

This is a repository copy of Reporting and scrutiny of reported cases in four jurisdictions where assisted dying is lawful:A review of the evidence in the Netherlands, Belgium, Oregon and Switzerland.

White Rose Research Online URL for this paper: https://eprints.whiterose.ac.uk/112238/

Version: Accepted Version

#### Article:

Lewis, Penney and Black, Isra orcid.org/0000-0001-5324-7988 (2013) Reporting and scrutiny of reported cases in four jurisdictions where assisted dying is lawful:A review of the evidence in the Netherlands, Belgium, Oregon and Switzerland. Medical Law International. pp. 221-239.

https://doi.org/10.1177/0968533213508973

#### Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

#### **Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



#### **Abstract**

This article examines the reporting requirements in four jurisdictions in which assisted dying (euthanasia and/or assisted suicide) is legally regulated: the Netherlands, Belgium, Oregon and Switzerland. These jurisdictions were chosen because for each there is a substantial amount of empirical evidence available. We assess the available empirical evidence on reporting and what it tells us about the effectiveness of such requirements in encouraging reporting. We also look at the nature of requirements on regulatory bodies to refer cases not meeting the legal criteria to either prosecutorial or disciplinary authorities. We assess the evidence available on the outcomes of reported cases, including the rate of referral and the ultimate disposition of referred cases.

#### 1. Introduction

In this article we examine the reporting requirements in four jurisdictions in which assisted dying (euthanasia and/or assisted suicide) is legally regulated: the Netherlands, Belgium, Oregon and Switzerland. These jurisdictions were chosen because for each there is a substantial amount of empirical evidence available. We assess the available empirical evidence on reporting and what it tells us about the effectiveness of such requirements in encouraging reporting. In the Netherlands and Belgium, the reporting rate can be calculated by comparing the number of reported cases with the rates of euthanasia derived from anonymous prevalence surveys of doctors. (In Oregon and Switzerland, the available data does not permit the calculation of a reporting rate.)<sup>1</sup>

We also look at the nature of requirements on regulatory bodies to refer cases not meeting the legal criteria to either prosecutorial or disciplinary authorities (or both). We assess the evidence available on the outcomes of reported cases, including the rate of referral and the ultimate disposition of referred cases. Our sources include the legal provisions in the various jurisdictions, quantitative and qualitative research studies on aspects of end of life decision-making in those jurisdictions, work which reviews the empirical data, and the official reports of the relevant reviewing bodies.

#### 2. Legal and regulatory frameworks for reporting and scrutiny

## 2.1 Legally permissible assistance

In the Netherlands, both euthanasia (understood as termination of life on request) and assisted suicide are legally permitted, if performed by physicians in accordance with the statutory due care criteria set out in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.

<sup>&</sup>lt;sup>1</sup> See sections 5.1 and 6.1 below.

mli.sagepub.com/content/13/4/221.

In Belgium, the Euthanasia Act 2002 allows only physicians to perform euthanasia (also

understood as termination of life on request). Assisted suicide is not explicitly covered, although

Belgium's oversight body, the Federal Control and Evaluation Commission, has accepted that

cases of assisted suicide fall under the law.

In Oregon, the first Death with Dignity Act was passed in 1994. The act permits physician assisted

suicide in one form: the provision of a prescription for lethal medication, to be self-administered

by the patient. Neither euthanasia, nor any other form of physician assisted suicide is permitted.

In Switzerland it is only a criminal offence for a person to assist another person's suicide if the

assistor has a selfish motive. Almost all assisted suicides take place within frameworks set up by

individual not-for-profit right to die organisations such as Dignitas, Exit ADMD and Exit

Deutsche Schweiz (EDS). Euthanasia is not permitted in Switzerland, although the offence of

homicide at the request of the victim carries a lower sentence than murder.

2.2 Reporting obligations and scrutiny of reported cases

Termination of life on request and assisted suicide remain criminal offences in the Netherlands.

The defences inserted into the Penal Code by the Termination of Life on Request and Assisted

Suicide (Review Procedures) Act 2001 require the physician to report the case as euthanasia or

assisted suicide to the municipal pathologist, who then passes the file to the relevant Regional

Review Committee (RRC). If the RRC finds that the physician did not act in accordance with the

statutory due care criteria, the case is referred to the Public Prosecution Service and the regional

inspector of the Healthcare Inspectorate. A doctor who intentionally files a false statement as to

<sup>2</sup> Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, Art.9(2).

3

the cause of death commits a criminal offence punishable by up to three years imprisonment or a fine of the fourth category (£18500).<sup>3</sup>

Compliance with the Belgian law is monitored by the Federal Control and Evaluation Commission (FCEC), to which all cases of euthanasia must be reported. If a two-thirds majority of commissioners is of the view that the statutory conditions have not been fulfilled, the dossier is sent to the local state prosecutor, although it is not clear what offence will have been committed. No penalty is currently included in the Belgian statute for failure to report, and the advice of the National Order of Physicians is not to disclose the fact that a death was caused by euthanasia on the death certificate.

In Oregon, the physician must report each prescription written under the Act to the Oregon Department of Human Services (ODHS), and report each death resulting from the ingestion of the prescribed medication. There are no penalties specifically for failure to report:

The Oregon Act does not assign enforcement authority to the Department of Human Services and is silent on what action the agency should take if non-compliance is encountered. When problems with documentation or reporting from physicians are encountered, the Department of Human Services will query those health care professionals for clarification. If the Department of Human Services encounters a violation of the Oregon Act, the individual committing the violation will be reported to the appropriate licensing board.<sup>9</sup>

In Switzerland, assisted suicides must be reported as unnatural deaths to the local police and coroner. There is no national body to which assisted suicides must be reported and thus no

<sup>6</sup> John Griffiths, Heleen Weyers and Maurice Adams, Euthanasia and the law in Europe (Hart, 2008), p.327.

<sup>&</sup>lt;sup>3</sup> Penal Code (Netherlands) 1881, Art.228(1).

<sup>&</sup>lt;sup>4</sup> Euthanasia Act (Belgium) 2002, Arts.5,7.

<sup>&</sup>lt;sup>5</sup> Op. cit., Art.8.

<sup>&</sup>lt;sup>7</sup> Although there is currently a bill before the Senate which would make failure to report an administrative offence: Sénat de Belgique, Proposition de loi modifiant la loi du 28 mai 2002 relative à l'euthanasie en vue d'imposer une amende administrative au médecin qui ne respecte pas l'obligation de déclaration (S 5-1935).

<sup>&</sup>lt;sup>8</sup> Griffiths and others, *Euthanasia and the law in Europe*, p.324; National Council of the Order of Physicians (Belgium), *Opinion relative to palliative care, euthanasia and other medical decisions concerning the end of life* (2003).

