

Second Supplementary Submission

to the

Parliament of Western Australia
Joint Select Committee
on
End of Life Choices

from

Neil Francis



DyingForChoice.com
PO Box 303, Mont Albert
Victoria 3127, Australia.

17th May 2018

Ms Amber-Jade Sanderson
Chair, Joint Select Committee on End of Life Choices
Parliament of Western Australia
Harvest Terrace, Perth, 6005

17th May 2018

Dear Ms Sanderson,

Having recently had the time to 'write up' two empirical studies from my extensive library of primary research about end-of-life decision making and practices, I felt it important to communicate the results of further careful scientific studies to you and your Committee.

These studies provide further evidence of the carefulness of end-of-life decision making when lawful voluntary assisted dying (VAD), with qualifying and procedural safeguards, has been carefully embedded within mainstream medical practice.

The results of these studies show that rates of *clearly inappropriate* medical end of life decision making are significantly lower in jurisdictions where VAD is legal and well-accepted than where it is not. Multiple sources of peer-reviewed primary research not only do not support, but directly contradict, the expectations or even claims of some VAD opponents that decision making practice would deteriorate under VAD laws.

I trust this information will further assist the Committee, and the Parliament of Western Australia, to inform its views about assisted dying law reform.

If the Committee has any further questions, I would be happy to do my best to answer them.

Yours sincerely



Neil Francis
DyingForChoice.com

Introduction

This brief report discusses the relationship between assisted dying legalisation and standards in end-of-life decision making. In particular, it reports results from two studies: a 2006 multinational study of doctor attitudes toward decision making in classic patient cases,¹ and a 2012 study of Belgian doctors, distinguishing between the Flemish north and Walloon south.²

Doctor attitudes toward end of life decision making that are clearly *inappropriate* are highlighted in this report, in relation to how deeply and how long voluntary assisted dying (VAD) has been embedded in medical practice (or not) in each jurisdiction. It adds to previously-reported empirical research showing that:

- the rate of non-voluntary euthanasia has dropped significantly and stayed lower in both the Netherlands and Belgium since their Euthanasia Acts came into effect, along with improvements in other end-of-life decision making;³ and
- the rate of nurse administration of life-ending drugs has dropped significantly in Belgium (with a VAD law) at the same time it has increased significantly in New Zealand (no VAD law).⁴

A. Multinational study

The 2006 multinational study determined the attitudes of doctors in seven countries towards decisions they would make in classical given patient cases.¹ The seven countries included in the study and their VAD law statuses are shown in Table 1. The fieldwork — when doctors filled out and returned surveys — was completed in 2003.*

Table 1: Countries included in the multinational study and their VAD law status at the time

Country	Code	VAD law status	Religion [~]
The Netherlands	NL	VAD court cases and public debate since 1970s, regulated and widespread practice since mid-1980s, enshrined in statute in 2001 (effective from early 2002). Both self- and doctor-administration is lawful in restricted circumstances.	28%
Australia	AU	No VAD law. [†]	43%
Sweden	SE	No VAD law.	18%
Switzerland	CH	Assisted suicide (i.e. self-administration) lawful since 1942, but rarely practiced within medicine. Assistance provided by several private membership societies. Administration by others illegal.	48%
Denmark	DK	No VAD law.	28%
Belgium	BE	VAD law since late 2002 (i.e. only a few months). Both self- and doctor-administration is lawful in restricted circumstances. Unlike the Netherlands, no prior regulation or tacit approval.	37%
Italy	IT	No VAD law.	74%

[~] Proportion of the general population who believe in God. Sources: Netherlands, Sweden, Denmark, Belgium and Italy, https://en.wikipedia.org/wiki/Religion_in_the_European_Union; Switzerland, https://en.wikipedia.org/wiki/Irreligion_in_Switzerland; Australia, <https://cra.org.au/belief-in-god-is-the-%E2%80%98new-atheism%E2%80%99-influencing-australians/>

[†] Australia's smallest jurisdiction by population, the Northern Territory, had a VAD law for eight months in 1996, under which four people died before the law was extinguished by the Federal Parliament.

* Advised by study co-author Prof. Colleen Cartwright.

