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Assisted dying regimes

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Introduction

A small but growing number of jurisdictions now permit euthanasia and/or assisted suicide. This briefing note discusses the how the law was changed in those jurisdictions, outlines the regulatory regimes, and summarises the empirical evidence of the practice of euthanasia and assisted suicide (defined in box 1).

How the law was changed to permit assisted dying

The Netherlands

In the Netherlands, euthanasia and assisted suicide were effectively legalised through the use of the defence of necessity in prosecutions of (primarily) doctors. The defence is available when the doctor faced a conflict between his or her duties to preserve life and relieve suffering. The courts held that only doctors can face such a conflict of duties because only doctors have a professional duty to relieve suffering: lay-persons (who include relatives) and nurses do not. Over some thirty years, the courts developed this duty-based defence of necessity in euthanasia cases, placing conditions on the defence, including: an express and earnest request; unbearable and hopeless suffering; consultation; careful termination of life; record-keeping; and reporting. These conditions became known as *requirements of due care* or *careful practice*. The Dutch legislature eventually codified the parameters of the defence in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, which lists six *due care criteria* which must be met in cases of euthanasia and assisted suicide (see box 2). The judicially-developed necessity defence is still applied to cases involving incompetent persons, particularly neonates.

Belgium

Unlike in the Netherlands, there had been few criminal prosecutions in euthanasia cases prior to its legalisation in Belgium, so legal change had to come from outside the judiciary. The 1980s and 1990s witnessed a series of unsuccessful legislative moves to allow euthanasia. After a change of government and intense legislative debate, the Law on Euthanasia was passed in 2002. It allows only doctors to perform euthanasia. Assisted suicide is not explicitly covered, although Belgium's oversight body, the Federal Euthanasia Control and Evaluation Commission (CFCEE) has accepted cases of assisted suicide as falling under the law.[1]

Luxembourg

The Law on Euthanasia and Assisted Suicide came into force in Luxembourg in 2009 after a heated political and public debate. The law is closely based on the Belgian law, although it does specifically permit assisted suicide as well as euthanasia.

Box 1. Definitions

- *Euthanasia*: an intervention undertaken with the intention of ending a life to relieve suffering. In the Dutch and Belgian contexts, the term *euthanasia* refers only to the termination of life upon request.

  Some common (and often confusing) modifiers of *euthanasia* are:
  - active: a deliberate intervention to end life
  - passive: withdrawal/withholding of life-sustaining treatment
  - voluntary: at the request of the person killed
  - involuntary: in the absence of a request by the person killed, although that person is competent
  - non-voluntary: in the absence of a request by the person killed, when that person is not competent and has not made an advance request for euthanasia
- *Assisted suicide*: any act which intentionally helps another person to commit suicide, for example by providing him or her with the means to do so. In the Netherlands, *assisted suicide* is often included in the term *euthanasia*. Legal regimes often permit only *physician-assisted suicide* which is commonly referred to as PAS.
- *Assisted dying*: (voluntary active) euthanasia and assisted suicide. (Though sometimes used as a synonym only for *assisted suicide*.)

Switzerland

In Switzerland, it is a criminal offence to assist a suicide only where the assister has a selfish motive. This provision in the Penal Code has not changed since 1942. When it was originally drafted in 1918, "the attitudes of the Swiss public were shaped by suicides motivated by honour and romance, which were considered to be valid motives. Motives related to health were not an important concern, and the involvement of a physician was not needed."[2] Euthanasia is not permitted in Switzerland, although as in many other European jurisdictions, the separate offence of murder at the victim's request carries a lower minimum sentence than murder.