<sup>&</sup>lt;sup>9</sup> The Task Force to Improve the Care of Terminally-Ill Oregonians, *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals* (2008), p.90.

national reporting data is available.<sup>10</sup> The lack of independent or judicial oversight of assisted suicide has been a subject of concern both inside and outside Switzerland.<sup>11</sup> Indeed, the establishment of a "medical or official supervisory authority" was recently considered by the Federal Council,<sup>12</sup> but tighter regulation was ultimately rejected.<sup>13</sup>

## 3. The Netherlands

# 3.1. Reporting rate

Figure 1 shows that more and more deaths from euthanasia came to be reported as the Dutch control system became established,<sup>14</sup> that the Dutch reporting rate improved significantly over time and that it has stabilised at approximately 80% over the last ten years.<sup>15</sup> The latest Dutch reporting rate (from 2010) is 77%.<sup>16</sup> The difference between the rate in 2005 (80%) and the rate in 2010 (77%) is not statistically significant.<sup>17</sup>

<sup>&</sup>lt;sup>10</sup> Georg Bosshard, Esther Ulrich and Walter Bar, '748 cases of suicide assisted by a Swiss right-to-die organisation', *Swiss Medical Weekly*, 133(21-22) (2003), 310, p.311.

<sup>&</sup>lt;sup>11</sup> UN Human Rights Committee, *Concluding observations of the Human Rights Committee: Switzerland* (2009), para.13; <a href="http://www.ejpd.admin.ch/content/ejpd/en/home/dokumentation/mi/2010/2010-09-17.html">http://www.ejpd.admin.ch/content/ejpd/en/home/dokumentation/mi/2010/2010-09-17.html</a> Federal Department of Justice and Police (Switzerland), 'Specific regulations for organised assisted suicide in Switzerland' (2010) accessed 23 March 2011.

<sup>&</sup>lt;sup>12</sup> Federal Department of Justice and Police (Switzerland), 'Specific regulations for organised assisted suicide in Switzerland', op. cit.

http://www.admin.ch/aktuell/00089/index.html?lang=en&msg-id=39905 Federal Department of Justice and Police (Switzerland), 'Assisted suicide: strengthening the right of self-determination' (2011) accessed 6 September 2011.

<sup>&</sup>lt;sup>14</sup> See John Griffiths, Alex Bood and Heleen Weyers, *Euthanasia and the Law in the Netherlands* (Amsterdam Univ Press, 1998), chapters 2 and 3.

<sup>&</sup>lt;sup>15</sup> Agnes van der Heide, Bregje D Onwuteaka-Philipsen, Mette L Rurup, Hilde M Buiting, Johannes JM van Delden, Johanna E Hanssen-de Wolf, Anke GJM Janssen, H Roeline W Pasman, Judith AC Rietjens, Cornelis JM Prins, Ingeborg M Deerenberg, Joseph KM Gevers, Paul J van der Maas and Gerrit van der Wal, 'End-of-life practices in the Netherlands under the Euthanasia Act', *New England Journal of Medicine*, 356(19) (2007), 1957, Table 1; Griffiths and others, *Euthanasia and the law in Europe*, p.198; Regional Review Committees Euthanasia, *Jaarverslag 2011* (2012); Regional Review Committees Euthanasia, *Jaarverslag 2009* (2010); Regional Review Committees Euthanasia, *Jaarverslag 2007* (2008).

<sup>&</sup>lt;sup>16</sup> Bregje D. Onwuteaka-Philipsen, Arianne Brinkman-Stoppelenburg, Corine Penning, Gwen J. F. de Jong-Krul, Johannes J. M. van Delden and Agnes van der Heide, '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', *The Lancet*, 380(9845) (2012), 908, 913.

<sup>&</sup>lt;sup>17</sup> The 95% confidence interval (CI) for the 2010 rate is 72%-92%, and for the 2005 rate is 72%-90%. Agnes van der Heide, Arianne Brinkman-Stoppelenburg, Hans van Delden and Bregje Onwuteaka-Philipsen, *Euthanasie en andere medische beslissingen rond het levenseinde: Sterfgevallenonderzoek 2010* (ZonMw, 2012), Table 5.1.

[insert Reporting Rate figure here]

# Figure 1. Estimated and reported deaths from euthanasia (EUT) or physician-assisted suicide (PAS) in the Netherlands

## 3.2. Referral

Sixty cases were referred to prosecutors between 1999 and 2011 (0.20% of all reported cases). The rate of referral over time is shown in Figure 2.

[insert Referrals figure here]

## Figure 2. Rate of referral to prosecutors by RRCs over time (% of reported cases)

No prosecutions have been brought following these referrals.<sup>18</sup> The primary reasons for each referral by the RRC are illustrated in Figure 3. In a few cases, more than one of the due care criteria was at issue.

[insert Reasons Stacked Bar figure here]

Figure 3. Principal ground(s) for referral to prosecutor by RRC<sup>19</sup>

<sup>-</sup>

<sup>&</sup>lt;sup>18</sup> Data compiled from: Regional Review Committees Euthanasia, *Jaarverslag 2011*, pp.64-65; Regional Review Committees Euthanasia, *Jaarverslag 2010* (2011), pp.55,58; Regional Review Committees Euthanasia, *Jaarverslag 2009*, p.50; Regional Review Committees Euthanasia, *Jaarverslag 2008*, p.36; Regional Review Committees Euthanasia, *Jaarverslag 2007*, casi 5,11,12; Griffiths and others, *Euthanasia and the law in Europe*, pp.214-215.

<sup>&</sup>lt;sup>19</sup> Data compiled from: Regional Review Committees Euthanasia, *Jaarverslag 2011*, casi 15-19; Regional Review Committees Euthanasia, *Jaarverslag 2010*, casi 4,14-16,18; Regional Review Committees Euthanasia, *Jaarverslag 2009*, casi 10,12-19; Regional Review Committees Euthanasia, *Jaarverslag 2008*, casi 5-14; Regional Review Committees Euthanasia, *Jaarverslag 2007*, casi 5,11,12; Griffiths and others, *Euthanasia and the law in Europe*, pp.214-216. Note that the English versions of the *Annual Reports* are incomplete and do not contain reports of some cases which have been referred to prosecutors. For the first (and thus far only) time, the 2010 Dutch language Annual Report, *Jaarverslag 2010*, did not contain descriptions of every referred case. Only 5 of the total of 9 referred cases were described, thus 4 are missing. Two of the described cases were referred because of concerns with the way in which euthanasia was carried out (inadequate performance). Since the text mentioned that *5* cases were referred on this ground, it can be inferred that 3 of the missing 4 cases were referred on this ground: Regional Review Committees Euthanasia, *Jaarverslag 2010*, pp.6,46. The reason for referral of the remaining missing case is unknown.