The multinational study provided evidence about doctor attitudes toward decisions that were clearly *inappropriate*: the doctor deciding to take action in regard to a dying patient who was *competent to make her own decisions*, but without discussing the decision with the patient.

The decisions taken were:

1. *Withholding chemotherapy*. Chemotherapy may be medically futile, or may for example temporarily reduce tumour size and pressure, or provide hope to the patient.
2. *Intensified relief of pain and other symptoms with medication*. This reduces the consciousness of the patient, who may prefer to endure her suffering to be able to interact with loved ones, or to feel less groggy.
3. *Continuous deep sedation until death*. This renders the patient unconscious until death, eliminating the possibility of the patient interacting with loved ones or participating in decision making prior to death.
4. *Ending of life*. A deliberate decision to actively hasten the patient's death.

There were two standard patient cases (1 and 2) in which the patient was competent: that is, *the patient ought to have been informed of options and been actively engaged in decision making*. These cases illustrate where doctors have decided to act without consulting their competent patient: an offence to ethical conduct and the fundamental principle of patient autonomy.

Patient case 1

This patient is actively dying, and is:

- Anticipated to die within two weeks
- Competent to make end of life decisions
- Experiencing strong, refractory pain

Figure 1 shows the proportion of doctors in each country who would take each type of decision (e.g. continuously sedate the competent patient until death) **on the request of the patient's family, without** informing the patient.

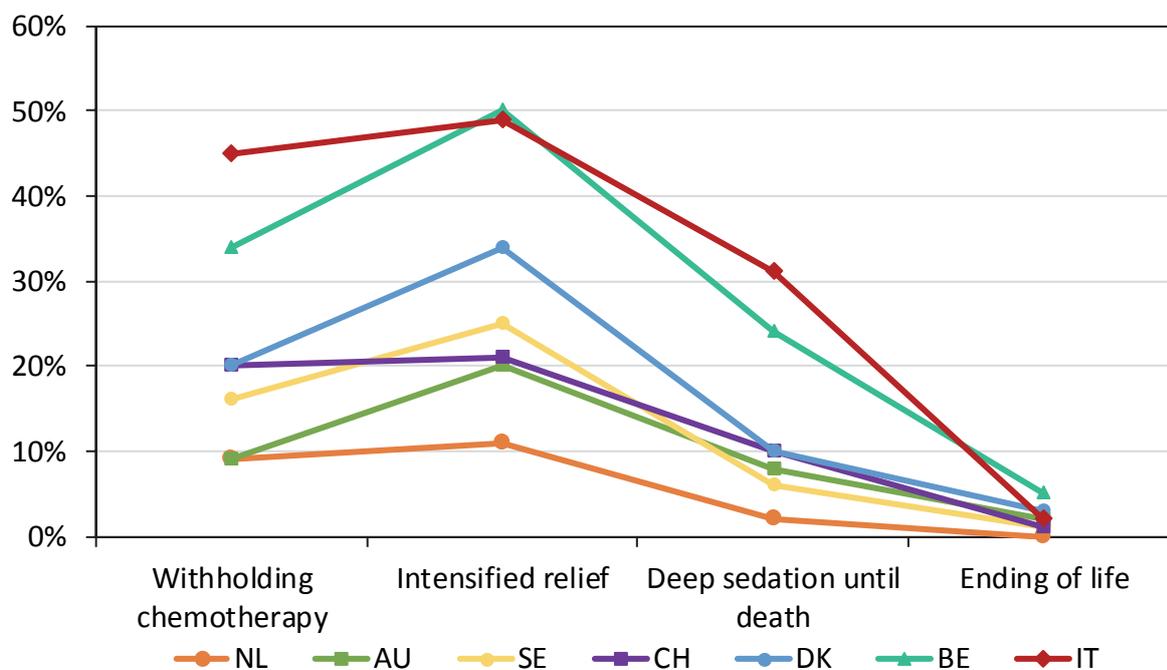


Figure 1: Case 1 — Percent of doctors who would act on relatives' request *without* informing the patient

Inappropriate decision-making without consulting the decisionally-competent patient was, overall, lowest in the Netherlands and highest in Italy.

