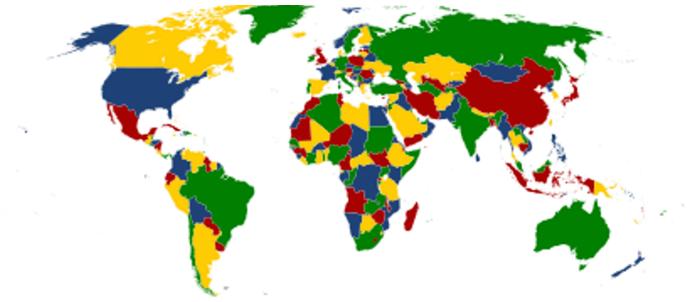
ETHICAL RIGHTS
VOLUNTARY ASSISTED DYING SURVEY 2021

SUMMARY REPORT (WORLD RESPONSES)



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1 INTRODUCTION

The Ethical Rights Voluntary Assisted Dying (VAD) Survey 2021 aims to provide data and to remove subjectivity from the euthanasia debate. Its objectives are to:

- seek views of VAD advocates on a range of VAD issues
- provide data which can be used to inform VAD organisations so that they can make cogent cases to politicians, media and detractors
- help VAD advocates and others to think more about VAD issues
- broaden the VAD debate as appropriate, and
- provide a basis for a longitudinal VAD study.

VAD is commonly used to refer to 'the assistance provided to a person by a health practitioner to end their life. "Voluntary" indicates that the practice is a voluntary choice of the person, and that they are competent (have capacity) to decide to access VAD'.[1] Other terms such as medical aid in dying, physician-assisted suicide and voluntary euthanasia are also commonly used to describe the practice of VAD or variations of it.

The survey was not intended to determine whether people agreed that VAD should be legally available. That question has been tested regularly in many polls—with responses dependent on the jurisdiction[2]—but generally 70%–80% or more of people are supportive of VAD.[3] The survey instead sought the views of VAD advocates and supporters on the many ethical and regulatory issues, and individual choices, that make up the VAD debate. The views of these stakeholders are critical to the development of any VAD regulatory systems.

Sections 2 and 3 of this *Summary Report* contain the key messages and summary of survey responses respectively. The survey's background and demographic data for respondents are summarised in sections 4 and 5. This *Summary Report*, the *Results* document (which underpins this document), *Supplementary Material* (containing some analysis of issues) and the *Survey Questions* are available at www.ethicalrights.com.

2 KEY MESSAGES

There were 1640 VAD advocates and supporters worldwide who responded to the survey during 2020 and 2021.[4] The following key messages can be inferred from trends in survey responses.

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[1] Euthanasia and Assisted Dying. Queensland University of Technology. Accessed July 20, 2021. https://end-of-life.qut.edu.au/euthanasia.
[2] A jurisdiction is the country, state or region where particular laws must be obeyed.
[3] See, for example, Key Questions. Dying with Dignity. Published March 2, 2017. Accessed July 22, 2021. https://dwdnsw.org.au/faqs/
[4] While 1640 people around the world responded to the survey, not all questions were answered by all respondents.

2.1 Key message 1: VAD should be legalised or better regulated in jurisdictions.

Most respondents (VAD advocates and supporters) do not have legalised VAD in their jurisdiction. Respondents consider that:

(a) they have the right to implement plans to end their lives and want to do so in their own jurisdictions
(b) VAD regulatory systems should focus on giving effect to the VAD choice of well-informed adults with decision-making capacity
(c) having limited life expectancy, being terminally ill, having 2 doctors approve drugs or residency/citizenship criteria are unnecessary VAD eligibility criteria.

2.2 Key message 2: VAD regulatory models should be expanded in scope to meet the needs of people who want to access VAD.

Respondents' major concerns were a person's right to bodily autonomy, a desire to avoid suffering, and to have a good quality of life. VAD regulatory models should be improved and expanded in scope to allow people to:

(a) specify their choice for VAD in an advance directive[5]
(b) access VAD if they are suffering unbearably, whether or not they are terminally ill
(c) have ready access to VAD if they are in the final stages of palliative care or are of advanced years
(d) request that a doctor prescribe a single dose of a lethal drug for their personal use, noting regulation would be needed to prevent ineligible people obtaining lethal drugs
(e) self-administer a lethal drug and that non-doctors, such as family members or designated persons, should be allowed to assist them
(f) access VAD if they are suffering from mental illness, dementia or clinical depression (especially if specified in an advance directive)
(g) access VAD for children and infants who may have unbearable suffering (guardian/doctor support necessary).

[5] An advance directive is a written instruction that a person makes about their future medical treatment in the event that they lose their decision-making capacity. With respect to VAD, it might list the medical and other circumstances that, if a person were to be so afflicted in the future, would result in their advance request for VAD being granted.