Lack of,<sup>20</sup> or inadequate, consultation is clearly the most significant reason for referral. Consultation may be considered inadequate if the doctor consulted is insufficiently independent from the attending doctor,<sup>21</sup> or the consultation takes place too early<sup>22</sup> or too late.<sup>23</sup> Consultation has not always headed the list of reasons for referral. Prior to the setting up of the RRCs, during the period 1991-1995, the quality of the consultation was the main reason for discussion in 24% of cases discussed by the Assembly of Prosecutors-General.<sup>24</sup> The most significant reason for discussion (in 38% of cases discussed) was that the patient was not in the terminal phase (which is not a due care criterion).<sup>25</sup>

Problems with the way in which euthanasia is carried out (inadequate performance) are the second-most significant reason for referral. In recent years, most of these cases involve concerns about the dosage of the coma-inducing sedative administered prior to the muscle relaxant which causes death<sup>26</sup> and the need to ascertain the depth of the patient's coma before administering the muscle relaxant.<sup>27</sup> In some older cases referred on the ground of inadequate performance, the reason was that the lethal medication had been left unsupervised with the patient.<sup>28</sup> This practice has almost entirely disappeared<sup>29</sup> which is evidence of an improvement in practice through the

<sup>&</sup>lt;sup>20</sup> Griffiths and others, *Euthanasia and the law in Europe*, p.94; Regional Review Committees Euthanasia, *Annual Report 2009* (2010), case 14; Regional Review Committees Euthanasia, *Annual Report 2010* (2011), case 15.

<sup>&</sup>lt;sup>21</sup> Griffiths and others, *Euthanasia and the law in Europe*, p.96; Regional Review Committees Euthanasia, *Jaarverslag 2008*, casi 5,8,9,11.

<sup>&</sup>lt;sup>22</sup> Griffiths and others, *Euthanasia and the law in Europe*, pp.97-98; Regional Review Committees Euthanasia, *Jaarverslag 2011*, casus 16; Regional Review Committees Euthanasia, *Jaarverslag 2010*, casi 4,14; Regional Review Committees Euthanasia, *Jaarverslag 2008*, casus 6.

<sup>&</sup>lt;sup>23</sup> Griffiths and others, *Euthanasia and the law in Europe*, pp.97-98; Regional Review Committees Euthanasia, *Jaarverslag 2009*, casus 13.

<sup>&</sup>lt;sup>24</sup> The Assembly of Prosecutors General discussed between 1-2.5% of all reported cases during this period: G van der Wal, P J van der Maas, J M Bosma, B D Onwuteaka-Philipsen, D L Willems, I Haverkate and P J Kostense, 'Evaluation of the notification procedure for physician-assisted death in the Netherlands', *New England Journal of Medicine*, 335(22) (1996), 1706, p.1709.

<sup>&</sup>lt;sup>26</sup> Regional Review Committees Euthanasia, *Jaarverslag 2008*, casi 12-14; Regional Review Committees Euthanasia, *Jaarverslag 2009*, casi 15,16; Regional Review Committees Euthanasia, *Jaarverslag 2010*, casi 16,18 and 3 additional cases mentioned at pp.6,46. Some of these cases have been defended on medical grounds by the physicians involved. See Bram Sprij, 'Mag het ietsje minder zijn? Laat dosis thiopental bij euthanasie afhangen van lichaamsgewicht', *Nederlands tijdschrift voor geneeskunde*, 154 (2010), A1983; Eric H J van Wijlick and Gert van Dijk, 'Zorgvuldige euthanasie', *Medisch Contact*, 65(33/34) (2010), 1612, p.1613.

<sup>&</sup>lt;sup>27</sup> Regional Review Committees Euthanasia, *Jaarverslag 2011*, casi 16,18,19; Regional Review Committees Euthanasia, *Jaarverslag 2009*, casus 12.

<sup>&</sup>lt;sup>28</sup> Regional Review Committees Euthanasia, *Jaarverslag 2000* (2001), casi 13, 14; Regional Review Committees Euthanasia, *Jaarverslag 2003* (2004), casi 13, 14.

<sup>&</sup>lt;sup>29</sup> Although there is one recent such case: Regional Review Committees Euthanasia, *Jaarverslag 2009*, casus 18 (also available in English: Regional Review Committees Euthanasia, *Annual Report 2009*, case 18).

'educative function'<sup>30</sup> of the RRCs via the publication of both individual judgments and annual reports.

## 4. Belgium

## 4.1. Reporting rate

Prevalence data from a 2007 death certificate study in Flanders – which used a similar methodology to the Dutch national surveys – provides a good picture of reporting practice and the differences between reported and unreported cases. The reporting rate was estimated at 52.8% (95% confidence interval (CI) 43.9% to 60.5%).<sup>31</sup>

#### 4.2. Referral

No cases have been reported to the prosecutorial authorities by the FCEC.<sup>32</sup> One case involving the assisted suicide of a patient with dementia was investigated by the Public Prosecutor in 2006 as it had not been formally reported by the doctor involved (who had instead disclosed the details to the media).<sup>33</sup> The investigation was subsequently closed as the statutory requirements had been met.<sup>34</sup>

#### 5. Oregon

<sup>30</sup> Agnes van der Heide, Johan Legemaate, Bregje Onwuteaka-Philipsen, Eva Bolt, Ineke Bolt, Hans van Delden, Eric Geijteman, Marianne Snijdewind, Donald van Tol and Dick Willems, *Tweede evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding* (2012), p.41.

<sup>&</sup>lt;sup>31</sup> Tinne Smets, Johan Bilsen, Joachim Cohen, Mette L Rurup, Freddy Mortier and Luc Deliens, 'Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases', *British Medical Journal*, 341 (2010), c5174, p.3; Johan Bilsen, Joachim Cohen, Kenneth Chambaere, Geert Pousset, Bregje D Onwuteaka-Philipsen, Freddy Mortier and Luc Deliens, 'Medical end-of-life practices under the euthanasia law in Belgium', *New England Journal of Medicine*, 361(11) (2009), 1119, p.1120.

<sup>&</sup>lt;sup>32</sup> Commission fédérale de contrôle et d'évaluation de l'euthanasie, *Cinquième rapport aux chambres législatives (2010-2011)* (2012), p.10; Commission fédérale de contrôle et d'évaluation de l'euthanasie, *Quatrième rapport aux chambres législatives (2008-2009)* (2010); Commission fédérale de contrôle et d'évaluation de l'euthanasie, *Troisième rapport aux chambres législatives (2006-2007)* (2008); Commission fédérale de contrôle et d'évaluation de l'euthanasie, *Deuxième rapport aux chambres législatives (2004-2005)* (2006); Commission fédérale de contrôle et d'évaluation de l'euthanasie, *Premier rapport aux chambres legislatives (2002-2003)* (2004).

