The emotional impact on physicians of hastening the death of a patient" (2001) 175 Med J Aust 520.

professional stigma and mistakes. Research participants representing the RDMA and SCEN estimated that at least half of Netherlands doctors have now had some engagement in AD, and a majority of those express willingness to remain involved on request. In contrast, after 10 years in Oregon, only 3.4 percent of eligible doctors had written a prescription,⁸⁰⁰ and after two decades Compassion and Choices doctors are still completely essential to seeker access. The most obvious differences between these two jurisdictions, it seems, are the engagement of the medical association, general acceptance of AD in the medical profession and the availability of detailed guidance and mentoring (all causally related) in The Netherlands but not yet sufficiently in Oregon.

3.2 How important is the support of professional medical bodies?

It is apparent from the comments of doctors interviewed and those in Malpas and colleagues' New Zealand research that doctors are deterred from AD participation by a fear of professional stigma. However without closer investigation it is unclear whether doctors are concerned about reprimand from their medical association specifically or more generally from colleagues and employers. A question remains as to how influential the views of the medical association are as distinct from those of the professional colleges.

Of course the support of a medical association has value, at least in a campaign for legalisation. In 2014 the Canadian Medical Association changed its policy to take a neutral stance on AD, allowing each individual doctor to make their own decision as to what level of engagement they might have in legalised AD, as did the Oregon Medical Association under pressure from its membership in 2004.⁸⁰¹ Recently the Californian Medical Association (CMA) followed suit by changing its opposition to a neutral stance.⁸⁰² Although these latter three associations have stopped well short of actively endorsing AD or engaging in the development of standards or training, research participants saw a potential for the latter in Canada and California as their laws come into force. The active support of at least one medical professional body does seem to be instrumental in doctors' AD participation, if for no other reason than that doctors do not need to fear reprimand even as a possibility. An additional value of medical association involvement is the enhanced likelihood that there

⁸⁰⁰ Hedberg and others, above n 121.

⁸⁰¹ Personal communication, former Board member of the Oregon Medical Association, 18 June 2014.

⁸⁰² "Physician aid in dying: California Medical Association removes opposition to bill" *San Jose Mercury News*, 20 May 2015.

will be more discussion of AD and its impact on the profession, potentially encouraging doctors to consider AD participation rather than avoid it altogether.

Commentators in the US have pointed out, however, that membership of the AMA, which opposes AD, has been in steady and significant decline over the past decade and now represents less than 17 percent of US doctors, fewer than the American College of Physicians, whereas memberships of alternative organisations are growing,⁸⁰³ and several of them, like the American Public Health Association, the American Medical Women's Association and the American Medical Students Association, formally support legal AD.⁸⁰⁴ While the US national nurses' association remains opposed, at a state level nurses' organisations are providing end-of-life care training programmes that include a focus on AD and/or terminal sedation.⁸⁰⁵ In contrast, membership of the medical colleges has grown in importance. In Québec the drivers of the Bill consciously worked with the Collège des Médecins rather than with the Québec Medical Association in recognition that the engagement of the latter was desirable but of the former crucial.

However the participation of the medical and pharmacy regulatory bodies is pivotal. Without delegating responsibility to them (or whichever responsible authority applies in the particular jurisdiction) for producing standards and practice guidelines, doctors will remain cautious to participate. The P-TEAG Report acknowledges this implicitly in Recommendation 42.⁸⁰⁶

D Making AD law that 'works'

1 Caveat

I wish to clarify at this point that I do not claim any expertise in legal drafting or law-making. My Australian law degree, from the Queensland University of Technology, is more than 20 years old and my only prior involvement in law-making as such has been writing submissions on proposed law reforms in New Zealand and Queensland, including examining and commenting on draft Bills. To gain knowledge for the present research, I read widely on drafting theory and practice, both New Zealand and overseas materials,

⁸⁰³ Rob Bluey "Doctors, Medical Students Abandon AMA in Search of Alternatives" *Daily Signal* (online ed, 23 June 2011).

⁸⁰⁴ Ryan B Clodfelter and Eli Y Adashi "The Liberty to Die – California Enacts Physician Aid-in-Dying Law" (2016) 315(3) JAMA 251.

⁸⁰⁵ Participants' comments; ELNEC, above n 454.

⁸⁰⁶ At 50.

examined in detail the existing AD statutes, the Bills that preceded them and Bills as yet unsuccessful, and discussed their development with as many of the authors as were available to talk with me. The thoughts that follow are my perspectives as a former social science academic and current professional evaluator, health policy analyst and graduate law student.

2 How to determine what constitutes 'good' AD law

From my research, there appear to be several factors that need consideration in determining how to regulate effectively for AD, where 'effective' includes both implementation (process) and outcomes aspects. They include:

- Whether a specific statute is necessary or desirable;
- Whether there is a 'best' statutory framework or model for AD;
- The tension between under- and over-regulating;
- What can and cannot, or should or should not, be regulated;
- How important is legislative intent in AD law;
- Issues with legal transplantation;
- Whether there is value, or feasibility, in a 'model' AD statute;
- What processes are important for effective AD law-making.

The important starting principle, however, is that law-making is a decision-making process. Each of the factors above involves multiple parties coming to a consensus about statute content, how provisions will be phrased and framed, what level of detail is ideal, and what should be left to the discretion of those operationalising the law.

2.1 Is a specific statute necessary or desirable?

The evident advantage of not having a specific statute is that no formal amendment is required to modify that law over time and the limits will, arguably, be set by societal standards and tolerance, as tested in the courts. However this approach has risks attached. Some Swiss research participants noted that there are in fact few controls on the AD provider agencies in that country and there is already significant criticism amongst Swiss people about some of the eligibility and administration practices used and fees charged by the agencies that provide AD to non-Swiss, and the benignness of their motives.⁸⁰⁷ Most

⁸⁰⁷ Imogen Foulkes "Switzerland plans new controls on assisted suicide" *BBC News* (online ed, Geneva, 2 July 2010).

importantly, many Swiss doctors who might otherwise engage in AD decline to do so for their clients because they feel insufficiently guided and protected in the absence of a specific statute. Canton by canton, the Swiss are introducing legislation for AD.

The consensus of research participants was that a specific statute for AD is always preferable: to ensure that essential infrastructure functions are delegated by statute to appropriate government bodies, in particular to prompt the development of medical standards and guidelines by the regulatory bodies; to clarify the intent of the law and provide guidance to the courts when needed; to set out the eligibility and due care requirements as law, for clarity and consistency, rather than those crucial aspects being left to AD provider agencies to develop; to set standards for safe implementation, for the protection of both the public and participating health practitioners; and so that seekers have clarity about what is legal and what they can or cannot ask from a doctor. Wherever AD has been legalised by a court decision proponents have still sought legislation.

2.2 Legal transplantation and local feasibility

Until recently there has been a reliance, especially in the US and UK, on legal transplantation without either formative evaluation to first identify how well the statutes work where they have been implemented or sufficient feasibility analysis to determine whether a statute will transplant effectively into the health systems or local cultures – institutional, societal and ethnic - of the adopting jurisdiction. Alan Watson has argued that transplantation of laws is not only sensible, for efficiency, but inevitable and valuable in a globalised context.⁸⁰⁸ However that claim overlooks two factors: first, a transplanted law is unlikely to be valuable in a new context if it is ineffective in the original context; and second, there are no important cross-jurisdictional benefits of harmonising in the case of AD law - rather, it is vital both that the legislation suit the local culture and that it be shaped at least initially to gain traction amongst legislators. The Netherlands and Québec statutes appear to have managed both of these features. The Netherlands decided on a completely other eligibility set for AD than the precedent legislation in Oregon. The Québec statute was based on an extensive interrogation of the viability of the statutes in operation internationally, including Select Committee visits to the US and Benelux jurisdictions, as a result of which Bill 52 included some valuable novel provisions for enabling both seeker

⁸⁰⁸ Alan Watson *Legal Transplants and European Private Law* (Alan Watson Foundation, University of Belgrade School of Law, 2006).

and health practitioner access (as discussed variously in Chapter 4). It is no coincidence that these are the two jurisdictions where key medical professional bodies, and those of other health professions such as pharmacy, have been fully and enthusiastically engaged in the formulation of the legislation.