Oregon, Washington, Colorado, California, Vermont, District of Columbia, USA ("Oregon-model states")

Many US states allow legislation to be enacted if a majority votes for an initiative placed on the ballot following a petition signed by a minimum number of voters. Following two narrowly unsuccessful attempts to permit physician-assisted suicide by ballot initiative in Washington and California, Oregon voters passed the first Death with Dignity Act in 1994 by a majority of 52%. The Act permits the provision of a prescription for lethal medication to be self-administered by the patient. The Act was controversial from the moment the ballot measure was passed, and there were a number of ultimately unsuccessful legal challenges to it. Washington state voters passed an almost identical Act in 2008, as did Colorado voters in 2016. In 2013,

2015 and 2016 respectively, Vermont and California state legislators and District of Columbia council members passed statutes very similar to the Oregon Act, all of which are now in force. The Vermont Act was amended in 2015 to remove certain sunset clauses which would have changed the regulatory framework after three years from a regime modelled on Oregon to a professional practice standard. This would have permitted PAS on the basis of a valid request from a terminally ill patient, without requirements for consultation with a second physician, psychiatric evaluation, or waiting periods. The Oregon-model regime will now continue.

Colombia

In 1997, the Colombian Constitutional Court ruled that a physician should not be prosecuted for ending life at the repeated request of a terminally ill patient who is suffering unbearably because the physician's action "is justified". The Court called on Congress to establish a regulatory regime to vindicate the fundamental right to die with dignity. Although a number of Bills were introduced, no progress was made in Congress on this issue. In 2014, the Constitutional Court reviewed the case of a terminally ill patient who had repeatedly and unsuccessfully sought euthanasia. The Court ordered the Ministry of Health immediately to issue a directive to health care providers requiring them to set up local expert committees to respond to requests for euthanasia. A national expert committee collaborated in the writing of the resulting Resolution which came into force in 2015.

Canada & Québec

In 2014, the provincial legislature of Québec passed *An Act Respecting End of Life Care* which came into force on 10 December 2015 and legalised euthanasia ("medical aid in dying") for patients at the end of life. In February 2015 in *Carter*, the Supreme Court of Canada struck down the criminal prohibition on assisted suicide found in the federal *Criminal Code* on the grounds that it infringes the rights of competent adult patients with a grievous and irremediable medical condition causing enduring and intolerable suffering who consent to an assisted death.[3] The Court granted a one year suspension of the declaration of invalidity to give the Parliament of Canada the opportunity to craft a regulatory regime. The suspension was subsequently extended by four months; during the extension individuals were permitted to access assisted dying by making a court application.[4] Just after the expiry of the extension in June 2016, the Parliament of Canada enacted a statute amending the *Criminal Code* to permit medical assistance in dying, which is defined as "(a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death."

Features of assisted dying regimes

This section outlines and compares the main legal regimes permitting assisted dying: those in the Netherlands, Belgium, Luxembourg, Oregon (the model for Washington, Colorado, California, Vermont and the District of Columbia), Colombia, Québec and Canada.

The requesting person's condition and experience of suffering

The legal requirements relating to the requesting person's condition and experience of suffering vary widely across these jurisdictions. It is notable that despite this variation, over 70% of all reported cases of euthanasia or physician-assisted suicide involve cancer patients.[5]

In the Netherlands, the "attending physician . . . must have been satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement". The patient's suffering need not be related to a terminal illness and is not limited to physical suffering such as pain. It can include, for example, the prospect of loss of personal dignity or increasing personal deterioration, or the fear of suffocation.[6] A related due care criterion (see box 2) is that there must be "no reasonable alternative in light of the patient's situation". In cases where the source of the suffering is a physiological disorder, the patient's reasonable decision to refuse a realistic treatment possibility (whether curative or palliative) which might ease his or her suffering does not stand in the way of a request for euthanasia based on that suffering.

In Belgium, the "patient [must be] in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident". As in the Netherlands, there is no requirement that the patient be suffering from a terminal illness, although additional procedural requirements are imposed if the patient is "clearly not expected to die in the near future". Again there must be "no reasonable alternative" to euthanasia. However, euthanasia is permissible only if the disorder is incurable, so a patient's reasonable refusal of potentially curative treatment will generally prevent access to euthanasia;[7] the reasonable refusal of a palliative treatment possibility will not have this effect.[8] In recent years, the CFCEE has accepted the possibility that refusal of a potentially curative treatment with particularly serious side-effects could be reasonable and would not, therefore, prevent access to euthanasia.[9]

The Netherlands permits assisted suicide in cases where the source of the patient's suffering is a psychiatric rather than a physiological disorder. In such cases, the patient may not reject "a realistic alternative to relieve the suffering",[10] although "patients are not obliged to undergo every conceivable form of treatment."[11] In Belgium, the permissibility of euthanasia in psychiatric cases was initially unclear, but such cases are now accepted by the CFCEE.[12]