<sup>&</sup>lt;sup>33</sup> Jane Burgermeister, 'Doctor reignites euthanasia row in Belgium after mercy killing', *BMJ*, 332(7538) (2006), 382; M. Cosyns, *De Huisarts/Le Généraliste*, February 9, 2006, p. 6-7.

<sup>&</sup>lt;sup>34</sup> Griffiths and others, *Euthanasia and the law in Europe*, p.315.

## 5.1. Reporting rate

ODHS is required both to collect data on patients and physicians who participate in PAS under the DWDA, as well as report physician noncompliance to the Oregon Board of Medical Examiners. The risk of referral to the Board of Medical Examiners renders it extremely difficult for ODHS to collect data on conduct that falls outside the DWDA, a point conceded in the first report. No attempt has been made by ODHS, or any independent researchers, to document unreported PAS in Oregon since the entry into force of the DWDA, although a survey conducted in 1998 found that 3.3% of physicians practising in the United States had assisted suicide during their career. The reporting rate in Oregon is therefore unknown.

#### 5.2. Referral

A total of 22 physicians were referred to the Board of Medical Examiners between 1998-2012 for noncompliance with the provisions of the DWDA.<sup>37</sup> Noncompliance with the DWDA identified by the ODHS has been almost exclusively of a clerical nature, the most common items being incomplete or late physician reporting forms, or incomplete witness forms (missing signatures). However, in 2010, one physician was referred for failing to wait 48 hours between

<sup>&</sup>lt;sup>35</sup> Oregon Department of Human Resources, *Oregon's Death with Dignity Act: The First Year's Experience* (1999), p.9.

<sup>&</sup>lt;sup>36</sup> D E Meier, C A Emmons, S Wallenstein, T Quill, R S Morrison and C K Cassel, 'A national survey of physician-assisted suicide and euthanasia in the United States', *The New England journal of medicine*, 338(17) (1998), 1193, Table 3.

<sup>&</sup>lt;sup>37</sup> Oregon Department of Human Resources, ODHR, 1st Report; Oregon Department of Human Services, Oregon's Death with Dignity Act: The Second Year's Experience (2000); Oregon Department of Human Services, Oregon's Death with Dignity Act: Three years of legalized physician-assisted suicide (2001), p.4; Oregon Department of Human Services, Fourth Annual Report on Oregon's Death with Dignity Act (2002), p.4; Oregon Department of Human Services, Fifth Annual Report on Oregon's Death with Dignity Act (2003); Oregon Department of Human Services, Sixth Annual Report on Oregon's Death with Dignity Act (2004), p.13; Oregon Department of Human Services, Seventh Annual Report on Oregon's Death with Dignity Act (2005), p.14; Oregon Department of Human Services, Eighth Annual Report on Oregon's Death with Dignity Act (2006), p.13; Oregon Department of Human Services, Ninth Annual Report on Oregon's Death with Dignity Act (2007), p.10; Oregon Department of Human Services, Tenth Annual Report on Oregon's Death with Dignity Act (2008); Oregon Department of Human Services, Eleventh Annual Report on Oregon's Death with Dignity Act (2009), p.2; Oregon Department of Human Services, Twelfth Annual Report on Oregon's Death with Dignity Act (2010), p.2; Oregon Department of Human Services, Thirteenth Annual Report on Oregon's Death with Dignity Act (2011), p.2; Oregon Department of Human Services, Fourteenth Annual Report on Oregon's Death with Dignity Act (2012), p.3; Oregon Department of Human Services, Fifteenth Annual Report on Oregon's Death with Dignity Act (2012)

receipt of the patient's written request and writing the prescription. The consequences of referral are unknown, although in 2007 and 2009, the Board of Medical Examiners found no violations of "good faith compliance" with the DWDA, and thus "did not sanction any [of the 12] physician[s] for 'unprofessional conduct'." In 2005, one physician was referred to the Board of Pharmacy after an individual regained consciousness 65 hours after ingesting lethal medication. The professional conduction of the process of the professional conduction of the process of the professional conduction.

## 6. Switzerland

## 6.1. Reporting rate

Despite the absence of a regulatory regime like those in the Netherlands, Belgium and Oregon, there is a significant amount of oversight of assisted suicide in Switzerland since "each case of assisted death must be investigated by the police to determine if the suicide was in compliance with the law, [... if it is not] the matter is referred to the public prosecutor". The reporting rate for assisted suicides which involve a right to die organisation would appear to be very high as there is no evidence that those organisations fail to report deaths to police. Indeed, it has been noted that suicides reported by the right to die organisations match "the results of an international study on medical end-of-life decisions based on anonymous reports by a large number of physicians attending dying patients".

#### 6.2. Referral

<sup>&</sup>lt;sup>38</sup> Oregon Department of Human Services, *ODHS*, *13th Report*, p.2.

<sup>&</sup>lt;sup>39</sup> Oregon Department of Human Services, *ODHS*, *9th Report*, p.2; Oregon Department of Human Services, *ODHS*, *11th Report*, p.2.

<sup>&</sup>lt;sup>40</sup> Oregon Department of Human Services, *ODHS*, 8th Report, p.13.

<sup>&</sup>lt;sup>41</sup> Stephen J Ziegler, 'Collaborated death: an exploration of the Swiss model of assisted suicide for its potential to enhance oversight and demedicalize the dying process', *Journal of Law, Medicine & Ethics*, 37(2) (2009), 318, p.323.

<sup>&</sup>lt;sup>42</sup> A 2003 study found that 92% of *physician*-assisted suicide in Switzerland takes place with the involvement of a right-to-die society. Agnes van der Heide, Luc Deliens, Karin Faisst, Tore Nilstun, Michael Norup, Eugenio Paci, Gerrit van der Wal and Paul J van der Maas, 'End-of-life decision-making in six European countries: descriptive study', *Lancet*, 362(9381) (2003), 345, 347.

<sup>&</sup>lt;sup>43</sup> Bosshard and others, '748 cases of suicide assisted by a Swiss right-to-die organisation', p.313.

<sup>&</sup>lt;sup>44</sup> Georg Bosshard, 'Switzerland' in John Griffiths, Heleen Weyers and Maurice Adams, eds., *Euthanasia and Law in Europe* (Hart, 2008), p.479, referring to the EURELD study: van der Heide and others, 'End-of-life decision-making in six European countries'.