Figure 2 shows the proportion of doctors in each country who would take each type of decision **on their own initiative**, because they perceived the patient’s case to be ‘medically futile’. Note that ‘medical futility’ encompasses only the *medical* context. It excludes the patient’s world views, beliefs and spiritual and social concerns.

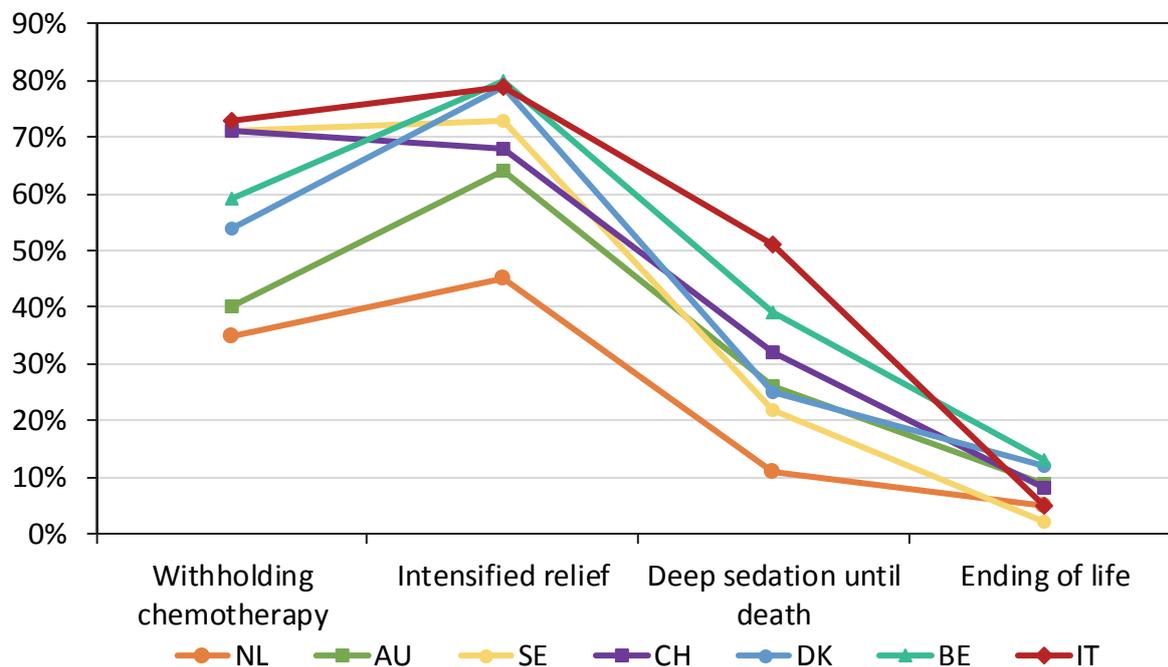


Figure 2: Case 1 — Percent of doctors who would act on their own initiative because of perceived ‘medical futility’

This inappropriate decision-making without consultation with the competent patient was again, overall, lowest in the Netherlands and highest in Italy.

Patient case 2

This patient is terminally ill, and is:

- Anticipated to have three or more months to live
- Competent to make end of life decisions
- Pain-controlled but experiencing extreme tiredness, breathlessness and is bedridden

Figure 3 shows the proportion of doctors in each country who would take each type of decision **on the request of the patient’s family**, *without* informing the patient even though she has at least three months to live and is competent to make decisions.

This inappropriate decision-making on the family’s request but without proper consultation with the competent patient with more than three months to live was, overall, lowest in the Netherlands and highest in Italy.