The Oregon-model states, Colombia and Québec all require a terminal diagnosis; the Canadian requirement is less clear. In Oregon, the patient must be suffering from a terminal disease, defined as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months". In Colombia, the patient must be in the terminal phase of an illness or serious pathology, which is progressive, incurable and irreversible, with death predicted in the relatively short term. Similarly in Québec, the patient must be at the "end of life". The Act requires that the patient "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 which cannot be relieved in a manner the patient deems tolerable." The Canadian Act requires that the patient have a "grievous and irremediable medical condition" for which there are four criteria: (1) a serious and incurable illness, disease or disability; (2) an advanced state of irreversible decline in capability; (3) that illness, disease or disability or that state of decline must cause the patient enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and (4) their natural death must have become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

The request

In the Netherlands, the patient's request must be "voluntary and carefully considered". The patient must be competent to make such a request. The request must also be well-considered.

In Belgium, the patient must be "legally competent". The request must be both "completely voluntary" and "not the result of any external pressure". The doctor must inform the patient about "his health condition and life expectancy" and "the possible therapeutic and palliative courses of action and their consequences".

In Oregon, the competence, voluntariness and information requirements are set out in some detail. The patient must have "the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available." Two witnesses must attest that the patient is acting voluntarily and is not being coerced to sign the request. The patient must make an "informed decision ... that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of: (a) his or her medical diagnosis; (b) his or her prognosis; (c) the potential risks associated with taking the medication to be prescribed; (d) the probable result of taking the medication to be prescribed; (e) the feasible alternatives, including, but not limited to, comfort care, hospice care and pain control."

In Colombia, the request must be free, informed and unequivocal. In Québec, the patient must have capacity, be informed and be acting freely. In Canada, the person must be a capacitous adult who has made a voluntary and informed request for assistance in dying.

The requesting person's age

The Dutch law applies both to adults and to patients under the age of majority (18). A patient between the ages of 16 and 18 who is "capable of making a reasonable appraisal of his own interests" may request euthanasia or assisted suicide. The parent(s) or guardian does not have a veto, but must be consulted. Patients aged between 12 and 16 must pass the same test of capacity. In addition, the consent of the parent(s) or guardian is required.

In Belgium, euthanasia was originally legal only for patients over the age of 18 and for minors over the age of 15 who have been legally emancipated by a judicial decision. In 2014, the Belgian Act was amended to include minors with the capacity of discernment, although this group of minors must be suffering from a terminal illness in order to access euthanasia. An additional consultation with a child psychiatrist or psychologist is required to verify capacity. The consent of the minor's legal representatives (usually the parents) is also needed.

The Oregon, Luxembourg, Québecois and Canadian laws apply only to patients over the age of 18.

Consultation and referral

All of the regimes require another physician (or nurse practitioner in Canada) to confirm the fulfilment of the legal requirements. A number of additional functions may be served by a consultation requirement, including quality control; avoidance of idiosyncratic judgments; provision of information to the attending physician; and enabling effective retrospective scrutiny of actions and decisions.[13]

> **Box 2. The Dutch due care criteria**
>
> The due care criteria are set out in section 2(1) of the 2001 Act. "The attending physician must:
>
> a. be satisfied that the patient has made a voluntary and carefully considered request;
> b. be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;
> c. have informed the patient about his situation and his prospects;
> d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
> e. have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in a. to d. above; and
> f. have terminated the patient's life or provided assistance with suicide with due medical care and attention."