The absence of a national reporting body means that the referral rate in Switzerland is unknown. A small number of prosecutions have taken place.<sup>45</sup>

#### 7. Analysis

## 7.1. Reporting rates

There is no data on the reporting rate in Oregon. The reporting rate within the right to die organisations in Switzerland may be 100%. The reporting rate is significantly higher (77%) in the Netherlands than in Belgium (53%) where legalisation occurred more recently. The reporting rate has risen over time in the Netherlands; it is not yet known whether this is the case in post-legalisation Belgium.

The rate in the Netherlands rose when the RRCs were inserted as a buffer between physicians and the authorities. The Swiss experience suggests that a buffer may not be needed to encourage reporting if the process leading up to the assistance involves several layers of administration involving a number of different actors coupled with few legal requirements.

In the Netherlands, "[t]he major reason for failure to report [a case as euthanasia] is that the physician does not regard the course of action as a life-terminating act." These unreported cases frequently involve the use of nontypical drugs to cause death (morphine rather than barbiturates and muscle relaxants) and/or a very short life expectancy. The number of *estimated* deaths from euthanasia includes such cases, since it does not rely on physicians' labelling of their own practice. Since 99% of cases involving typical euthanasia drugs are reported, this inconsistent labelling is

<sup>&</sup>lt;sup>45</sup> Bosshard, 'Switzerland', pp.475-476.

<sup>&</sup>lt;sup>46</sup> B Onwuteaka-Philipsen, JKM Gevers, A van der Heide, JJM van Delden, HRW Pasman, JAC Rietjens, ML Rurup, HM Buiting, JE Hanssen-de Wolf, AGJM Janssen and PJ van der Maas, *Evaluatie: Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding* (Zon/Mw, 2007), p.15.

<sup>&</sup>lt;sup>47</sup>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', pp.913; Onwuteaka-Philipsen and others, *Evaluatie: Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, p.15; H M Buiting, A van der Heide, B D Onwuteaka-Philipsen, M L Rurup, J A C Rietjens, G Borsboom, P J van der Maas and J J M van Delden, 'Physicians' labelling of end-of-life practices: a hypothetical case study', *Journal of Medical Ethics*, 36(1) (2010), 24.

<sup>&</sup>lt;sup>48</sup> Onwuteaka-Philipsen and others, *Evaluatie: Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, p.15; Mette L Rurup, Hilde M Buiting, H Roeline W Pasman, Paul J van der Maas, Agnes van der

now likely to account for almost all unreported cases. This thesis is supported by data collected on physicians' willingness to report euthanasia. In 2007, of physicians who stated that they had performed euthanasia since the 2002 Act, 97% stated that they had always reported it. <sup>49</sup> In the 2010 national survey, 100% of acts termed *by physicians* as euthanasia and assisted suicide were reported. <sup>50</sup>

In Belgium, the low reporting rate appears in part to have a similar explanation to the Netherlands (although the Dutch rate is much higher). Physicians only report those cases they perceive to be euthanasia, while many more cases are labelled as euthanasia by researchers. The reporting rate for cases that physicians perceived as euthanasia was 93.1%. Cases were more likely not to be perceived as euthanasia when the shortening of life was less than one week (which may mean that it would not have been possible to comply with the due care criteria). Cases involving older patients were less likely to be reported and more likely to involve opioids. The researchers conclude that "[i]t is possible that physicians find that older patients' requests or suffering are not explicit enough to merit what is in their eyes real euthanasia by bolus injection. A lack of knowledge about the reporting obligation also appears to play a significant role in non-reporting in Belgium, indicating a need for an education programme when rolling out a new reporting regime.

The 2007 death certificate study covered only the Dutch-speaking region of Belgium (Flanders) and there is some evidence in support of the proposition that euthanasia is *reported* less frequently in the French-speaking region. In a recent survey which included hypothetical cases,

Heide and Bregje D Onwuteaka-Philipsen, 'The reporting rate of euthanasia and physician-assisted suicide: a study of the trends', *Medical care*, 46(12) (2008), 1198, p.1201; 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', pp.912-913.

<sup>&</sup>lt;sup>49</sup> Onwuteaka-Philipsen and others, *Evaluatie: Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, p.176.

<sup>&</sup>lt;sup>50</sup> 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', pp.912,914.

<sup>&</sup>lt;sup>51</sup> Tinne Smets, Joachim Cohen, Johan Bilsen, Yanna Van Wesemael, Mette L Rurup and Luc Deliens, 'The labelling and reporting of euthanasia by Belgian physicians: a study of hypothetical cases', *Eur J Public Health*, 22(1) (2012), 19-26; Tinne Smets, Johan Bilsen, Lieve Van den Block, Joachim Cohen, Viviane Van Casteren and Luc Deliens, 'Euthanasia in patients dying at home in Belgium: interview study on adherence to legal safeguards', *British Journal of General Practice*, 60(573) (2010), e163, p.e168.

<sup>&</sup>lt;sup>52</sup> Euthanasia Act (Belgium) 2002, s.3(2)(2) requires that the physician have several conversations with the patient over a reasonable period of time to be certain of the persistence of the patient's suffering and the enduring character of the patient's request.

<sup>&</sup>lt;sup>53</sup> Smets and others, 'Reporting of euthanasia in medical practice in Flanders, Belgium', p.6.

<sup>&</sup>lt;sup>54</sup> Op. cit., p.5; Smets and others, 'Euthanasia in patients dying at home in Belgium', p.e168.

mli.sagepub.com/content/13/4/221.

"the lower actual reporting intention of Walloon [French-speaking] physicians for the euthanasia case with muscular relaxants could not be explained entirely by their more frequently incorrect labelling of the case". 55 Additional factors include a lack of information about the euthanasia law and unwillingness to report:

Walloon physicians indicated considerably more often than their Flemish counterparts that euthanasia was a matter between patient and physician in which a Control and Evaluation Committee need not interfere and considerably less often agreed that the reporting requirement contributes to more careful practice.<sup>56</sup>

In the 2005-2006 SENTI-MELC<sup>57</sup> study, of all of the patients who received euthanasia whose GP was interviewed (N=9), the reporting rate was 55.6%:

One physician who did not report gave as the reason that they had forgotten (case 6). Another said it was not a case of euthanasia but of terminal sedation with the intention of hastening death so did not have to be reported (case 7). The GP in case 8 did not report the case for the same reason that they did not consult a second physician [procedure too burdensome and not useful]. The physician in case 9 did not report it because they mistakenly thought that according to the law they should have waited for another 15 days.<sup>58</sup>

The Dutch experience suggests that education about the requirements may improve reporting in Belgium, and that physician confidence in the robustness of the buffer and consequent willingness to report is likely to improve over time.