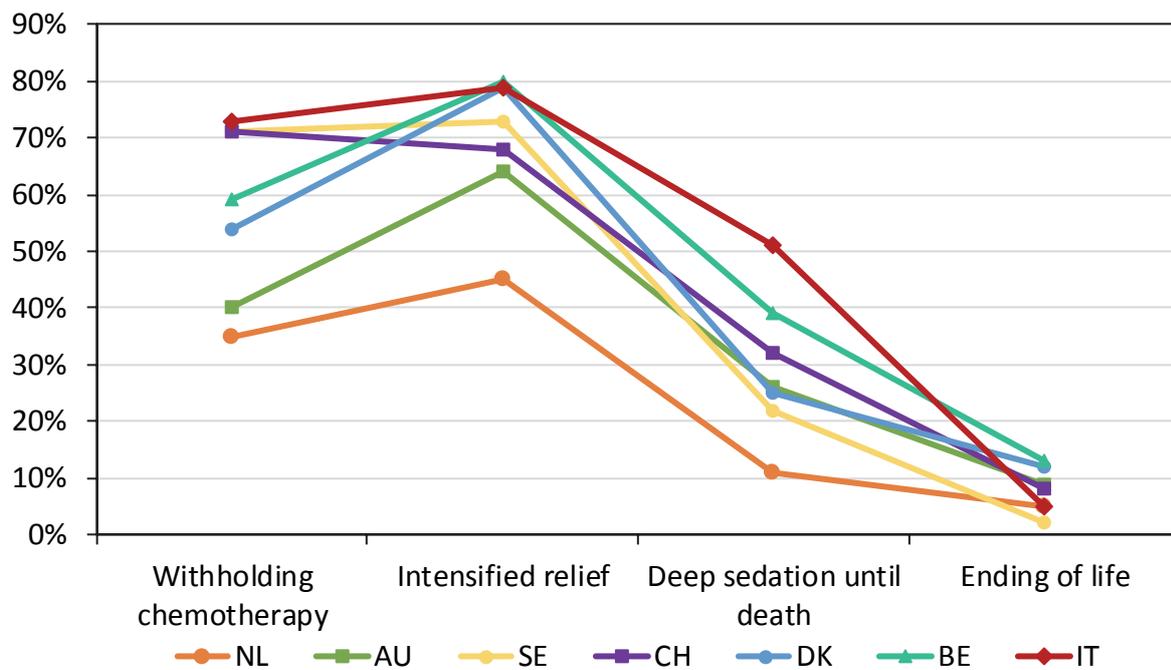


Figure 3: Case 2 — Percent of doctors who would act on relatives' request *without* informing the patient

Figure 4 shows the proportion of doctors in each country who would take each type of decision **on their own initiative**, because they perceived the patient's case to be 'medically futile'.