Cultural/societal factors that will affect AD implementation, and need to be taken into account in shaping the legislation, include the local history of AD practices, local systems of primary and secondary health care provision, societal attitudes and practices around death and dying, and generational change. Netherlands research participants emphasised that the much greater uptake of AD by both the population and health practitioners in their country is significantly a function of Netherlands' society's relative secularity, openness about death, long history of unregulated euthanasia provision, intergenerational family doctor tradition, and societal practice of open and non-adversarial debate on controversial issues, together with a long-standing practice of collaboration between the medical and legal institutions. While it is obviously valuable to draw on those features of existing legislation internationally that are clearly effective - or in the Seidmans' terminology, the features that "work" - it is essential in the shaping of a new statute to identify statutory weaknesses and gaps, based on an evaluation of implementation, and cultural suitability.⁸⁰⁹

2.3 Is there a 'best' statutory framework or model for AD?

It is tempting to pose the question whether there is greater functionality in the Benelux statutes, which are framed to create an immunity from criminal liability where a doctor provides AD directly in compliance with the due care provisions in the statutes, or the US statutes, which allow a seeker to obtain a lethal dose of medication with the assistance of a prescribing doctor. However under both models the doctors must still demonstrate compliance with the due care provisions in the statute, and the seeker must meet the eligibility criteria, so functionally these two models are equivalent. The important distinctions between them in terms of accessibility to seekers are, rather, on the basis of what infrastructure and other supports are put in place to facilitate safe implementation. Of course, the statute itself can facilitate those supports, as has occurred with the Québec legislation and been proposed for the Canadian provincial-territorial laws.

⁸⁰⁹ Seidman and Seidman, above n 357, at 443.

As noted previously, the effectiveness of a statute needs to be assessed in terms of both its processes and its outcomes. Access by both seekers and doctors, based on evidence of uptake and participation respectively, appears better under the Benelux laws, but the differences can be attributed to two main factors – the infrastructure supports established in The Netherlands (and used also by Belgian doctors), and the broader eligibility criteria, based on suffering rather than terminal illness. Thus it is only useful to compare statute effectiveness based on the collective impact of all of the factors that distinguish them.

Moreover, it is not possible to make a judgment about how effective any of these laws is in terms of outcomes, because there are no agreed indicators for measuring those. For example, if going by the primary intention of the law, that is, to regulate an existing underground practice and make AD available, then the criteria might be based on two sets of parameters:

- Successful seeker access to AD – how many people seek AD; how many of those are declined; how many have declines reversed; has legalisation resulted in fewer people at end of life or with grievous and irremediable medical conditions suiciding, starving themselves to death or refusing life-prolonging treatment; has it resulted in people being abused;
- Doctors' participation and compliance - what proportion of doctors participate in AD; how many do not comply with the law; and how many people requesting AD ultimately receive CPS or terminal sedation.

Without clarity as to the *several* intentions of each law, and measurable indicators for each of those, judgments of outcomes effectiveness cannot be made. Currently no jurisdictions where AD is legal are keeping the statistics necessary to measure most of the factors suggested above, and to be fair, even where some of those statistics are kept, their interpretation is open to question in the absence of clarity about doctors' attitudes and motives. Moreover, the factors outlined above reflect outputs (completed activities or products), rather than outcomes impacts consequent on those activities or products). The more important questions in judging the effectiveness of an AD law's outcomes must include parameters that reflect the impacts of health practitioners' (and others') actions, for example: When people have AD, do they achieve the gentle death they wanted? Was the death achieved worth the effort required to achieve it? Was the experience satisfactory for the family and/or for the doctor and other participating health practitioners? Does

witnessing an assisted death affect uptake and participation? Why/not? When seekers are declined, do they receive care that they consider appropriate after that point? These are the kinds of questions that can only be answered well through qualitative research and evaluation.

2.4 The tension between under- and over-regulating

As discussed in the previous chapter (Part 1), AD statutes need to achieve a balance between including too much or not enough detail. The yardstick might well depend on the level of engagement of government and the health professional bodies prior to enactment. For example, the authors of the Netherlands statute were happy for it to comprise relatively minimal operational detail because the RDMA and government health agencies were already fully engaged in developing and publishing guidance to doctors and the NVVE was willing to undertake AD provider functions. By comparison, the Oregon and Washington statutes delegated no significant functions or budget requirements to government and kept the statutes to a minimum to avoid opposition from the citizenry whose support was essential for the Bills to pass referendum,⁸¹⁰ or overt opposition pre-referendum from politicians concerned at a “burden on the state’s resources”.⁸¹¹

In contrast, the Québec statute, because it was supported ultimately across all significant political parties through extensive efforts by the opposition MPs driving the Bill to obtain their buy-in, was able to incorporate significant detail, including delegation of statutory responsibilities to many key organisations. The P-TEAG Report makes recommendations for a high level of detail in the statute. Likewise, research participants almost all supported that approach. Their rationale was threefold, that detail in the statute would: provide guidance to the bodies responsible for supplementary regulation and policy development, including end-of-life care providers, where gatekeeping occurs most; provide certainty about the eligibility and due care requirements, and avoid inconsistent interpretations by health providers and health professional bodies; and ultimately provide certainty and clarity for both the general public and health practitioners. They also recommended strongly that infrastructure supports be clearly described in the statute and responsibility for those be clearly delegated, with time frames for implementation, to avoid access by doctors and

⁸¹⁰ The Oregon referendum achieved a 51 percent majority and the Washington one 58 percent, so the strategy appeared justified to proponents at the time; participants’ comments.

⁸¹¹ As in previous chapters, verbatim quotes in the text are from research participants unless otherwise referenced.

seekers alike being impeded by a lack of enabling systems. Stanley Cohen's argument is that, where there will be "ideological contradiction" through continuing vocal opposition to a law reform, it is important to set up visible systems to avoid those intended to benefit from the reform being intimidated by the rhetoric.⁸¹²

2.5 What can and cannot, or should or should not, be regulated?

In Part 1 (section 5.1) I discussed some pros and cons of using a statute to detail enablers, rather than leaving those to supplementary regulation. Maria Mousmouti describes legislative effectiveness in terms of the *observable* causal relations between the law and its effects,⁸¹³ arguing that causality is more able to be attributed if the statute includes tangible, measurable indicators. Following this line of argument, the P-TEAG Report recommends that the forthcoming Canadian legislation include more detailed provisions where there is likely to be significant uncertainty in implementing the law. For example, in relation to an effective response to conscientious refusal, the P-TEAG authors note that they:⁸¹⁴

heard repeatedly from groups representing individuals who want access to physician-assisted dying to be available that they believe that, without legislation establishing a duty to inform and a duty of non-abandonment (manifest as a duty to ensure an effective transfer of care either directly or through a third party), there may be problems with access. It is our hope that this approach will increase trust in the health care system among these individuals *by setting out these duties in law. Health care providers will not be harmed by a redundant provision and members of the public who support access for physician-assisted dying will benefit. It therefore seems reasonable and prudent to enshrine the duties in legislation.*

Spelling out clearly in the statute what is required for the seeker to receive the response that they merit based on what 'equitable' access should entitle them to, enables the kind of 'slow' thinking that Kahneman says leads to effective, rational decision-making, and enshrining them in the statute means that they cannot be ignored. The diverse recommendations of the P-TEAG Report suggest that those authors at least believe that there are few enablers that cannot, with some creativity, be incorporated into a statute, including some parameters for evaluating the statute's effectiveness (see below). However that Report also notes that there is a point at which attempts to define detail will become counterproductive. For example it concluded that some concepts that are inevitably

⁸¹² Cohen, above n 238, at 90.

⁸¹³ Maria Mousmouti "Operationalising Quality of Legislation through the Effectiveness Test" (2012) 6 *Legisprudence* 191, cited in Xanthaki, above n 109.

⁸¹⁴ At 43; emphasis added.

dynamic should not be defined, for example, while “grievous” might be defined by reference to case law on grievous bodily harm:⁸¹⁵

... ‘grievous’ and ‘irremediable’ should not be defined in terms of specific health conditions. No list of specific conditions could capture the range of illnesses, diseases and disabilities that might meet the parameters established by the Supreme Court. Instead, we recommend that regulatory authorities develop tools to assist physicians in making this determination on a case by case basis.