In sum, the primary reason for not reporting in the Netherlands and Belgium appears to be a difference in labelling between physicians and researchers. Well over 90% of cases labelled as

<sup>55</sup> Joachim Cohen, Yanna Van Wesemael, Tinne Smets, Johan Bilsen and Luc Deliens, 'Cultural differences affecting euthanasia practice in Belgium: One law but different attitudes and practices in Flanders and Wallonia', Soc Sci Med, 75(5) (2012), 845-53, p.849.

<sup>&</sup>lt;sup>56</sup> Joachim Cohen, Yanna Van Wesemael, Tinne Smets, Johan Bilsen and Luc Deliens, 'Cultural differences affecting euthanasia practice in Belgium: One law but different attitudes and practices in Flanders and Wallonia', Soc Sci Med, 75(5) (2012), 845-53, p.851.

<sup>&</sup>lt;sup>57</sup> The Sentinel Network Study Monitoring End-of-Life Care Study (SENTI-MELC) involved a national network of general practitioners who reported on patient deaths in 2005-2006 and categorised these as sudden or non-sudden. For the latter, data were collected on end of life decisions under the same framework used in the Dutch national surveys and the earlier Belgian studies: Lieve Van den Block, Viviane Van Casteren, Reginald Deschepper, Nathalie Bossuyt, Katrien Drieskens, Sabien Bauwens, Johan Bilsen and Luc Deliens, 'Nationwide monitoring of end-of-life care via the Sentinel Network of General Practitioners in Belgium: the research protocol of the SENTI-MELC study', BMC Palliative Care, 6 (2007), 6. <sup>58</sup> Smets and others, 'Euthanasia in patients dying at home in Belgium', p.e166.

euthanasia by physicians in both jurisdictions are reported. In the 2010 Dutch national survey the researchers argued that:

our finding that about 100% of the cases in which the advised drugs were used were reported suggests that non-reporting by physicians is not related to unwillingness to report cases of euthanasia. This finding seems more related to lack of clarity about or discrepancy between effects of drugs and intention with regard to hastening death. Further education seems the most appropriate way to further increase the reporting rate.<sup>59</sup>

In its response to this data and the researchers' recommendation, the Dutch medical association (the KNMG) has stated that it intends to attend to this educational need in both general and continuing medical education.<sup>60</sup>

Physicians do need more clarity on when to report,<sup>61</sup> but the extent to which the reporting rate would be increased by further education of physicians in the identification and correct labelling of cases meeting the definition of euthanasia is uncertain.

In the Netherlands, the archetypal unreported euthanasia case involves the administration of either a sedative, an opioid or a combination of the two, <sup>62</sup> in relation to which the doctor answers 'yes' to the following question: "was death the *consequence* of the use of a drug that was prescribed, supplied or administered by you . . . with the explicit *intention* of hastening the end

<sup>&</sup>lt;sup>59</sup> 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', pp.912, 914.

<sup>60</sup> http://knmg.artsennet.nl/web/file?uuid=9417b9de-4dd3-48be-99a6-

<sup>&</sup>lt;u>5a472e9aac57&owner=a8a9ce0e-f42b-47a5-960e-be08025b7b04&contentid=129109</u> Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst (KNMG), 'Brief aan Minister Schippers: reactie van de KNMG op het Sterfgevallenonderzoek en de tweede evaluatie Wet toetsing levensbeëindinging op verzoek en hulp bij zelfdoding' (2013).

<sup>&</sup>lt;sup>61</sup> Griffiths and others, *Euthanasia and the law in Europe*, pp.202-204.

<sup>&</sup>lt;sup>62</sup> All reported cases of euthanasia in 2010 involved the use of the standard euthanatica (coma-inducing substance (usually barbiturate) followed by muscle relaxant) although in five cases (including casi 16 and 18) the dosage of the coma-inducing substance was lower than recommended and the doctor was found not to have acted with due care: Regional Review Committees Euthanasia, *Jaarverslag 2010*, pp.6,46. As 77% of euthanasia cases were reported, and 80.1% of euthanasia cases involved muscle relaxants or barbiturates, the unreported cases almost all involved either benzodiazepines and opioids together, benzodiazepines, or opioids: 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', Table 3.

mli.sagepub.com/content/13/4/221.

of life?" According to the Dutch researchers, two related factors contribute to the mis-labelling by doctors of cases of euthanasia which should be reported. The first is a "lack of clarity about or discrepancy between effects of drugs". Put simply, the doctor may wrongly believe that the patient's death was a *consequence* of the administration of an opioid, as a result of the "myth that satisfactory symptom control at the end of life is inevitably associated with hastening death."64 Since it is possible to cause death using an opioid, it is not possible to determine what proportion of the unreported euthanasia cases are incorrectly described by doctors due to this myth, but better initial and continuing education in palliative care could improve doctors' ability to assess whether death is a consequence of the administration of an opioid.

Another related problem may be that in some cases Dutch doctors may *choose* not to use the typical euthanasia drugs. A number of reasons have been proposed for this. In difficult cases the doctor's intention may be to avoid the reporting obligation. Thus opioids may be used so that it is less clear or unclear whether death has been hastened. 65 Alternatively, opioids or other nontypical means may be used with the intention of prolonging the death because doctors "have the experience that the patient dies too soon after the administration of regular euthanatics, which can be unpleasant for the doctor himself or for the relatives."66

A more fundamental problem may exist in relation to the role of the second factor, *intention*, which may be resistant to attempts to improve the reporting rate based on education and clarification. As John Griffiths has argued, "people do not necessarily know what their own intentions are - more precisely, they can think about their behaviour in terms of a variety of different intentions without experiencing any difficulty." Drawing on the Dutch evidence,

<sup>63</sup> Questionnaire End-of-Life Decisions in Medical Practice, Q7, published as Supplementary Appendix to 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'; To be categorised as euthanasia (as opposed to termination of life without request), there must also be a request for termination of life from the patient.

<sup>&</sup>lt;sup>64</sup> Nigel Sykes and Andrew Thorns, 'The use of opioids and sedatives at the end of life', *The lancet oncology*, 4(5) (2003), 312, p.317.

<sup>&</sup>lt;sup>65</sup> See Mette Rurup, 'Setting the stage for death: New themes in the euthanasia debate', PhD Thesis, Vrije Universiteit Amsterdam, 2005, pp.119,121.

<sup>66</sup> M L Rurup, B D Onwuteaka-Philipsen, A van der Heide, G van der Wal and P J van der Maas, '[Trends in the agents used for euthanasia and the relationship with the number of notifications]', Nederlands tijdschrift voor geneeskunde, 150(11) (2006), 618-24, p.623 (translation by first author), citing Annemieke Horikx, 'De rolverdeling tussen arts en apotheker bij euthanasie: 'Wie doet wat, en hoe zorgvuldig?'', Pharmaceutisch weekblad, 139 (2004), 1319, 1321.