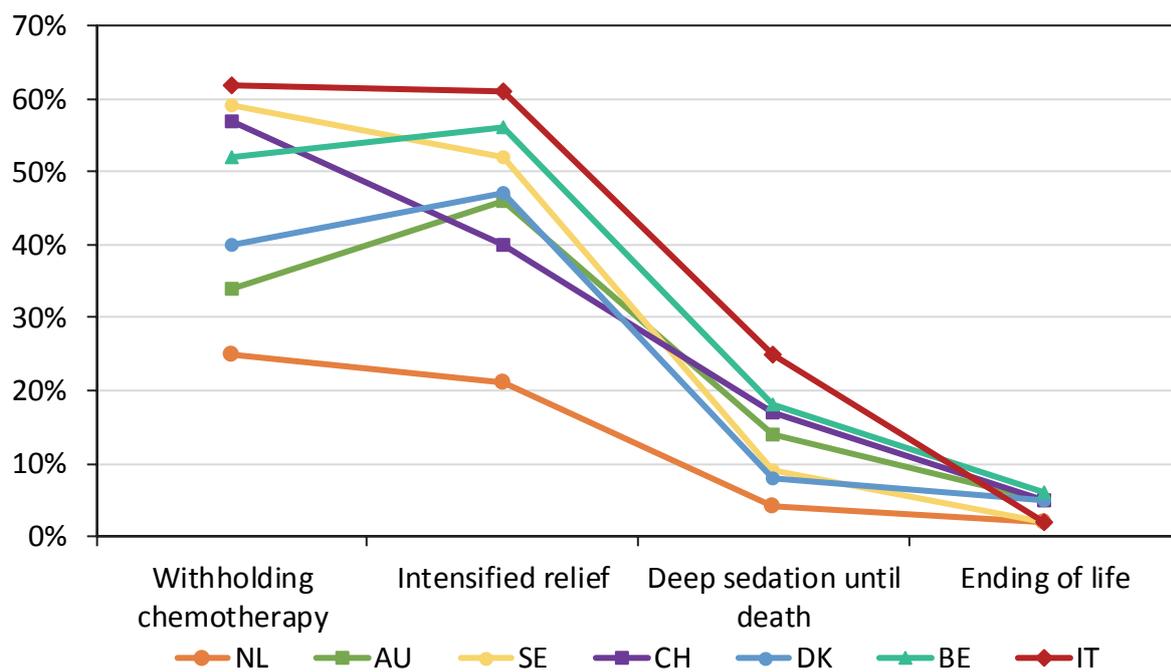


Figure 4: Case 2 — Percent of doctors who would act on their own initiative because of perceived 'medical futility'

Again, inappropriate decision-making was, overall, lowest in the Netherlands and highest in Italy.

Discussion

Of the studied countries, the Netherlands had by far the longest, active VAD experience and which was most deeply embedded in broad medical practice. The Netherlands had conspicuously the lowest overall rates of inappropriate end of life decision making in respect of competent patients.

With the exception withholding chemotherapy from competent patients more often, Swiss doctors made inappropriate end of life decisions at similar rates to Australian doctors. Switzerland has the world's oldest assisted suicide law (in effect since 1942) while Australia has no VAD law.

Overall, Italy had the worst rates of inappropriate end of life decision making, followed by Belgium. Since Italy has no VAD law and Belgium's law had been in effect for only a few months at the time of this study (and Belgium's non-voluntary euthanasia rate has dropped since the law came into effect), the figures are clearly uninfluenced by VAD law.

Indeed, a study published earlier found that end-of-life decisions (of all kinds) were discussed with competent patients at significantly higher rates in countries with some form of VAD law, than in countries without one (Table 2).⁵ The study also found that doctors in non-VAD countries were far more likely to *fail* to consult relatives or the prior decisions of a now-incompetent patient, than were doctors in VAD countries.

Table 2: End-of-life (EOL) decision discussion in six European countries

Country	Competent patient: Decision discussed with patient	Incompetent patient: Decision discussed with <i>neither patient nor</i> <i>relatives</i>	Any VAD law
The Netherlands	92%	12%	Yes
Switzerland	78%	29%	Yes
Belgium	67%	20%	Yes
Denmark	58%	46%	No
Sweden	38%	58%	No
Italy	42%	58%	No

Italian doctors, 82% of whom are Catholic, have on average significantly more negative attitudes toward VAD: only 16% would consider providing a requesting patient with a lethal prescription and just 12% would consider injecting a requesting patient with a lethal prescription.⁶ The study found that religion was the major reason for Italian doctors opposing VAD. This compares with an Australian Medical Association study that found 60% of its member doctors said VAD should be provided by doctors if lawful, and more than half of those (total 32%) said they would be willing to honour patient requests.⁷

Despite high disapproval of VAD by Italian doctors, they were found to be far more likely to 'play God' with their dying patients. They were less than half as likely as Dutch doctors to consult competent patients about decisions, and nearly five times more likely than Dutch doctors to make end of life decisions without referring to a now- incompetent patient's prior decisions or consulting her relatives.

Overall, these studies demonstrate a much higher standard of end of life decision making consultation by doctors in VAD countries — with the Netherlands clearly in the lead — than in non-VAD countries.

B. Belgian comparison

Belgium provides a unique opportunity to examine attitudes and behaviour within a single country, since the nation is comprised of a Dutch-culture north (Flanders/Flemish) representing 65% of the population, and a French-culture south (Wallonia/Walloon) with 35% of the population. In Flanders, 47% of residents are Catholic and 36% non-religious, while in Wallonia 68% are Catholic and 25% non-religious.[†]

An empirical study examined the differences in attitudes between Flemish and Walloon doctors.² It found that Walloon doctors were fundamentally more opposed to VAD:

“Walloon physicians were more often in no circumstances prepared to administer lethal drugs, would more often rather perform sedation than administer lethal drugs, more often agreed that good palliative care prevents most requests for euthanasia, more often agreed that a physician should always strive to preserve life and less often agreed that euthanasia can be a part of good end-of-life care.” — p 847

Discriminating between official VAD reports filed in Dutch (Flemish) and French (Walloon), the VAD rate as a percent of all deaths in Flanders has been found to be almost three times the rate of Wallonia,⁸ in part because Flemish doctors receive more VAD requests from their patients but also because Walloon doctors were less likely to grant them.²

However, these findings did not translate into more careful attitudes toward medical practice and superior end of life decision making in Wallonia. Rather, the reverse was evident.