In the Netherlands, the independent physician must see the patient and give a written opinion on the extent to which the due care criteria are met (see box 2). The consultation requirements are more stringent if the patient's suffering is due to a psychiatric disorder.[14] The state-funded programme Support and Consultation on Euthanasia in the Netherlands (SCEN) trains physicians to be consultants and to provide support and advice for doctors treating patients at the end of life. The "vast majority" of reported euthanasia cases involve a SCEN consultant.[15]

In Belgium, the consulting physician must examine the patient and the medical record and ensure that the suffering requirement has been met. Moreover, if the patient "is clearly not expected to die in the near future", there is a mandatory additional consultation with either a psychiatrist or relevant specialist (and a waiting period of at least one month). Although a consultation with a palliative care expert is not legally required, many Catholic hospitals in Flanders impose such a *palliative filter* in addition to the statutory criteria.[16]

In Oregon, the attending physician must refer the patient to "a consulting physician for medical confirmation of the diagnosis, and for determination that the patient is capable and acting voluntarily." Further, a counselling referral must be made if either the attending or consulting physician suspects that the patient "may be suffering from a psychiatric or psychological disorder, or depression causing impaired judgment". PAS is allowed only if the counsellor determines that the patient is not suffering from such a condition.

In Québec, the consulting physician was originally required to be independent of both the attending physician and the patient. This was interpreted as meaning that the consulting physician could not be involved in the patient's care. This requirement has now been re-interpreted by the Commission on End of Life Care, so that the consulting physician may have a treating (but not a personal) relationship with the patient.[17]

The person providing assistance

In the Netherlands, the courts originally required that the person who providing euthanasia was the patient's *treating* physician.[18] The current requirement focuses more closely on its purpose: the doctor must know the patient sufficiently well to be able to assess whether the due care criteria are met (see box 2).[19]

The Belgian Act requires that the physician have "several conversations with the patient spread out over a reasonable period of time" in order to be certain of the persistence of the patient's suffering and the enduring character of the request. The Dutch purpose-focused argument (that in order to assess whether the due care criteria are met, the doctor must have some familiarity with the patient) might also be applied in Belgian euthanasia cases. However, the legislative history makes clear that the patient should be able to bypass his or her attending physician if so desired – from which one might infer that there is no requirement for a pre-existing physician-patient relationship.[20]

In Oregon, the attending physician is defined as "the physician who has primary responsibility for the care of the patient and treatment of the patient's terminal disease". The evidence suggests that many patients who sought assisted suicide had to ask more than one physician before finding one who was willing to provide a prescription. Over the first three years of operation of the Oregon law, only 41% of patients received their prescription from the first physician asked.[21] This suggests that in many cases there was no longstanding or pre-existing physician-patient relationship.[22] The median duration of that relationship in Oregon over the first ten years was 11 weeks. The range was between 0 and 1440 weeks.[23] Commentators opposed to the Oregon law have raised the possibility that a patient refused PAS by one physician on the grounds of failing to meet one of the statutory criteria may obtain the prescription from a more accommodating physician.[24]

The laws in Belgium, the Oregon-model states, Québec and Canada contain conscientious objection provisions. Although there is no such provision in the Dutch law, it is nonetheless clear that "no doctor has any obligation to accede to a request [for euthanasia], however well-founded."[25] The Royal Dutch Medical Association (KNMG) has reiterated this position, stating that "physicians are not under any obligation to assist in euthanasia. Physicians who have fundamental objections to euthanasia and assisted suicide must be respected in their views."[26]

Reporting and scrutiny

Termination of life on request and assisted suicide remain criminal offences in the Netherlands. The defences inserted into the Penal Code by the Act require the doctor to report the case as euthanasia or assisted suicide to the municipal pathologist, who then passes the file to the relevant Regional Euthanasia Review Committee (RERC). If the RERC finds that the doctor did not act in accordance with the due care criteria (see box 2), the case is referred to the Public Prosecution Service. Ninety three cases were referred between 1999 and 2016 (0.17% of reported cases).[27] No prosecutions have been brought following these referrals. Lack of, or inadequate, consultation is the most significant reason for referral. Consultation may be considered inadequate if the doctor consulted is insufficiently independent from the attending doctor, or the consultation takes place too early or too late. Problems with the way in which euthanasia is carried out 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 and the need to ascertain the depth of the patient's coma before administering the muscle relaxant.[28]

Compliance with the Belgian law is monitored by the CFCEE, to which all cases of euthanasia must be reported. Only one case has been reported to the prosecutorial authorities by the CFCEE (in late 2015; 0.008% of reported cases). It is not yet known on what grounds the referral was made. The biannual report covering this period does not describe this case in any detail.[29] Concerns have been raised in the media about the patient's underlying medical condition, the consultation requirement for cases where the patient is not expected to die in the near future, and the waiting period for such cases.[30]

Compliance with the Luxembourgeois law is monitored by the National Commission of Control and Evaluation of the Law of 16 March 2009 on Euthanasia and Assisted Suicide (CNCE). From 2009 to 2016 there were 52 reported cases. No cases have been referred to the prosecutorial or medical authorities by the CNCE.