<sup>67</sup> John Griffiths, 'Criminal Law is the Problem, Not the Solution' in Charles A. Erin and Suzanne Ost, eds., The Criminal Justice System and Health Care (Oxford University Press, 2007), pp.130-131. An earlier version

Griffiths argues that the reporting rate demonstrates the ineffectiveness of the criminal law. The intention problem suggests that education and clarification may not be sufficient to improve the reporting rate in any system requiring doctors to distinguish between those end of life decisions (ELDs) which must be reported and those which are not subject to the reporting obligation. To avoid such a difficult distinction, Griffiths proposes including *all* medical behaviour which potentially shortens life in the reporting obligation. Griffiths provides only a sketch of his proposed system which would involve professional self-regulation with a local reporting obligation, tailored to the ways in which doctors themselves describe their behaviour. No interaction between the regulatory system and the criminal justice system is mentioned; presumably there would be no such interaction, in order to encourage reporting effectively.

Were this proposal implemented, the volume of cases in which there would be an obligation to report would be enormous. In the UK, Clive Seale's second national survey of ELDs involving doctors found that 39.2% of all deaths occurred following such a decision. The 2010 Dutch national survey found that ELDs occurred in 57.8% of all deaths. It is unclear what sort of impact this would have on the health care system, but it would be resource-intensive. It might also generate an incentive to provide less than optimal care, for example, decreased use of pain-relief in any cases in which the doctor believes (even if that belief is unfounded) that the patient's death may be hastened by the administration of pain-relief.

appears in Griffiths and others, *Euthanasia and the Law in the Netherlands*, §6.2. See also, van der Heide and others, *Euthanasie en andere medische beslissingen rond het levenseinde: Sterfgevallenonderzoek 2010*, p.56. <sup>68</sup> Griffiths, 'Criminal Law is the Problem, Not the Solution'. Although the rate has since improved, it still remains at 77% in the most recent national study. 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', p.913.

<sup>&</sup>lt;sup>69</sup> Griffiths, 'Criminal Law is the Problem, Not the Solution', p.133.

<sup>&</sup>lt;sup>70</sup> Op. cit., pp.133-135.

<sup>&</sup>lt;sup>71</sup> Op. cit., p.133.

<sup>&</sup>lt;sup>72</sup> The 95% CI for this figure is 35.9%–42.4%. It does not include cases of continuous deep sedation: C Seale, 'End-of-life decisions in the UK involving medical practitioners', *Palliative medicine*, 23(3) (2009), 198, Table 1.

<sup>&</sup>lt;sup>73</sup> The 95% CI for this figure is 56.7–59.0%: 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', Table 1.

<sup>&</sup>lt;sup>74</sup> Peter Allmark, Mark Cobb, B Jane Liddle and Angela Mary Tod, 'Is the doctrine of double effect irrelevant in end-of-life decision making?', *Nursing philosophy: an international journal for healthcare professionals*, 11(3) (2010), 170; P D Good, P J Ravenscroft and J Cavenagh, 'Effects of opioids and sedatives on survival in an Australian inpatient palliative care population', *Internal medicine journal*, 35(9) (2005), 512; Sykes and Thorns, 'The use of opioids and sedatives at the end of life'; Nigel Sykes and Andrew Thorns, 'Sedative use in the last week of life and the implications for end-of-life decision making', *Archives of internal medicine*, 163(3) (2003), 341; T Morita, J Tsunoda, S Inoue and S Chihara, 'Effects of high dose opioids and sedatives on survival in terminally ill cancer patients', *Journal of pain and symptom management*, 21(4)

A recent suggestion by Right to Die-NL (the NVVE, formerly the Dutch Association for Voluntary Euthanasia) is consistent with Griffiths' proposal to remove the criminal justice system from the review of reported cases. Relying on the extremely low referral rate (or more precisely, the extremely low number of cases in which the RRCs find that the doctor has not met the due care criteria), the NVVE suggested that the review of euthanasia cases should be abolished:

Doctors are very careful in performing euthanasia. Being professionals, they think hard about it. Ten years after the euthanasia law, the NVVE, Right to Die-NL, wonders whether it is not time to abolish the review [of reported euthanasia cases].<sup>75</sup>

## 7.2. Referral

The regimes in the Netherlands, Belgium and Oregon all require the referral of cases that do not meet the statutory criteria to either the prosecutorial authorities, or the professional disciplinary authorities, or both. In the Netherlands, 0.20% of reported cases were referred to the prosecutorial authorities by the RRCs between 1999 and 2011. No prosecutions have been brought following these referrals. In Belgium, no cases have been reported to the prosecutorial authorities by the FCEC. If, hypothetically, a similar referral rate to the Netherlands were expected, then one would expect approximately eleven referrals relating to cases that were reported between 2002 and 2011. (Of course there may be good reasons why the referral rate in Belgium would be different from the Dutch rate.) There is no evidence that the FCEC is not

<sup>(2001), 282-9;</sup> A Thorns and N Sykes, 'The use of sedatives at the end of life', *Palliative medicine*, 15(4) (2001), 347; A Thorns and N Sykes, 'Opioid use in last week of life and implications for end-of-life decision-making', *Lancet*, 356(9227) (2000), 398; See also <a href="https://www.apmonline.org/documents/128499915346380.pdf">www.apmonline.org/documents/128499915346380.pdf</a> Association for Palliative Medicine of Great Britain and Ireland, 'Position statement on the double effect' (2009) accessed 12 December 2012.

<sup>&</sup>lt;sup>75</sup> http://www.nvve.nl/nvve2/pagina.asp?pagkey=151373 NVVE, 'NVVE start discussie over opheffing toetsing euthanasie' (25 September 2012) accessed 15 October 2012 (translation by first author).

<sup>&</sup>lt;sup>76</sup> Data compiled from: Regional Review Committees Euthanasia, *Jaarverslag 2011*, pp.64-65; Regional Review Committees Euthanasia, *Jaarverslag 2010*, pp.55,58; Regional Review Committees Euthanasia, *Jaarverslag 2009*, p.50; Regional Review Committees Euthanasia, *Jaarverslag 2008*, p.36; Regional Review Committees Euthanasia, *Jaarverslag 2007*, casi 5,11,12; Griffiths and others, *Euthanasia and the law in Europe*, pp.214-215.