2.5.1 ‘Sunset’ clauses

A ‘sunset’ clause, of three years, has been included so far only in the Vermont AD statute (and in Lord Falconer’s Bill). This concept was based on the notion that, in an ideal health system, the stringent processes for determining eligibility could be made by doctors in the same way that they apply medical standards of care in making other end-of-life clinical decisions, thus promoting normalisation of AD as an end-of-life option and giving control of the appropriate standards to the medical profession. It was justified on the grounds that the more than 20 year experience available from Oregon and Washington states had demonstrated that doctors were capable of providing safe AD and could do so with “less government intrusion”.⁸¹⁶ While this concept has some attractions, the Vermont clause was repealed one year after the law came into force, apparently on the initiative of doctors who believed that the profession would be safer with clear statutory requirements to guide them.⁸¹⁷ Sandra Johnson and Diane Hoffman have emphasised how health practitioners struggle to interpret and apply health law in general, and permissive laws in particular, often baulking at the discretionary decision-making around permissive laws to avoid any potential for professional censure or litigation that might destroy a whole career and livelihood.

2.6 How important is legislative intent in AD laws?

Despite the difficulties in determining legislative intent, some clarity about intent is desirable in AD for at least two reasons: to guide both any court decisions in legal actions potentially arising from the laws and any future amendments, as needed; and to have some certainty about whether the legislation is intended to be primarily permissive or restrictive, or a balance of both. In my view, it needs to be the latter – that is, there should be a balance

⁸¹⁵ At 34.

⁸¹⁶ Kathryn L Tucker “Vermont’s Patient Choice at End of Life Act: A Historic Next Generation Law Governing Aid in Dying” (2014) 38 Vt L Rev 687 at 688.

⁸¹⁷ Morgan True “Lawmakers weigh safeguards set to sunset in assisted suicide law” *VTDigger.org* (Montpelier, 18 February 2015).

of both protections for the vulnerabilities of all parties involved, including health practitioners, and constructive enablers, to protect against gatekeeping of access.

The TJ lens is valuable in this regard, because it applies a universal (optimally) value of the dual wellbeing of individuals and society, which need to be kept in balance with each other and with the core values and principles of justice and the law generally. Thus AD laws will, and should, vary across jurisdictions, to reflect societal and cultural diversity and the views of the particular society at a particular point in time. On that basis, the statutes need to contain some explicit acknowledgement that societal values are likely to change over time, as are understandings of core concepts such as ‘unbearable’, based on developments in palliative care, or ‘irremediable’, based on medical developments. The experience of legislating for AD has shown that societal acceptance of that option increases over time, so that jurisdictions may well want to begin with relatively tight requirements and then relax some subsequently, as for example with the use of advance directives for AD or extending authorisation for AD provision to nurses or physician assistants.

Intent can be clarified explicitly, for example in the introductory statements in the statute, and implicitly. For example, omitting a more precise definition of ‘grievous’ indicates an intent that this concept should remain somewhat flexible to interpretation.⁸¹⁸ The intent of the law can also be implied in the language used. Several commentators have stressed the importance, for example, of distinguishing AD from suicide and not using that term for a rational choice by a competent person.⁸¹⁹ As one way to soften the potential for clinician stigma, Gerrit Kimsma has suggested the term “medicide” to describe death actively assisted by a clinician.⁸²⁰ Including provisions for early evaluation and potential amendment of a statute can comprise a clear indication that its general provisions are intended to be dynamic, as does setting a particular time frame for a comprehensive review of the statute.

⁸¹⁸ See the reasoning in the P-TEAG Report, above n 277, at 35.

⁸¹⁹ See the discussion in Tucker and Steele, above n 13.

⁸²⁰ Kimsma, above n 267.

3 What comprises 'good' AD law-making? A suggested paradigm for constructing effective AD legislation

3.1 Effective laws

Helen Xanthaki defines 'effective' legislation in terms of both implementation processes that work and outcomes that reflect what the law intended.⁸²¹ To construct legislation that will 'work' in operation, AD should be seen within a decision-making framework. That is, risk-focused decision-making requires a context for the decision-makers that will enhance 'slow' thinking - effortful, conscious, calculating, logical and above all evidence-based.⁸²² A function of the statutory provisions should be to facilitate that context and those processes. Constructing the statute, then, requires the same slow thinking, also undertaken by a multidisciplinary team representing all valid interests.

Seidman and Seidman have set out a four-step 'ILTAM' model for drafting effective legislative, based on a decision-making paradigm:

- Step 1. *Describe the social problem* and whose and what behaviours comprise it – that is, identify the key stakeholders affected and *how* they are affected;
- Step 2. *Explain* the behaviours the constitute the problem – that is, examine the causes of the behaviours (eg institutional factors) that constitute the problem that needs resolving;
- Step 3. Create a *legislative solution* – that is, a solution that addresses each of the identified causes of the problem;
- Step 4. *Monitor and evaluate* – that is, check early to see whether the statute does actually reduce the problem.

Steps 1 and 2 of the Seidmans' model are reflected in the present research – that is, a thorough analysis of the underlying as well as presenting causes of AD access barriers. The 'legislative solution' is slow, multidisciplinary decision-making in the drafting of AD laws. The Seidmans emphasise that good drafting requires a close collaboration between the policymaker and the drafter. Ideally, of course, there would be a larger team of policymakers, with representation from all of the disciplines essential to understanding what will and will not work. The composition of the carefully selected P-TEAG group, for example, included expertise in health law (and specifically AD law), human rights law,

⁸²¹ Xanthaki, above n 109.

⁸²² Kahneman, above n 231.

bioethics, medicine (including medical governance), nursing, health policy, mental health services, patient quality and safety, health sector communications, and religion, including at least one person firmly opposed to AD. Likewise, applying the ‘two heads’ principle, having more than one drafter involved is probably desirable. However the role of policymakers has historically focused on translating principles into policy, whether the policy is consistent with the principles of the government of the day, not on translating policy into practice.⁸²³ There are two players missing, I believe, in the Seidmans’ model – the evaluator, and the consumer representative.

The participation of consumer representatives, including essential indigenous representation, is vital in any policy group, to provide input on the acceptability of and flaws in both policy and the proposed systems for implementing it from the service user’s perspective. While there are acknowledged issues in what constitutes valid ‘representation’, there are also good models for this function, including indigenous models.⁸²⁴

As noted briefly in Chapter 3, it is now accepted good health sector practice to undertake an assessment of the likely health and social impacts on individuals and communities of significant *proposed* health policy reform – that is, prior to implementing it. The value of evaluation expertise is that evaluators are trained specifically to test the feasibility of policy in practice, using tools like intervention logics, feasibility assessment and impact assessment. The value of these evaluation tools, used in combination, is that they are highly effective in identifying the risks and barriers that have not been identified or sufficiently addressed in the proposed implementation systems,⁸²⁵ so that those issues can be anticipated and mitigating solutions developed as part of the drafting process, ‘walking through’ the proposed processes with representatives of the intended stakeholders, using a feedback loop until solutions are found to any likely implementation problems. This process does not appear to have been applied generally with proposed AD legislation (the exception being The Netherlands). However it has been occurring very recently with AD law development internationally as the various Canadian committees and panels have examined the laws elsewhere to see what does and does not work for “equitable and effective” access. Ideally

⁸²³ Brenton Prosser and others “Developing a public health policy-research nexus: An evaluation of Nurse Practitioner models in aged care” (2013) 40 Eval Program Plann 55.

⁸²⁴ Elisa Muzzini *Consumer Participation in Infrastructure Regulation: Evidence from the East Asia and Pacific Region* (World Bank Working Paper No 66, Washington DC, 2005).

⁸²⁵ Sue C Funnell and Patricia J Rogers *Purposeful program theory: Effective use of theories of change and logic models* (Wiley & Sons, San Francisco, 2011).

each newly drafted Bill would go through this process. The particular value of an intervention logic is that its construction involves identifying indicators of effectiveness for both the processes and intended outcomes⁸²⁶ of the planned intervention, so undertaking that for a law would provide indicators for monitoring and evaluation of the statute in operation (see below).