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. A total of 22 physicians were referred by the ODHS to the Board of Medical Examiners between 1998 and 2016 for non-compliance with the provisions of the Oregon Act (1.96% of all reported deaths under the Act). Non-compliance with the Oregon Act 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.[31] In relation to the other Oregon-model states, there is no evidence to suggest that non-compliance with the Washington or California Acts is reported to the state medical authorities. There was originally no requirement for physicians to report prescriptions written under the Vermont Act or deaths resulting from the ingestion of prescribed medication. A reporting requirement was added by amending the Vermont Act in 2015. The first biennial statistical report of the data collected must be published in 2018.

In Colombia, the Resolution requires requests for euthanasia to be approved by a special three-person multi-disciplinary hospital-based committee comprising a specialist in the patient's condition (not the treating physician), a lawyer, and a psychiatrist or clinical psychologist. The committee also bears responsibility for ensuring that the assistance in dying is provided within strict time-limits, and for accompanying the patient and their family members. A retrospective reporting requirement is also imposed.

Between 10 December 2015 and 30 June 2017, the Québec Commission on End of Life Care received 786 reports of medical aid in dying. At the time of publication of the second annual report, the Commission had examined 703 of these and reached decisions on 648. In 43 cases (6.6%) the Commission found that one of the legal requirements had not been met. In 29 of these 43 cases, the consultant physician was not professionally independent of the patient (ie was treating the patient). As previously noted, this interpretation of the independent consultation requirement has since been abandoned. Leaving out these cases, the referral rate would be 2.2%. All of these cases were referred to the professional regulatory body.[32] In Canada, a monitoring system will be implemented by regulations in 2018. Interim official data indicate that at least 2149 cases were reported across Canada between June 2016 (after the federal legislation came into force) and June 2017.[33]

Empirical evidence

What is known about the effectiveness of safeguards?

An extensive body of empirical evidence exists relating to the safeguards and criteria outlined above, and how they operate in permissive regimes, with the most detail available in the Netherlands, Belgium, Oregon and Switzerland.[34] The evidence from these jurisdictions suggests that the legal criteria that apply to an individual's request for assisted dying are well respected: individuals who receive assisted dying do so on the basis of valid requests; third parties who assist individuals to die do not act unlawfully.[35]

What is known about reporting?

Evidence of the effectiveness of the reporting requirement and the scrutiny of reported cases in the Netherlands, Belgium, Oregon and Switzerland is less consistent. 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 in the Netherlands rose when the RERCs were inserted as a buffer between physicians and the authorities, although 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.[36] The reporting rate is significantly higher (81% in 2015) in the Netherlands than in Belgium (53% in 2007) where legalisation occurred more recently.[37] 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 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".[38] These unreported cases frequently involve the use of non-typical drugs to cause death (morphine rather than barbiturates and/or muscle relaxants which are typically used in euthanasia cases) and/or a very short life expectancy.[39] The number of *estimated* deaths from euthanasia includes such cases, as it does not rely on doctors' labelling of their own practice. Since almost all cases involving typical euthanasia drugs are reported,[40] this inconsistent labelling now likely accounts for almost all unreported cases. This thesis is supported by anonymous data collected from physicians which indicates that consistently close to 100% of the acts termed *by physicians* as euthanasia and assisted suicide were reported.[41]

What is known about vulnerable groups?

In 2007, researchers examined data from the Netherlands and Oregon in order to see if members of vulnerable groups were more likely to receive assistance in dying (either euthanasia or PAS). They examined the frequency of such assistance in ten groups of potentially vulnerable patients, defined by gender, age, ethnicity, educational and socio-economic status, illness and disability. They found "no evidence of heightened risk ... with the sole exception of people with AIDS." It should be noted though that the lack of Oregon data on pre-existing disabilities weakens the force of this conclusion with respect to disability.[42] The researchers concluded that "the available data ... shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges."[43]

What is known about the frequency of end of life decisions?