Walloon doctors were less likely to be supportive of VAD reporting obligations, more often considered VAD a private matter between the doctor and patient, less often thought the reporting requirements contributed to more careful practice, and less often thought that the requirement of a second doctor consultation was useful and contributed to more careful practice.

Thus, the data indicates that while VAD practice in Flanders is significantly higher than in Wallonia, it is likely to be practiced with considerably greater care in Flanders.

[†] Sources: Belgium, https://en.wikipedia.org/wiki/Religion_in_Belgium#Catholic_Church; Flanders, <https://en.wikipedia.org/wiki/Flanders>; Wallonia, <https://en.wikipedia.org/wiki/Wallonia>.

Conclusion

Empirical studies have been previously reported showing that end of life decision making has improved in several jurisdictions with VAD laws:

- The non-voluntary euthanasia rate in both the Netherlands and Belgium has dropped significantly since their Euthanasia Acts came into effect; and
- The rate of nurse administration of life-ending drugs in Belgium has dropped significantly at the same time as the rate in New Zealand (with no VAD law) has significantly increased;

This report provides further peer-reviewed empirical research data showing that:

- Doctors' inappropriate end of life decision making (failure to consult the patient or relatives) is lowest (of the studied countries) in the Netherlands with its extensive, long-term VAD experience, and highest in Italy which has high doctor disapproval of VAD but where doctors are most likely to 'play God'; and
- Doctor attitudes toward VAD practice are more professional in the Flemish north of Belgium with its much higher VAD rates, than in the Walloon south with lower rates.

In conclusion, these peer-reviewed empirical findings consistently point to better quality decision making — across a wide range of end-of-life decision types — in jurisdictions where VAD is practiced more often in a lawfully regulated medical environment, than where it is not.

References

- 1 Onwuteaka-Philipsen, BD, Fischer, S, Cartwright, C, Deliens, L, Miccinesi, G, Norup, M, Nilstun, T, van der Heide, A & van der Wal, G 2006, 'End-of-life decision making in Europe and Australia: a physician survey', *Archives of Internal Medicine*, **166**(8), pp. 921-929.
- 2 Cohen, J, Van Wesemael, Y, Smets, T, Bilsen, J & Deliens, L 2012, 'Cultural differences affecting euthanasia practice in Belgium: one law but different attitudes and practices in Flanders and Wallonia', *Soc Sci Med*, **75**(5), pp. 845-53.
- 3 Francis, N 2018, *Supplementary submission to the Parliament of Western Australia Joint Select Committee on End of Life Choices*, Melbourne, pp. 6.
- 4 Francis, N 2017, *Submission to the Parliament of Western Australia Joint Select Committee on End of Life Choices*, Parliament of Western Australia, pp. 67.
- 5 van der Heide, A, Deliens, L, Faisst, K, Nilstun, T, Norup, M, Paci, E, van der Wal, G & van der Maas, PJ 2003, 'End-of-life decision-making in six European countries: descriptive study', *The Lancet*, **362**(9381), pp. 345-350.
- 6 Cocconi, G, Caminiti, C, Zaninetta, G, Passalacqua, R, Cascinu, S, Campione, F, Todeschini, R, Zani, S, D'Aloia, T & Migone, L 2010, 'National survey of medical choices in caring for terminally ill patients in Italy, a crosssectional study', *Tumori*, **96**(1), pp. 122-130.
- 7 Francis, N 2017, *AMA uncovered: How its own review exposed its assisted dying policy as indefensible*, DyingForChoice.com, Melbourne, pp. 50.
- 8 Francis, N 2016, *Assisted dying practice in Benelux: Whitepaper 1*, DyingForChoice.com, viewed 13 Nov 2016, <http://www.dyingforchoice.com/resources/fact-files/assisted-dying-benelux-whitepaper-1>.