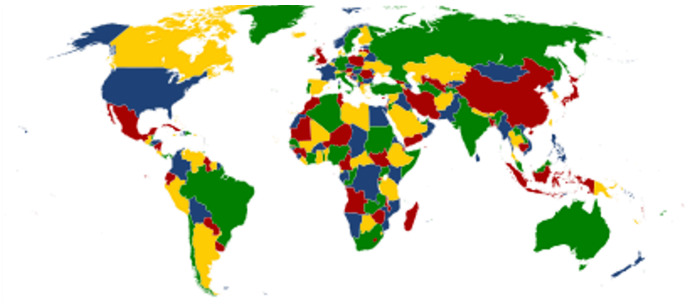
ETHICAL RIGHTS
VOLUNTARY ASSISTED DYING SURVEY 2021

SUPPLEMENTARY MATERIAL (WORLD RESPONSES)



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INTRODUCTION

This *Supplementary Material* is a companion to the *Summary Report* and *Results* documents for the Ethical Rights Voluntary Assisted Dying Survey 2021. All 3 documents, as well as the *Survey Questions*, are available on the Ethical Rights website (www.ethicalrights.com).

APPENDIX 1.
A BRIEF ANALYSIS OF SOME UNRESOLVED VAD ISSUES

Significant key messages

The survey's key messages in the *Summary Report* follow rationally from survey responses, which are presented graphically in the *Results* document. The key messages are important because they represent the majority views of voluntary assisted dying (VAD) advocates and supporters worldwide. Significantly, respondents indicated overwhelmingly (99%) that every person has the right to implement plans for the end of their life. This right was also reflected in comments that reflected respondents' concerns for individual autonomy—a typical comment was 'It is my choice'—and a desire to avoid suffering that would decrease their quality of life.

They key messages should be influential in guiding regulatory reform that meets the needs of all people who wish to access VAD. They are summarised here for ease of reference.

KM1: VAD should be legalised or better regulated in jurisdictions.
KM2: VAD regulatory models should be expanded in scope to meet the needs of people who want to access VAD.
KM3: 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.
KM4: VAD regulation that effectively meets the end-of-life needs of people can give them peace of mind and a better quality of life.

Although many response options received strong support, a range of responses was offered to other questions. Subject to the note in the highlighted box below, this appendix analyses some of these responses and also contrasts survey responses with conditions common in some VAD regulatory systems. Do they align, or can VAD regulatory systems be improved?

Note. This appendix highlights some contentious VAD issues.
If VAD regulation is to better meet the needs of people who are suffering, then conventional VAD thinking must be challenged.
These issues do not undermine, or should be construed as undermining, VAD's ethical merit or the need for regulatory reform overwhelmingly supported by the survey's respondents.

Thinking better to develop rational solutions

The diversity of respondents' views is shown by two examples. Access to VAD for dementia sufferers (not specified in an advance directive) was supported by 56% of respondents. Similarly, 65% considered that it might be better for a child to access VAD to avoid suffering (see section A1.7). Although a majority thought these outcomes to be desirable, VAD regulatory systems do not usually allow people with dementia or children to access VAD.

If inconsistencies are found after contrasting the survey's key messages and responses with what is possible with regulated VAD, then something needs to change. Are VAD advocates expecting too much or is VAD regulation too restrictive? To encourage debate, the appendix poses questions after each issue for further consideration.

The key to resolving these conflicts is for people to think critically to construct their own rational, justifiable argument for an action or behaviour to be ethically right. That said, it can be rather difficult to refute arguments that are premised on individual autonomy and optimising a person's quality of life by having them avoid unnecessary suffering.

Finally, it is important to note that there could be other reasons why participants responded as they did to various questions. In this appendix's analysis it is assumed that responses (within the survey's margin of error) accurately reflect respondents' perspectives on VAD issues. Further work may be required to elicit why survey participants responded as they did to some of the survey questions.

With that background, the following situations should be considered, assessed against the key messages and justifiable arguments developed in response to an issue.

A1.1 Unbearable suffering: a sufficient but not a necessary condition for VAD

While 80% of respondents worldwide said that a person with unbearable suffering should be immediately eligible for VAD, only 34% thought that unbearable suffering should be an eligibility criterion. In other words, 66% of respondents thought that a person does not need to be suffering unbearably to access VAD. There might be health or other reasons for a person choosing VAD, such as age-related ailments, the prospect of worsening dementia with a

decreasing quality of life or being in a vegetative state (a condition included in the person's advance directive).