3.2 Is there value, or feasibility, in a ‘model’ AD statute?

Two ‘model’ statutes have been developed to date for AD – one by Compassion and Choices National,⁸²⁷ to guide development of new laws for the US states, and the other by Professor Jocelyn Downie, as a model on which the Canadian provincial-territorial governments might base their AD laws.⁸²⁸ As a way to demonstrate how as yet untried enablers might be incorporated into legislation or regulations, I developed a draft ‘demonstration model’ statute for ‘medical aid in dying’.⁸²⁹ The purposes of doing so were twofold: to ‘test’ the various suggestions made in this thesis, as summarised in **Table 2**; and for the purposes of a submission to the Parliamentary Health Committee on Assisted Dying. The draft comprises a mix of effective features from existing statutes, proposed features in Bills developed in the past two years, and novel features that I have proposed and canvassed with research participants and other informants in relevant stakeholder roles. The draft in the Submission document does not include all of the enablers identified as potentially valuable in **Table 2**, because it was customised specifically to the New Zealand context, taking into account factors such as national and regional health authority structures, findings from recent New Zealand research with health practitioners (as discussed variously in the foregoing chapters), and the apparent readiness of the New Zealand public to accept certain statutory features, based on a rapid analysis of the submissions to the Parliamentary Health Committee on Assisted Dying available at 1 February 2016 (the deadline for submissions).⁸³⁰

The value of a ‘model’ statute is that it sets out diverse statutory possibilities in detail, introduces novel provisions and thus prompts slow thinking by lawmakers, offering the opportunity to ‘pick’n’mix’ what might or might not work in a particular societal context, or

⁸²⁶ ‘Effectiveness’ and ‘efficacy’ respectively in Helen Xanthaki’s terminology.

⁸²⁷ Not available publicly.

⁸²⁸ Downie, above n 44.

⁸²⁹ See Oliver, above n 785, Appendix 1.

⁸³⁰ New Zealand Parliament, above n 110.

depending on existing legislation or other relevant factors, and potentially to improve creatively on those tentative innovations as relevant to the particular jurisdiction. However they should always be considered as suggestive and a ‘work in progress’, as AD legislation evolves across jurisdictions and time.

4 What revisions are possible to the existing laws?

The research participants involved in implementing the US laws, while recognising their limitations, were reluctant to attempt amendment through the legislatures because of fears that doing so would open a Pandora’s box of opposition and backfire. Instead their strategy has been to focus on greater education of all parties as a facilitator of good practice and on mitigating access barriers for doctors and seekers through organisational policy and informal practice. However they acknowledged that leaving the statutes unchanged perpetuates the access barriers described in Chapter 4. There appear to be two solutions – to leave the statutes unchanged and instead develop policy to address the implementation problems, or to establish a structure for amending the laws that does not run the risk of their being overturned or made more restrictive. Though the latter is not impossible, for example by a strategic collaboration between the AD provider agencies and the government authorities, the former is almost certainly safer. The Netherlands has developed a robust model for continuous quality improvement through the RRCs, and that model might be introduced in the US states through a collaboration between the Health Department, whose mandate it is to facilitate AD implementation accountability, and the AD provider agencies.

5 What is the role of the courts in facilitating access to legal AD?

There is widespread agreement amongst commentators that it is not appropriate for access to legal AD to be controlled by a court or tribunal, but that seeker access should be a matter between a seeker and their doctor.⁸³¹ However the courts will continue to have important functions in interpreting the laws, even if infrequently. As particular societies undergo increasing generational secularisation, it may be that more seekers will undertake legal challenges to clarify the eligibility criteria or due care requirements in the ways that *Heringa* and *Haas* have done. The judgments variously in *Nicklinson*, *Carter*, *Stransham-Ford* and *Seales*, by canvassing the international evidence base for and against AD, have laid down important precedent that subsequent courts can use when such challenges occur.

⁸³¹ *Carter No 2*, above n 49; see also the discussion in the External Panel Report, above n 296, at 96-97.

The Supreme Courts of Canada have played a vital role recently (and provided a model for other jurisdictions) in facilitating access to AD for the Québécois, and for seekers across provincial-territorial jurisdictions by permitting application to the respective superior court of each, while still permitting a reasonable extension of the time frame for the provinces and territories to enact AD legislation.⁸³² Anticipating further delays to legislation, the Supreme Court of Nova Scotia has compiled a thoughtful draft process and rules to assist seekers, doctors and lawyers making AD applications that will engage sector comment.⁸³³

E Evaluating AD law reform

1 Why evaluate AD law reform?

Historically, evaluative review of laws has occurred because of controversy - either continuing controversy was predicted and a review body established by the statute, as with New Zealand's abortion legislation, or sufficient unanticipated controversy erupted that prompted a government inquiry, such as following New Zealand's prostitution law reforms. A core theme in my argument here has been the need for health laws, like policy, to be evaluated rigorously and continuously, to address issues in implementation and to keep pace with rapid change in society, ethics and health technologies, so as to avoid the kinds of inevitable law-breaking by doctors described by James Childress, Sandra Johnson, Diane Hoffmann and others. Sandra Johnson proposes better investigation of how doctors respond to legal risk, clarifying through research the principles that doctors draw on in responding to 'bad' law and using those to inform regulation. Commenting specifically on AD law reform, Diane Hoffman suggests that "legislators should be open to new information and data about the impact and effectiveness of the laws that they passed, willing to consider a recalibration of the balance"⁸³⁴ – that is, new statutes need to anticipate a potential for revision at some point, as does good policy development. Similarly, ongoing evaluation of people's reasons for seeking AD could provide information essential for both assessing the appropriateness of the eligibility criteria and informing the development of palliative care.

The importance of formative evaluation of AD laws is starting to be recognised. The P-TEAG Report proposes a 'continuing quality improvement' system for the Canadian

⁸³² "Supreme Court gives federal government 4-month extension to pass assisted dying law" *CBC News* (online ed, 15 January 2016).

⁸³³ Joseph P Kennedy and James L Chipman "Memorandum: Draft Temporary Practice Memorandum on Physician Assisted Death" (Supreme Court of Nova Scotia, Halifax, 1 March 2016).

⁸³⁴ Hoffmann, above n 143, at 1087-1088.

provincial-territorial laws, emphasising that new questions will arise during early and ongoing implementation of the AD laws in Canada that “will require the research community and governments to work collaboratively to advance a coordinated research agenda in service of Canadians”.⁸³⁵ The submission of the Human Rights Commission to the Health Committee on Assisted Dying specifically acknowledges the need for formative evaluation of AD legislation, recommending that any statute developed in New Zealand must include “independent oversight of [the] system ... to prevent abuse or misuse, to ensure public transparency about what is occurring *and to assist early identification of any potential problems*”.⁸³⁶

2 Indicators and standards for evaluation of laws

With reform as controversial as AD, where there is likely to be continuing vocal opposition, thoroughgoing and transparent evaluation can not only provide essential early identification of problems but also identify solutions for safe practice and outcomes. However valid assessment of effectiveness requires first identifying measurable outcomes indicators that are firmly based on the outcomes *intended* by the reform. In contrast, to date AD laws have been assessed quite unsystematically and using the absence of abuse as the primary indicator of effectiveness – that is, how rapid are the increases in uptake, and can they be seen as evidence of a ‘slippery slope’?

For example, since key reasons for legalising and regulating AD are respectively to reduce the incidence of end-of-life suffering and to increase accountability for doctors’ end-of-life practices, better data need to be gathered on the rates of withholding and withdrawal of life-prolonging treatments, including nutrition and hydration, and the rates of suicide, active and ‘passive’,⁸³⁷ amongst terminally ill people and people who have been declined AD, so that some conclusions can be made as to whether legal AD is effective in reducing the rates of those choices. Evaluation should include information from people who have been granted AD, to identify what the impacts of that are for them and their families, and for example, on why consistently around a third or more of those receiving a prescription for self-administration in fact never use the drugs.⁸³⁸ The stories of declined seekers would also

⁸³⁵ Above n 277, at 50.

⁸³⁶ Human Rights Commission “Submission to the Health Select Committee in Relation to its Investigation into End of Life Matters” (29 January 2016) [49].

⁸³⁷ Eg deliberate refusal of nutrition and/or hydration.

⁸³⁸ Oregon Public Health Division, above n 303.

provide valuable insights into the pattern of barriers experienced, their apparent causes and their impacts. Likewise, evaluation needs to focus not just on monitoring how many doctors do not comply completely with the due care requirements, but on clarifying the reasons why non-compliance occurs, so that training can be modified to address those problems. To date, the surveys undertaken in Belgium and The Netherlands have only been able to surmise on those factors in the absence of qualitative information.

Evaluation parameters should always include any aspects of the law that the authors believe may have weaknesses, but might also include areas for potential further reform. For example, the P-TEAG Report recommends that the Canadian legislation include specific provision for considering, after a year of operation, whether the laws should extend eligibility to AD via an advance directive “and update legislation if needed”.⁸³⁹

One problem in determining how effective AD laws are in terms of outcomes is that it is not possible to develop a standard for ideal uptake based on demand in relation to available resources in the way that one might, for example, for childhood vaccination rates. Supporting standards for health there needs to be a set of standards for ‘good’ law generally. David Wexler proposes that TJ be used as a filter for examining proposed law reform, and in fact all laws, using the conceptual basis of TJ as the standard – that the law operate in practice for the benefit of *all* stakeholders – and applying Des Rosier’s five parameters for good law-making:⁸⁴⁰

- Law as lived as the scope of inquiry;
- Multi-disciplinary analysis as the method;
- Empirical studies as sources of knowledge;
- Consultation and participation as control mechanisms;
- Changing cultures as the measure of success.