2.3 Key message 3: If VAD is not legislated or better regulated, then the end-of-life needs of people will not be met and their quality of life will be adversely affected.

Respondents considered that, in the absence of legislation that meets their end-of-life needs, many people who are suffering:

(a) will continue to suffer knowing that they cannot draft advance directives with the practical option of VAD
(b) will either suicide prematurely if they obtain legal or illegal lethal substances (the latter being more likely the older a person is) or they will continue to suffer (if they cannot access lethal drugs)
(c) will find it burdensome or stressful to comply with unnecessary regulatory hurdles, such as meeting citizenship/residency conditions or having the details of a terminal illness or limited life expectancy confirmed by multiple doctors
(d) would rather die at home with some palliative care support than die in hospital with palliative care or even leave their country or region to die—in which case in-home palliative care services will require greater support where they are deficient.

2.4 Key message 4: VAD regulation that effectively meets the end-of-life needs of people can give them peace of mind and a better quality of life.

Regulation that meets the needs of people who choose VAD means that they will:

(a) have reduced suffering, even if not terminally ill
(b) have peace of mind knowing that illegal options will be unnecessary
(c) not have to travel to find VAD-friendly regulatory systems in other jurisdictions
(d) have, with VAD-relevant advance directives, peace of mind knowing that they won't suffer even if their decision-making capacity deteriorates
(e) not require doctors for drug administration
(f) be able to legally have a partner, or family or other support with them, or assisting them, at their death.

3 RESPONSES SUMMARY

3.1 World responses

With few exceptions, trends in responses did not vary greatly with respondents' gender, age, religion, education level, disability or country of residence. This was not unexpected, given that the survey's target population were mostly VAD 'true believers'. The VAD true believers are people who, as VAD advocates and supporters, have given appreciable time and thought to VAD issues, have joined voluntary assisted dying organisations and would contemplate choosing VAD. Their views on ethical and regulatory aspects of VAD are highly relevant; indeed they are necessary to achieving a good regulatory solution.

These following outcomes have been drawn from survey responses.

3.1.1 Ethical issues (Q1, Q2)[6]

The first two survey questions concerned the ethics of voluntary assisted dying.

- 1633 of 1640 respondents agreed that:

  > 'it should be legal for a doctor to assist a terminally ill adult of sound mind in ending their life, if that is the person's wish'.

  The 7 people who did not agree were exited from the survey.
- 99%[7] of respondents then agreed that:

  > 'every adult of sound mind has the right to implement plans for the end of their life'.

  These respondents effectively consider VAD as a right. It does not necessarily require that a person be terminally ill or that doctors be involved.

3.1.2 Regulatory eligibility (Q4, Q5)

With respect to VAD eligibility, respondents expressed views that:

- the 3 most important VAD eligibility criteria were deciding voluntarily (95%), being well-informed (71%) and having decision-making capacity (70%)
- common eligibility criteria in existing regulations were the least supported: having limited life expectancy (25%), being terminally ill (22%), having 2-doctor approval and citizenship (each <20%)

[6] Q numbers refer to the questions in the survey from which the outcomes have been inferred.
[7] All percentages are rounded to the nearest whole number.

- being of sound mind was somewhat important (35%), but of those people who did not think it important, most respondents offered other options, such as immediate VAD eligibility for people with unbearable suffering or advance directives
- people with advance directives or unbearable suffering (both ≥80%), being of advanced years or in palliative care (both ≥58%) should be immediately eligible.

3.1.3 Regulatory access and means (Q3, Q6)

Most respondents (72%) did not have access to regulated VAD. Respondents indicated they should be able to:

- obtain a single dose of a lethal drug and administer the drug themselves (both ≥88%)
- have a lethal drug prescribed by a doctor (81%)
- have a spouse or other person assist (78%).

3.1.4 Regulatory ineligibility and ethical issues (Q7)

With respect to VAD ineligibility:

- 52% of respondents said untreated clinical depression, 48% said pregnancy and 35% said being a child should make a person ineligible
- 16% said a convicted criminal should be ineligible, while 33% said a person who was the subject of ongoing police investigations should be ineligible
- 17% said that people with dementia should be ineligible for VAD even if specified in an advanced directive, but this increased to 44% if dementia was not specified in an advance directive
- a quarter (26%) ruled out newborn infants being able to access assisted dying, even if it were a decision of the guardian/doctor.

3.1.5 Individual preferences (Q8)

With respect to individual VAD preferences:

- 63% of respondents indicated they would not want to leave their country to die and 48% would not want to leave their region to die
- Respondents indicated that dying at home with palliative care (not wanted by 23%) was preferred over dying in hospital with palliative care (not wanted by 45%).