Many of the empirical claims made about the practice of euthanasia and PAS under existing legal regimes misrepresent the data, take it out of context or neglect important comparisons with jurisdictions where these practices are prohibited.[44] Chart 1 shows the percentage of all deaths in specific years that were cases of euthanasia (EUT), PAS or termination of life without request (TLWR). It combines data from a number of different anonymous prevalence surveys of doctors.[45] All surveys were based on one originally designed by Dutch researchers.[46] The relatively broad and overlapping confidence intervals suggest that fine comparisons should not be made between countries with the lowest percentages. As indicated, some comparisons are from different years. Although similar, the surveys are not identical. The percentage of deaths in which an end of life decision (ELD) is made varies across jurisdictions.

This evidence does not support the argument that there is a slippery slope between the legalisation of euthanasia (termination of life on request) and termination of life without request (TLWR).[47] The rates of TLWR vary. The evidence suggests that TLWR takes place in both permissive and non-permissive jurisdictions, with some of the highest rates in non-permissive jurisdictions (eg Australia in 1997), although rates of TLWR in some permissive jurisdictions are higher than in some non-permissive jurisdictions. TLWR occurs more frequently than euthanasia in all countries that have been surveyed except the Netherlands and Belgium.[48] Rates of TLWR have decreased since legalisation in the permissive jurisdictions of the Netherlands and Belgium.[49]