Adopting a quite different approach, the Australian state of Victoria's Charter of Human Rights and Responsibilities Act 2006 creates a type of impact assessment system that operates in the legislative drafting process. The Act sets out 20 basic rights, freedoms and

⁸³⁹ Above n 277, at 31.

⁸⁴⁰ Nathalie Des Rosiers “Rights Are Not Enough: Therapeutic Jurisprudence Lessons for Law Reformers” (2001) 18 *Touro L Rev* 443.

responsibilities of all people and then requires the Victorian Government, public servants, local councils, Police and other public authorities to:⁸⁴¹

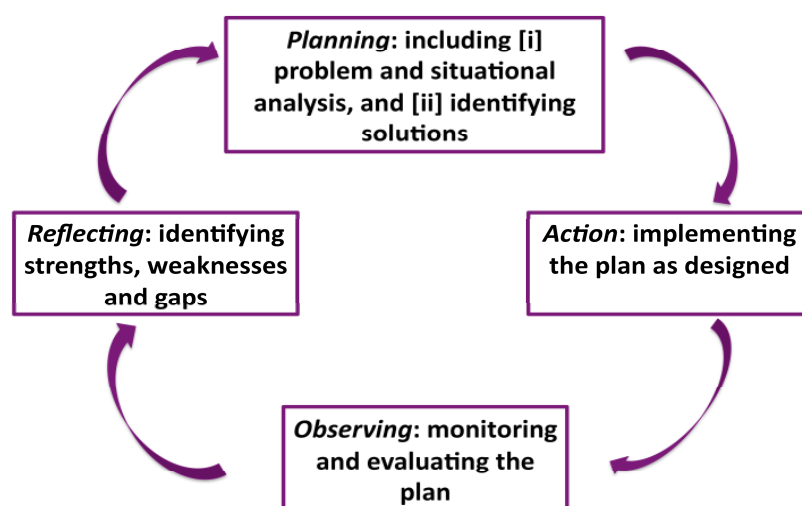
...act compatibly with human rights, and to consider human rights when developing policies, making laws and delivering services, ... [where] each new law must be checked against the Charter and requires a Statement of Compatibility to tell Parliament how it relates to human rights. ... This process aims to anticipate potential problems and prevent unfair treatment from occurring in the first place ... [where] the Supreme Court can issue a declaration of inconsistent interpretation [that] requires the minister who proposed the law to revisit it.

Each statute will need a customised approach to assessing its effectiveness. However the common features of the above approaches as they relate to health law are that the parameters of good law should be ‘patient-centred’, but also consider the impacts of the legislation on all key stakeholders, and on societies as a whole, anticipate problems and mitigate them *in* the statute, and assume that the law *will* need to be revisited.

3 A methodology for evaluation of health law reform

Step 4 of the ‘ILTAM’ model proposes that formative evaluation occur as standard practice with new laws aimed at significant social change. Evaluation theory provides a decision-making framework for this function in ‘action research’, which is used commonly for health impact assessment, as illustrated in **Figure 2** below.⁸⁴²

Figure 2: Action research cycle for evaluating new laws



⁸⁴¹ Victorian Equal Opportunity and Human Rights Commission “Charter of Human Rights and Responsibilities” <www.humanrightscommission.vic.gov.au>.

⁸⁴² This figure is developed by me, but based on a standard action research model; see for example Ernest T Stringer and Rosalie Dwyer *Action research in human services* (Prentice Hall, New Jersey, 2005).

This model is long established and would translate readily into evaluation of law reform. The action research cycle is continuous, using ongoing feed-forward mechanisms for continuous quality improvement, and has been used widely and successfully for decades in the development of good practice guidelines and continuous quality improvement in social, health and education sectors.

It is beyond the scope of this thesis to design a comprehensive evaluation framework for AD laws, though doing so should be prioritised. However for an accurate assessment of the effectiveness of AD laws, the features set out in **Table 3** are needed as a minimum. Most of these parameters could take the form of statutory provisions, as suggested in **Table 2**.⁸⁴³

Table 3: Aspects of methodology for evaluating AD law
Delegated responsibility to an End-of-Life Care Commission for formative evaluation commencing within three months of enactment
Detailed intervention logic to identify measurable indicators of process and outcomes effectiveness
Specification of implementation parameters that should be a priority evaluation focus (eg functions that are contentious or have acknowledged weaknesses)
Requirement for ‘independent’ evaluation
Full triangulation of the sample, including <i>all</i> stakeholder groups affected by AD law
Mixed method data collection, including appreciative inquiry to identify what is valuable in facilitating effective implementation while protecting the all potentially vulnerable groups, including health practitioners
Collection of data from both granted and declined seekers in person
Data on equitable access for minorities, eg cultural minorities, indigenous groups, people with disabilities
Data from seekers (versus doctors’ interpretations) on their reasons for wanting AD

The Seidmans note that the “monitoring and evaluating procedures must prove transparent and accountable. They must ensure that those affected, especially the poor and vulnerable, have opportunity to provide input and feedback of relevant evidence as to the law’s impact on their lives”.⁸⁴⁴ Michael Patton sets out several criteria of ‘independent’ evaluation, noting that the credibility of an evaluation depends on the transparent independence of those undertaking it.⁸⁴⁵

⁸⁴³ See Oliver, above n 785.

⁸⁴⁴ At 456.

⁸⁴⁵ Above n 23 at 708-709

Using this paradigm could help to turn around attitudes towards AD, accentuating the positive, so that it is seen as a core health service where equitable access requires both safeguards *and* enablement, as does any other health service.

F Implications for an AD law in New Zealand

There are a number of issues specific to the New Zealand context that will need to be addressed for a workable law to be introduced here.

1 Need for end-of-life and AD policy

Ideally an AD statute would take into account relevant government health policy, so the lack of government end-of-life (versus palliative care) policy appears a significant gap in New Zealand's health policy. The *New Zealand Palliative Care Strategy 2001* has not been updated since it was first published.⁸⁴⁶ The Ministry's 2011 guidelines, *Advance Care Planning: A guide for the New Zealand health care workforce*, are silent on AD, and the recent publication of the Ministry's *Ethical Challenges to Advance Care Planning* (2014) explicitly removes AD from its scope, as follows: "Advance care planning is not about euthanasia or assisted dying, or resource allocation. While these controversial topics are often bundled together with advance care planning, there is a clear distinction between the planning process, on the one hand, and the options that patients do or ought to have on the other".⁸⁴⁷

The practice of policy development following legislation may be inevitable, but ideally a ministry would be developing policy in anticipation of any mooted or politically likely law change with significant consequences for health practice.⁸⁴⁸

2 The End of Life Choice (EOLC) Bill 2015

It is beyond the scope of this thesis to provide a clause-by-clause analysis of the 'workability' (using the Seidmans' standard) of the current End of Life Choice (EOLC) Bill 2015 in the light of the systemic barriers identified in this research, but some comments may be valuable. That Bill has included some features that were absent from the 2012 EOLC Bill to facilitate access, in particular broader eligibility based on a "grievous and

⁸⁴⁶ Ministry of Health "New Zealand Palliative Care Strategy 2001" (February 2001) <www.moh.govt.nz>.

⁸⁴⁷ Ministry of Health *Ethical Challenges to Advance Care Planning* (June 2014) 2.

⁸⁴⁸ Personal communication from a former Minister of Health, 15 August 2015.

irremediable” medical condition (s 4), the proposal for a ‘SCENZ’ organisation to provide competent consulting doctors for eligibility assessment (s 19), an improved system for referral of requests where the doctor exercises conscientious refusal (s 7), and the creation of some additional offences for attempts to frustrate a seeker’s access by interfering with forms (s 27).