<sup>&</sup>lt;sup>77</sup> Prediction based on total number of reported cases 2002-2011 (5529). Commission fédérale de contrôle et d'évaluation de l'euthanasie, *Cinquième rapport aux chambres législatives (2010-2011)*; Commission fédérale de contrôle et d'évaluation de l'euthanasie, *CFCE, 4e rapport (2008-2009)*; Commission fédérale de contrôle et d'évaluation de l'euthanasie, *CFCE, 3e rapport (2006-7)*; Commission fédérale de contrôle et d'évaluation de l'euthanasie, *CFCE, 2e rapport (2004-5)*; Commission fédérale de contrôle et d'évaluation de l'euthanasie, *CFCE, 1er rapport (2002-3)*.

referring cases that should have been referred. A study of all reported cases from 2002 to 2007 concluded that the request and consultation requirements were met in all cases. An alternative explanation for the lack of referrals may be that Belgian doctors do not report cases unless they meet all of the legal requirements. This theory is supported by one small qualitative study.

In Oregon, the number of physicians referred to the Oregon Board of Medical Examiners for noncompliance with the DWDA as a percentage of the number of DWDA deaths between 1998 and 2012 is 3.3% (22/673), which suggests that ODHS operates a robust policy of referral in cases of noncompliance. This may be supported by the fact that ODHS referred a physician to the Board of Pharmacy in one of the three cases where an individual regained consciousness after ingesting medication – an act that may not be within its competence. Moreover, in consideration of the principally clerical nature of noncompliance with the DWDA, it is perhaps unsurprising that the Board of Medical Examiners has not, to our knowledge, to date sanctioned a single physician.

## 8. Conclusion

Education, particularly in the field of palliative care, <sup>81</sup> may have some upward effect on the Dutch and Belgian reporting rates. Despite the Dutch national researchers' confidence in the power of education, it may not be enough to improve the reporting rate in any system reliant on doctors' ability to recognise the cases that must be reported. As is now done in the Netherlands, <sup>82</sup> prevalence studies used to calculate the reporting rate should include questions asking how the *doctor* would classify the ELD so that the reporting rate for doctor-classified euthanasia can also be ascertained thus clarifying the extent of the difference between the way physicians label cases and researchers do.

<sup>&</sup>lt;sup>78</sup> Tinne Smets, Johan Bilsen, Joachim Cohen, Mette L Rurup and Luc Deliens, 'Legal euthanasia in Belgium: characteristics of all reported euthanasia cases', *Medical care*, 48(2) (2010), 187, Table 3. There were three cases for which information about consultation was unavailable.

<sup>&</sup>lt;sup>79</sup> Smets and others, 'Euthanasia in patients dying at home in Belgium', pp.e166,e169.

<sup>80</sup> Data compiled from Oregon Annual Reports at n 35.

<sup>81</sup> See above, text following n 64.

<sup>&</sup>lt;sup>82</sup> Griffiths and others, *Euthanasia and the law in Europe*, p.203; van der Heide and others, 'End-of-life practices in the Netherlands under the Euthanasia Act'; 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'.

What does a referral rate tell us about the effectiveness of a reporting requirement? To evaluate whether the referral rate in a particular jurisdiction is too low, we would need a detailed examination of all of the reported cases, identifying any which should have been referred but were not. Unfortunately no such data exists. Low referral rates are to be expected, either because of high rates of adherence to the rules, or because non-reporting is likely in cases which do not meet the statutory criteria. Nevertheless, in order to foster compliance with the regulatory regime, it is essential that bodies charged with referral do in fact exercise this power in appropriate cases.

In relation to improving the reporting rate, Griffiths' proposed solution is likely to be unpopular amongst the medical profession whose support was so central to legal change on euthanasia in the Netherlands. <sup>53</sup> Jurisdictions considering legalisation may have to accept that in an intention-based reporting system reflecting basic criminal law concepts, the reporting rate will be significantly below 100%. Over time, it may become possible to contemplate transferring the scrutiny of reported cases to a professional body, adopting a light-touch review similar to that in Oregon, or removing such scrutiny entirely as suggested by Right to Die-NL (the NVVE).

Although this article has focussed on the available empirical, predominantly quantitative evidence, decision-making about reporting and scrutiny should not be based solely on such evidence. The in-depth, fairly public review in the Netherlands is valuable not only in identifying cases in which referral is appropriate, but also in providing guidance to doctors and thereby shaping practice. Govert van Hartogh has described the review of euthanasia cases as a 'learning process' for both doctors and the committees. The recent second evaluation of the Dutch law has recommended that the RRCs'

conceptualization of key issues in the legal requirements should be clarified. This could be done by presenting important cases in medical journals. Further, the review committees or another organisation should develop a clear 'code of practice' that

84 See, eg. text accompanying nn 28-29.

<sup>&</sup>lt;sup>83</sup> Penney Lewis, *Assisted Dying and Legal Change* (Oxford University Press, 2007), pp.76,104-105; R.J.M. Dillmann, 'Euthanasia in The Netherlands: The Role of the Dutch Medical Profession', *Cambridge Quarterly of Healthcare Ethics*, 5(01) (1996), 100; Heleen Weyers, 'Euthanasia: The process of legal change in the Netherlands' in Albert Klijn, ed., *Regulating Physician-Negotiated Death* (Elsevier, 2001), pp.11,13–21; John Griffiths, 'Self-regulation by the Dutch medical profession of medical behavior that potentially shortens life' in Hans Krabbendam and Hans-Martien ten Napel, eds., *Regulating Morality: A Comparison of The Role of the State in Mastering the Mores in the Netherlands and the United States* (Maklu, 2000), pp.173,174-177.

<sup>&</sup>lt;sup>85</sup> Govert A den Hartogh, 'Regulering van euthanasie en hulp bij suïcide: hoe succesvol is het Nederlandse model?', *Tijdschrift voor GezondheidsRecht*, 26(4) (2002), 77.

includes an up-to-date overview of their conceptualization of key issues in the requirements of due care.<sup>86</sup>

Recent qualitative evidence from the Netherlands suggests that doctors experience euthanasia as more emotionally burdensome than other ELDs, and that they find the reporting procedure both reassuring and useful in coping with that experience.

Some of the doctors interviewed felt that too much time is spent in completing all the paperwork, while others were of the opinion that it is good that the process takes time and attention.

"It takes up considerable time, yes. But I don't mind, I don't think it should be a piece of cake. So, I think, it should always be something that is difficult and laborious, and time consuming. That is not an ordinary act, right, now I fill out the form and I'm done. It takes time, but I hope that it stays that way. It must be something that is looked at from all sides and should be considered and where the reasoning must also be clear and be clearly visible. So I have no problem with that, no." (GP)<sup>§7</sup>

Although the NVVE's proposal may appear attractive, the reporting process should not be abandoned without ensuring that these kind of benefits can be achieved in other ways.

<sup>87</sup> van der Heide and others, *Tweede evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, 100 (translation by first author). See also van der Heide and others, *Tweede evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, 143, 157 for similar comments about the entire euthanasia process including preparation, performance *and* reporting.

<sup>&</sup>lt;sup>86</sup> van der Heide and others, Tweede evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, 24.