Chart 1. Rates of euthanasia, PAS and termination of life without request

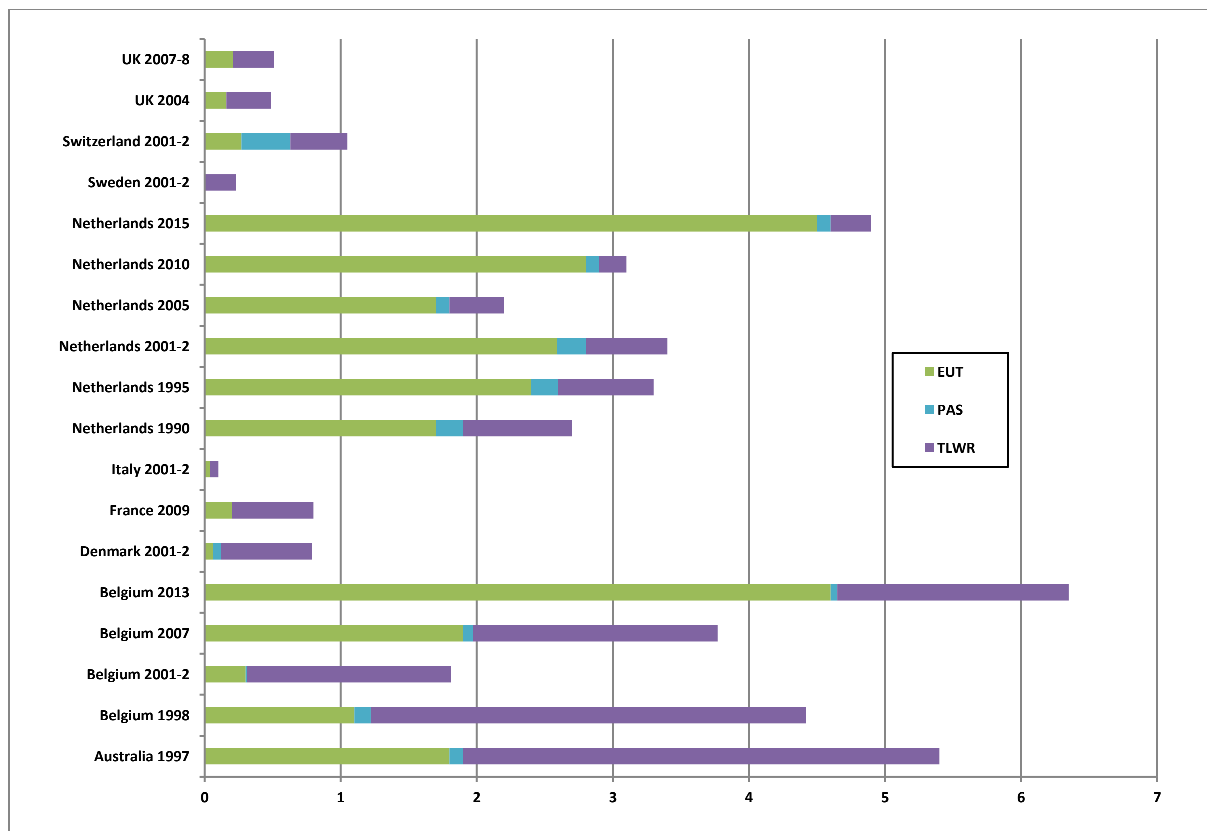
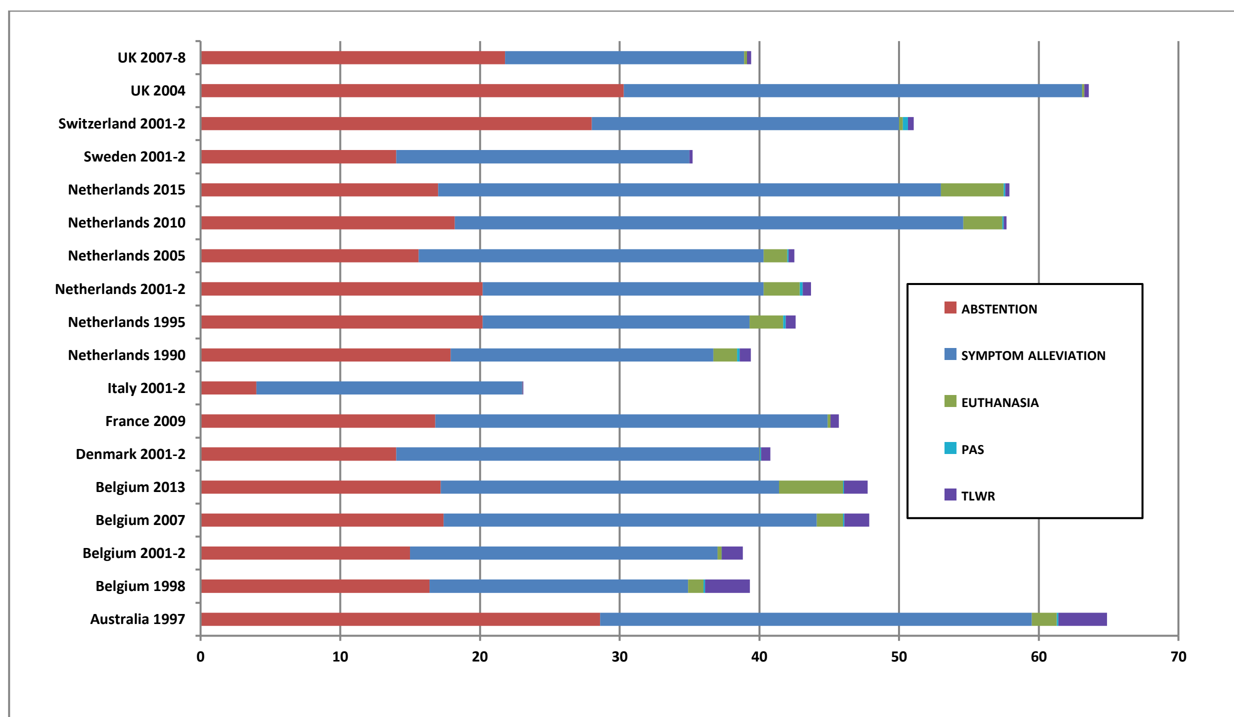


Chart 2: Rates of end of life decisions (percentage of all deaths)

Chart 2 compares the types of ELDs in the jurisdictions in which the original Dutch survey has been carried out. In addition to euthanasia (EUT), PAS and termination of life without request (TLWR), two much larger categories are included: *abstention* (withdrawing or withholding life-sustaining treatment) and *alleviation of symptoms* taking into account possible or probable hastening of death. In all countries, EUT, PAS and TLWR are relatively rare.



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