However in my view, the EOLC Bill in its current form contains a number of flaws that would result in several of the barriers identified in this thesis. Firstly, the eligibility conditions contain a redundancy - including “terminal illness” with a six months prognosis (s 4(c)(i)), when that condition is already covered by a “grievous and irremediable condition” (s 4(c)(ii)) – which is likely to cause confusion for health practitioners. Secondly, the proposal to mandate use of a SCENZ doctor (apparently unpaid) as the consulting doctor is likely to actually constrain capacity unless there is a very high enrolment in the SCENZ, which has not been the experience in The Netherlands. Thirdly, there is no provision to assist a seeker referral in the situation where a provider facility has no personnel who do not have a conscientious objection, leaving the onus on the seeker to find another doctor. Fourthly, there are no immunities for participating health practitioners from censure by an employer or a professional body. There are several other shortcomings that are also likely to allow for the access barriers experienced overseas, for example: lack of requirements for health practitioners to record seeker requests; insufficient response generally to an individual health practitioners’ conscientious objection; no requirement for doctors to discuss AD with people asking about other hastened death options; no requirement for interpreters; requiring that the seeker ingest without any physical assistance, even though injection is available as an administration option (s 15(3)); SCENZ capacity is left to the discretion of the Director-General of Health (s 19(1)), rather than being based on evidence of demand nationally and regionally; the provisions for ensuring mental competence (ss 10-12) are confusing; the review committee contains no lawyer and no community representative, leaving accountability in the hands of medical professionals only; and the initial review of the Act is deferred for three years (s 22). Presumably, if this Bill is drawn from the Ballot and passes a first reading, it will be referred to a select committee where those problems, hopefully, will be identified and the Bill modified accordingly.

3 Te Tiriti o Waitangi and other cultural considerations

The current EOLC Bill contains no provisions that reflect the status of Māori as tangata whenua or reflect wairua Māori (Māori spirituality).⁸⁴⁹ The provisions of an AD law for New Zealand will need to reflect the cultural preferences of Māori in relation to relevant requirements. Given particular tikanga Māori concepts and practices related to death, dying and suicide,⁸⁵⁰ those might include, for example, the option for the seeker to request, or be offered, the opportunity to discuss their wishes with a tohunga (spiritual leader) or kaumātua (tribal senior) rather than family or counsellors, or the option, with the consent of the attending doctor, to not have their death certificate show an assisted death if that might prevent them from being buried in their iwi or hapū urupa (tribal burial ground). Consistent with both the New Zealand government's health strategy focus on Māori access to health and reducing inequalities through Māori models of health,⁸⁵¹ and the role of Te Tiriti in New Zealand's constitution,⁸⁵² it is essential that Māori legal and cultural scholars and leaders be integrally involved in the drafting of any New Zealand statute.⁸⁵³ Given kaupapa Māori principles of engagement, it will be essential to have a broad participation by Māori in determining a health policy response to legal AD that is relevant to them. The particular role of whānau in decision-making will need to be considered in developing AD facilitation models such as a 'patient navigator' system in a tikanga Māori context.⁸⁵⁴

Similarly, leaders from Pasifika and relevant Asian and other migrant communities will need to be engaged. The submission of the Human Rights Commission highlights the need for the "framework and process" of any New Zealand AD statute to take into account "the cultural diversity of the New Zealand population, including those for whom English is a second language".⁸⁵⁵

⁸⁴⁹ Note that neither does the draft 'demonstration model' Bill that I developed, but that was drafted for an international context and assumes that the proposed provisions would be adapted to local cultures, institutions and systems. The External Panel Report (above n 296, at 87) includes comment from Canadian indigenous organisations that there is a "need generally to allow greater flexibility and understanding within medical settings for the presence of indigenous community and family members, and to accommodate different spiritual practices at end of life".

⁸⁵⁰ Tess Moeke-Maxwell, Linda Waimarie Nikora and Ngahua Te Awakotuku "End-Of-Life Care and Māori Whānau Resilience" (2014) 3(2) MAI Journal.

⁸⁵¹ Ministry of Health *He Korowai Oranga: Māori Health Strategy* (November 2002).

⁸⁵² Matthew Palmer "The Treaty of Waitangi in New Zealand's Law and Constitution in 2015" (public lecture, National Library, Wellington, 3 February 2015).

⁸⁵³ See also Phillipa Malpas and others (2015) "It's not just about the dying" Kaumātua Māori attitudes towards physician aid-in dying. Paper in progress.

⁸⁵⁴ Glenis Tabetia Mark and Antonia C Lyons "Māori healers' views on wellbeing: The importance of mind, body, spirit, family and land" (2010) 70(11) Soc Sci Med 1756.

⁸⁵⁵ At [49].

4 Rights

The Human Rights Commission submission also highlights an important omission in the NZBORA, specifically that it “does not specifically include the core human rights principles of dignity, personal autonomy or the liberty and security of the person as free-standing rights ... [which] stands in contrast with some overseas jurisdictions”.⁸⁵⁶ The Commission then suggests that “the Committee consider whether the current form of the NZBORA adequately engages the human rights issues that arise from end of life matters”. It is unclear whether the Commission is suggesting that a finding of the Health Committee might be to recommend a change to the NZBORA in order to be consistent with AD legislation in New Zealand, when that would not be necessary. However doing so might support the inclusion of enablers of equitable access. The Commission’s final recommendation is for a consideration of AD law provided that it (inter alia) is “accompanied by adequate legal and procedural safeguards to protect vulnerable members of society”.⁸⁵⁷ Following Henk ten Have’s argument that vulnerability is part of the human condition,⁸⁵⁸ such that all people with (or anticipating) unbearable suffering are vulnerable by dint of that situation alone, it can be argued that there should be adequate safeguards for seekers too, against gatekeeping.

5 Free AD

It is vital that a statute provide explicitly for publicly-funded AD, for the same reasons proposed in the P-TEAG Report. A key feature of New Zealand’s health care system is that it is publicly funded, specifically to facilitate the provision of good basic services - “appropriate, effective and timely (access)”⁸⁵⁹ - to New Zealand citizens and permanent residents free of charge or at a reasonable cost (taking into account funding limitations).⁸⁶⁰ Simply put, since already legal hastened death options are free to dying people, there are no grounds for charging people for any costs of AD.

⁸⁵⁶ At [d].

⁸⁵⁷ At [48]. Ironically, the New Zealand Law Commission, whose expertise would have been especially valuable, consciously declined to make a submission to the Health Committee because that could be seen as “conflicted” due to the Law Commission’s previous relationship with Lecretia Seales; personal communication, Law Commission staff, 11 February 2016.

⁸⁵⁸ Above, n 36.

⁸⁵⁹ Ron Paterson “Regulation of Health Care” in Peter Skegg and Ron Paterson (eds) *Health Law in New Zealand* (Thomson Reuters, Wellington, 2015) 5.

⁸⁶⁰ See the New Zealand Public Health and Disability Act 2000, s 3(1)(d) and (2).

G Directions for future research

There are two or three key areas where research is needed to clarify ways to facilitate equitable access for both seekers and health practitioners. The most pressing of these is the need for interview research with seekers, both granted and declined, and people at the various phases in the decision-making process. Using an appreciative inquiry approach could better identify how seekers have navigated the barriers effectively, whatever the decision outcome for them, and that information would be valuable in designing a ‘patient navigator’ role for AD. Several commentators have identified benefits for people at end of life being involved in research that clearly values their experiences and make a strong argument such people are being denied opportunities to be engaged in research partly due to the concerns of over-cautious ethics committees.⁸⁶¹ Collated seeker stories of their reasons for wanting AD would be valuable for undergraduate and continuing education purposes, as would the stories of participating doctors about their experiences, both positive and cautionary. Qualitative research recognises the value of storytelling research in communicating information in ways that are meaningful for audiences.⁸⁶²

Research is needed on what doctors and other health practitioners need in order to become engaged, and how that might be best provided. In anticipation of AD potentially being legalised in New Zealand, Phillipa Malpas and colleagues surveyed doctors and nurses about, inter alia, what might deter them from participating in AD, assuming no personal ethical opposition, and what might overcome those deterrents.⁸⁶³ The factors most likely to deter participation were a lack of training, skills, authorised guidelines and professional support together with fear of litigation or reprimand, and the enablers, not surprisingly, were the provision variously of training, guidelines, options to refer seekers to others, immunities from liability, and an independent review body monitoring compliance. However the open comments to these questions were revealing. Many respondents talked about highly personal deterrents to participation, such as the opposition of a member of their own family, perceived inconsistencies with one’s professional roles, such as mentoring younger colleagues, and fear of being chased down the street by protesters. Enablers identified by respondents included factors such as having undertaken roles perceived as

⁸⁶¹ Eg see Jocalyn Clark “Patient centered death: We need better, more innovative research on patients’ views on dying” (2003) 327(7408) BMJ 174; Claire Goodman, Katherine Froggatt and Elspeth Mathie *End of life care* (National Institute for Health Research, Methods Review 12, 2012).