3.1.6 Other (inc. Q9)

Other survey outcomes include:

- 85% of respondents said that their quality of life would be improved by ready access to an end-of-life substance
- 61% said that their quality of life could be improved by ready access to an illegal (or legal) drug; indeed older people are more likely to want to use an illegal lethal drug (36% in the 40–49 years age group increased to 75% for people ≥90 years old).

3.2 Regulate VAD and continue debating VAD issues

There are issues arising from survey responses that require and deserve further analysis. In most areas of public policy, stakeholders express a range of views on how various objectives can be achieved. It is no different with VAD.

Specific VAD issues can be complex, but they are not sufficient to postpone any regulatory or other measures that will allow people to access VAD.

Some of these issues are discussed in this survey's *Supplementary Material*. That document challenges people to think better to understand VAD's underlying ethical principles and develop rational solutions to address VAD issues. Ultimately however, law reform and democratic processes will determine whether the needs and wishes of many people seeking access to VAD can be met.

Some statements can be made about how the survey responses align with what is happening around the world on VAD. The current situations in many jurisdictions show that:

- VAD advocates are working hard to achieve regulated VAD for terminally ill people, noting that regulation is lacking in most jurisdictions
- having to be terminally ill and being required to comply with many VAD eligibility conditions does not meet the end-of-life needs of many people
- from a rights perspective, people (perhaps any person who can make sound, well-informed decisions) should have the right to implement plans for the end of their life
- from a public policy perspective, regulators must ensure that eligible people who want to access VAD can obtain the requisite lethal drugs.

It is imperative that the VAD debate continues to explore issues such as the freedoms people should have regarding the end of their lives, how much suffering governments might require people to endure contrary to their expressed wishes and what role governments should play in ensuring that VAD eligible persons can access VAD drugs and/or other assistance, as required.

The VAD debate must continue, promptly and helpfully. This *Summary Report* seeks to provide an objective contribution to that debate. People's well-being is at stake.

4 SURVEY BACKGROUND

The online survey opened 27 July 2020 and closed 27 February 2021.

- The survey was emailed to the World Federation of Right to Die Societies, as well as Exit International, Dying with Dignity Organisations (DWDs) and Voluntary Euthanasia Societies (VESs). Many of these organisations then forwarded the survey to their members.
- 1640 responses were received from around the world by the closing date. This is roughly estimated as ≈1.5% response rate, with an error <3% (95% confidence). This means that given a 50% response rate to a particular question, we can be 95% sure that the true percentage of the population who would choose a response lies within the margin of error, that is between 47% and 53%.

5 DEMOGRAPHICS

5.1 Demographics: world responses

Survey respondents are VAD advocates and supporters. The 1640 survey respondents can be characterised as follows.

- Respondents lived in 31 countries. 95% of responses came from 6 regions (Australia, other Europe (mostly France), USA, UK, Netherlands, Canada), each with >40 responses.
- 61% of respondents identified as female, 84% were >50 years, and 34% were 70–79 years old.
- Respondents were mostly non-religious (75%) and well-educated (72% have at least one degree, 40% have a higher degree).
- Over 70% of respondents did not have a disability. 27% of those who did have a disability indicated that they had needs or concerns. A typical survey comment was 'When I am suffering too much, I want to be killed when I ask'.
- There was no evidence of VAD specific cultural needs for First Nations peoples (4% of respondents).
- About 45% of respondents belonged to Exit, 43% to DWDs, 16% to VESs, and 25% to other organisations (or no organisation). Most people joined their organisations to obtain information, practical advice and support their organisation.

6 FURTHER INFORMATION

6.1 Future steps

Follow-up work on the survey analysis and distribution will occur and will include the following steps.

- Relevant information will be sent to respondents' jurisdictions (countries) and organisations, who will be asked to alert individual respondents of the survey results.
- Analysis, data and survey questions will be made available on the Ethical Rights website (www.ethicalrights.com). Further survey details and updates will also be made available on this site.
- Work will continue on data analysis. The possibilities of conducting a longitudinal study on perspectives of voluntary assisted dying advocates, to assess responses over time, will be explored.
- A further report or future book using the survey data as an evidence base may be produced. Contributors would ideally include leaders and experts in the VAD/voluntary euthanasia movement.

6.2 Acknowledgements

Ethical Rights thanks the following organisations and individuals:

- the World Federation of Right to Die Societies, Exit International and the other DWDs and VESs that passed the survey onto their members
- all the VAD supporters who responded to the survey; this survey reflects their perspectives
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- Dr Wendy Gunthorpe for her valuable comments on survey design (see www.straighttalkconsulting.org).

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