⁸⁶² Joe Lambert *Digital storytelling: Capturing lives, creating community* (Routledge, New York, 2012).

⁸⁶³ Malpas, Wilson and Oliver, above n 87.

equivalent, such as abortion consultancy, the availability of counselling and debriefing following participation, wanting AD for oneself or one's family, and the ability to change one's mind about participation at any point, including administration.

It would also be valuable to know more about the pathways that first engage health practitioners in AD. A major value of qualitative research, including open questions within surveys, is to identify factors that can inform training for health practitioners contemplating participation. Related research might explore how health practitioners understand medical futility, how they define conflict of interest, their understanding of what constitutes good end-of-life medical decision-making, and what they see as the best learning forum or medium for working in AD.

H Meta-evaluation of the research design

The approach I have used has, I believe, been effective for the purpose. In particular snowball recruiting of participants and extending data collection over nearly two years has resulted in a highly diverse sample and rich data. However ideally research on this topic would have had some additional features.

First, it would have been undertaken by more than one interviewer. Ideally, evaluation research should triangulate the researchers as well as the data sources, partly for safety reasons (see below) and partly to enhance validity of data interpretation. To compensate for the lack of a co-researcher, I invited all participants to provide further comment on their interview summaries, and many did, contributing thoughtful commentary on the big picture. I also sought out repeat opportunities to discuss what is and isn't possible or what would and wouldn't work in regulating for AD with research participants who were interested, in particular health practitioners across jurisdictions, and with key informants who were consulted in the construction of the draft 'model' statute. However a co-researcher would have been valuable, both for discussing findings and for managing ethical issues that arose, such as how to respond appropriately to distressed research participants, as occurs commonly with evaluation research on sensitive topics and is normally managed through a team peer supervision system. Academic supervisors may have skills in these areas but that cannot be assumed; it is not normally part of their role, and it might even be considered inappropriate to their role.

Secondly, the best source of information on barriers to accessing AD would have been seekers - both declined and accepted. In any sound evaluation project, the service users, both actual and potential, are a key stakeholder group. Despite being aware of that, I made a decision at the outset to not seek ethical permission to include them in my research sample, because it was apparent that obtaining such permission was likely to hold up undertaking the research for several months, when the greatest utility of the information would be within the time frame actually taken. The few researchers interviewed who had undertaken qualitative research had made the same decision, and the absence of seekers' voices in the research literature remains a major gap that needs to be rectified urgently.

Despite significant efforts to locate research participants representing indigenous groups in the US and Canada, none was available, and until the publication of the External Panel Report from Canada, I was unable to find any indigenous comment on legalising AD. If AD access is to be equitable, then it is important that indigenous and minority perspectives receive attention.

I A comment on undertaking interdisciplinary research and solo research on sensitive topics

Before I started this research, I had undertaken many research and evaluation projects on sensitive topics, including suicide, aging and dementia, that had challenged me personally, and I have spoken in many different fora on the importance of never undertaking evaluation solo, because of the safety issues in doing so for researchers and participants alike. So I was aware that I would need a mentor as well as academic supervisors and made arrangements accordingly. I make the same recommendation to anyone deciding to undertake thesis research in this area, since typically that requires the candidate to work independently. Amongst the challenges to me over the past two years have been very personal attacks in the New Zealand media, including television news, and anonymous phone attacks from people in my own small community, and, perhaps inevitably, requests from two friends to support them or a family member to seek AD in Switzerland. To my amazement, in one interview I was offered an opportunity to witness a legal assisted death the next day, without first meeting the person who was going to die and obtaining their informed consent, and found myself challenged to find a way to decline that offer without causing embarrassment to anyone at a highly sensitive time.

Of course it is not at all unusual for researchers to be asked for informal advice on their research topic by friends and acquaintances, but the potential for misunderstandings and upset is quite different when the topic is AD in a place where it is still illegal and currently highly controversial. Many of the research participants described having lived with these kinds of challenges for years and even decades as they have ‘outed’ themselves as supporters of AD. However the AD researchers I interviewed all worked in teams and had regular meetings where such matters could be discussed and team support was available. My strong recommendation to anyone undertaking research on this topic is to have a mentor who is available as needed to provide support in working through ethical issues, and your response to them.

J The last word

I found the TJ lens consistently effective as a benchmark for critically examining the value of particular mitigation strategies to address barriers to AD, including potential statutory provisions that might well result in creating new barriers in the attempt to remove others, for example deterring health practitioner participation in an attempt to enhance it. So I would like to give the last words to two very pragmatic TJers whose advice kept me focused.

TJ does not purport to be a ‘cure-all’ for those problems of modern society that are created directly by the operation of the law. Nor is it an end in itself. It is simply a menu of conceptual tools or approaches for confronting the dysfunctional elements within legal institutions and procedures. Its goal is to assist to bring about change which is humane and efficacious and which affirms the status of human agents as subjects, not objects, within the multitude of legal procedures that comprise the domain of the law.⁸⁶⁴

Sometimes TJ is described as a lens, providing benchmarks or criteria against which a legal rule, legal actor or legal process can be measured to look for anti-therapeutic effects and consequences. But don’t be fooled into thinking it can’t be used as a quite specific method for designing or reforming new laws or new legal practices. Or ... a set of procedural guidelines, protocols and techniques for making the justice system more effective in quite specific ways. TJ research comes up with conclusions and recommendations which are testable and which are tested to determine their validity.⁸⁶⁵

⁸⁶⁴ Warren Brookbanks (ed) *Therapeutic Jurisprudence: New Zealand Perspectives* (Thomson Reuters, Wellington, 2015) 3.

⁸⁶⁵ Nigel Stobbs “How to do therapeutic jurisprudence research” (20 May 2015) <www.mainstreamtj.wordpress.com>.

Appendix 1. Interview sample

Table 4: Interview sample												
Stakeholder	Existing legislation (June 2014)								Bills – current, tabled previously or proposed			
	Oregon	Washington	Other US	Belgium	Netherlands	Switzerland	Québec	SUB-TOTAL	UK/ Scotland	Canada (federal)	Other (NZ, Australia)	TOTAL
Doctors with significant legal AD participation	5 [#]	5	--	3	4	10	1	28			1 ^{##}	29
Other health professionals with significant legal AD participation - hospice managers, nurses and social workers	3	4	--	--	2	--	--	9	1			10
Others legal AD support roles - psychologists, psychiatrists, medical insurance liaison personnel	2	1	--	1	1	--	--	5				5
RTDs/AD provider agencies – support volunteers	1	2	--	--	2	--	--	5				5
RTDs/AD provider agencies – management, legal, medical, policy and administrative personnel	7	5	--	1	4	6	2	25	4	1	1	31
Researchers and academics monitoring legal AD implementation	1	2	3	6	3	3	1	19	4	2		25
Health officials responsible for monitoring legal AD implementation	1	1	--	--	1	--	-- ^{###}	3				3
Lawyers involved in legal aspects of AD	1	1	1	--	--	1	--	4				4
Legislators and others involved in drafting or sponsoring legislation	2	1	1	--	2	1	2	9	1	1		11
Medical associations and colleges	2	--	--	--	1	2	2	7			2	9
People with various stakeholder interests in AD (doctors, politicians, psychologists, researchers)											5	5
Total stakeholder viewpoints represented	25	22	5	11	20	23	8	114	10	4	9	137
Total participants	18	12	4	9	9	14	7	73	8	3	8	92

Numbers reflect roles represented (as distinct from numbers of actual participants); many participants had undertaken more than one stakeholder role and were questioned in relation to all roles undertaken. For example, several doctors and nurses with direct AD participation also held positions in advocacy agencies and/or professional associations, and some lawyers and RTD members had been involved in drafting the laws.

Overseas AD participation.

At the time of interviewing, the Québec statute had been passed only recently and had not come into force.

Appendix 2. Interview guide

Introduction

- Clarify purposes of the the interview
- Intended uses of data
- Feedback to research participants
- Independence of the researcher
- Confidentiality
- Permission to record (optional)

Respondent information

- Location/jurisdiction
- What roles have you had in relation to AD in (jurisdictions)?
- Length of experience in AD roles

Respondent's views on AD

- How did you come to have an involvement in AD?
- How did you form your personal stand on AD?
- Have your views towards AD changed over time? If so, in what ways?

Background to the legalisation

- What kinds of factors contributed to the legalisation of AD in (jurisdiction)?
- How did health professionals here react initially to the legislation being enacted?
- Have there been any significant legal challenges to the legislation? If so, what was their effect on the relevant health professions?

Effectiveness of the laws

- In your view, how effective has the implementation of the legislation/legalisation been here?
- What factors have facilitated effective implementation?
- What has been problematic? How have those issues been addressed?

Access to AD

- In your experience or perception, how straightforward is it for people who do meet the legal criteria to gain access to AD?

Barriers to accessing AD

- What are the main barriers to applicants' ability to successfully access assistance to die in this jurisdiction currently? ⁸⁶⁶ (Free response, followed by probes)

Probes

- ✧ Difficulty in locating a willing physician
- ✧ Physicians' anxiety re prescribing lethal dose (e.g fear of litigation or professional stigma)
- ✧ Physicians' personal values
- ✧ Physicians' difficulties in understanding or interpreting the legal requirements
- ✧ Physicians' expertise in making judgments of 'mental capacity'
- ✧ Timing factors
- ✧ Other?
- Are there any other factors that have resulted, directly or indirectly, in frustrating the intended access of applicants to the assistance sought?

Causes of barriers to accessing AD

- What factors - legal and other – underlie or cause or contribute to these barriers for patients successfully accessing AD?

⁸⁶⁶ Clarify definition of 'successful' access = obtain a lethal prescription within a relevant time frame, whether they use it or not, and have sufficient support to use the prescription if they want to.

- In what ways are the access barriers linked to how the relevant laws are framed and phrased?

Probes

- ✧ Eligibility criteria
 - ✧ Procedural requirements (eg requests in writing; required time delays)
 - ✧ Framework of the laws
 - ✧ Interpretation of terms (eg ‘unbearable’, ‘suffering’, ‘medical condition’, other?)
 - ✧ Regulatory or other systems, or their absence
 - ✧ Advance directives
 - ✧ Other?
- Do the legal criteria themselves create access barriers, in your view?

Probe – perceived appropriateness of criteria:

- ✧ Terminal illness
- ✧ Absence of mental illness
- ✧ Other?

- In your view, should the current legal criteria be modified in any way? If so, why?

Responses used to address access barriers

- What kinds of measures – legislative, regulatory, formal or informal – have been used to try to address the various barriers that you’ve identified?
- Are you aware of any other measures that have been used, successfully or unsuccessfully, in other jurisdictions?

Probes

- ✧ Guidelines or information for patients seeking AD
 - ✧ Guidelines or protocols for health professionals (including physicians)
 - ✧ Informal measures
 - ✧ Other
- Were any of those measures considered here? If so, what occurred? If not, what was the reason?

How effective have access facilitation measures been?

- Looking at each of the measures that have been adopted to facilitate access to AD, how effective do you think they have been?
- Has (jurisdiction) liaised or collaborated with any other jurisdiction/s to learn about access strategies or solutions that have been valuable there?
- Are there any remaining significant barriers to prima facie eligible people accessing AD successfully? If so, what else might be done to address those issues?

Supporting effective AD legislation

- In hindsight, what do you think could or should have been done differently in introducing your AD legislation?
- What difference would that have made to the early experience of both patients (and their families) and health professionals?
- Should any other aspects of the laws, regulations or procedures be changed? In what way/s?
- What are the lessons for the international legal, health and social communities interested in the area of AD?

Other comments

- Do you have any other comments about access barriers to AD or anything else related to implementing AD here or elsewhere?

Appendix 3. Consent form and Participant Information Sheet



The University of Auckland
Private Bag 92019
Auckland
New Zealand

Telephone: 64 9 3737599 ext 85971
Email: j.manning.auckland.ac.nz

Participant consent form

This form will be retained for six years under lock at the researcher's office.

Project title: Addressing patient barriers to legalised assisted dying

Researcher: Dr Pam Oliver, University of Auckland, New Zealand

Supervisors: Associate Professor Jo Manning & Dr Phillipa Malpas, University of Auckland, New Zealand

I have read the Participant Information Sheet. I have understood the nature of the research and why I have been invited to take part. I have had the opportunity to ask questions and have them answered to my satisfaction.

Protections

I understand that:

- ☐ My participation in this study is voluntary.
- ☐ I will participate in an interview for approximately one hour, longer if I wish.
- ☐ I can stop the interview or the recording at any time, and can decline to answer particular questions if I choose.
- ☐ I can withdraw any part of my information at any time before 31 December 2014.
- ☐ The interview will be recorded and/or notes taken during the interview.
- ☐ The interview notes will be made available to me confidentially, and I will be invited to make further comments, modify or withdraw any of my information in writing or in a follow-up phone call before 31 December 2014.
- ☐ I will be provided with a copy of all articles and papers arising from this research, and my name will be included in the acknowledgements for those papers and articles if I agree.

Consent

- ☐ I agree to take part in this research.
- ☐ I understand that my signing this form and returning it to the researchers means I have given my consent to participate.
- ☐ I agree/do not agree (*circle one*) to this interview being digitally recorded.

Name: _____

Date: _____

Signature: _____

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag, 92019, Auckland 1142.

Telephone (09) 373-7599 ext 83711. APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 13 May 2014 for 3 years, Reference Number 011803



The University of Auckland
Private Bag 92019
Auckland
New Zealand

Telephone: 64 9 3737599 ext 85971
Email: j.manning.auckland.ac.nz

Participant information sheet

Project title: Addressing patient barriers to legalised assisted dying

Name of researcher: Dr Pam Oliver (PhD Psychology, LLB)

I am a doctoral student in the School of Law at the University of Auckland. I am a professional researcher with 20 years experience in social research and evaluation, specialising in the access of citizens, especially vulnerable populations, to health, social and other services. I am undertaking interviews for this research from June to December 2014 in selected locations in the United States, Canada, the United Kingdom, Belgium, the Netherlands and Switzerland.

Research purpose and approach

The focus of this research is on identifying patient barriers to access to physician assisted dying and physician assisted suicide (PAD/PAS) in several jurisdictions where it is legal, both barriers arising from the framework of the legislation and other unforeseen barriers, and then exploring the ways in which those barriers have been addressed, both through formal mechanisms and informally. I am also interviewing key stakeholders in jurisdictions considering PAD/PAS legislation, to explore how much the experience of legalisation is being used to inform planned legislation. The aim is to identify, understand and describe strategies that have effectively addressed barriers for *prima facie* eligible patients seeking PAS/PAD, so that that learning can be shared both across jurisdictions that currently have assisted dying legislation and those where such legislation is being considered, including New Zealand.

Invitation to engage in an interview

You are warmly invited to engage in an interview of around one hour (or longer if you wish) to obtain your perspectives on the research topic. The interview will be held at your workplace or another location at your preference. You will be provided with a copy of the research plan and the literature review backgrounding the research. If you give permission, your interview will be recorded, though with the option to stop the recording or the interview at any time and/or decline to answer particular questions. You will be sent a confidential copy of the notes of the interview, together with an invitation to make further comment, modify or request removal of any information by writing track changes into the notes or in a follow-up phone call before 31 December 2014. You will be acknowledged, again with your permission, as a research participant in my doctoral thesis and in relevant publications arising from the research. You will also be sent electronic copies of any articles or papers that are produced from this research.

Participant protections

Taking part is voluntary and your information will not be shared beyond the research team. Data will be collated and reported in ways that no individual's views are identifiable. If using any information has a potential for a participant to be identifiable, that person's permission will be sought to include, or not, such information. You may withdraw your information at any time before 31 December 2014. All data will be kept under lock and password-protected for six years and then destroyed.

Further information

If you would like further information about the research project, or to verify its authenticity, you are welcome to contact any of the following people:

Researcher: Dr Pam Oliver, +64 93727749, pamo@clear.net.nz (Please note, a local phone contact for your jurisdiction will be provided closer to the time of interview; however I can reliably be reached via email.)

Supervisors: Associate Professor Jo Manning, +64 99238804, j.manning@auckland.ac.nz; Dr Phillipa Malpas, +64 99233775, p.malpas@auckland.ac.nz

Head of School: Dr Andrew Stockley, Dean of Law, +64 99238027, lawdean@auckland.ac.nz

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 3737599 extn. 87830/83761. Email: humanethics@auckland.ac.nz APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 13 May 2014 for 3 years, Reference Number 011803

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G Papers and submissions

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