VAD eligibility criteria are, by definition, necessary conditions for VAD. That is, they must necessarily be met for a person to be eligible for VAD. Respondents thus consider unbearable suffering as a sufficient, but not a necessary, condition for VAD. That is, if a person has unbearable suffering, then they should be able to access VAD. On the other hand, if they do not have unbearable suffering, they should not be precluded from accessing VAD.

This distinction is even more stark for a person with a terminal illness. While almost 100% of respondents considered a person's terminal illness sufficient to access VAD, only 22% said that the terminal illness should be an eligibility criterion or necessary condition for VAD.

While these responses on unbearable suffering are consistent with the concept of VAD as an individual right (that should be able to be exercised regardless of suffering), they are incompatible with most existing VAD regulatory systems that require that eligible persons be terminally ill. In addition, many respondents' comments simply referred to 'suffering', suggesting that the adjective 'unbearable' might be superfluous.

A fundamental question remains.

> If VAD is a right, and an aim is to meet the needs of people who want to avoid further suffering, should regulated access to VAD be available to any person regardless of the level of suffering, to a person who has unbearable suffering or to a person who is terminally ill?

A1.2 The role of doctors

If VAD is a right that people can exercise, the question arises as to what extent doctors need to be involved in VAD processes.

A majority of respondents (81%) indicated that doctors can prescribe lethal drugs but 89% said doctors should be unnecessary for administering those drugs, as self-administration should be possible. However, in most jurisdictions around the world, only doctors are permitted to prescribe lethal drugs, including those needed for VAD.

Most respondents (82%) did not want VAD that requires a 2-doctor approval process. If this were to mean that no doctors are required for approving VAD requests, then this would be consistent with the concept of VAD as a right. If doctors aren't involved at all (even for prescribing drugs), then VAD, without the 'assisted' element, essentially defaults to suicide.

If VAD is a right, then no person, including doctors, should be permitted to judge whether a person's level of suffering is sufficient to warrant VAD. Nor should they be permitted to refuse any eligible person's right to VAD any more than they would be able to refuse a woman's right to an abortion. However, doctors might be required to confirm, for example, that a person's admission of suffering is sincere and legitimate if doctors were to be prescribing lethal drugs.

With respect to doctor involvement, the relevant broad question is the following.

> If VAD is a right and a person can legally suicide, to what extent should doctors be involved in approving a person's fitness to access VAD?

A1.3 Regulating eligibility and lethal drugs

Worldwide, 81% of respondents said doctors should be able to prescribe end-of-life drugs. From a public policy perspective, doctors should not be prescribing lethal drugs to ineligible people. How can this situation be managed for people who want to access VAD?

Governments legislate to establish the rules of what is and is not acceptable. For VAD, they can legislate to ensure that only eligible people can access VAD. Where government intervention in a human activity is warranted—it is in the case of VAD—penalty provisions coupled with compliance, enforcement and monitoring regimes, as well as reporting and evaluation requirements, can be used to put legislative bounds around what is acceptable and what is not. Such VAD legislative systems do not exist in 72% of the jurisdictions in which respondents live.

Respondents indicated that legislated eligibility criteria should include that people choose VAD (voluntarily) without coercion, are well informed and have decision-making capacity. Those conditions can be straightforwardly legislated. Most VAD regulatory regimes, from the most restrictive (involving many regulatory steps) to more progressive or liberal arrangements, have successfully managed to restrict the use of VAD to eligible persons.

Under more restrictive regulatory systems, only terminally ill people with limited life expectancy and meeting many other eligibility criteria can access VAD. This is contrary to the wishes of most survey respondents. In jurisdictions such as Switzerland, assisted suicide for non-selfish purposes and involving self-administration is permitted. People having unbearable suffering and the elderly have been able to access VAD in Switzerland. Although this freedom is consistent with the views of many respondents, it would mainly benefit the Swiss, as only 37% of respondents were prepared to travel to another country to access VAD.

The issue of VAD regulation can be distilled to a single question.

> How should VAD be legislated to best give effect to the wishes of a person who deems their quality of life unacceptable and wants to access VAD, while also preventing ineligible persons from accessing VAD?

A1.4 Immediate access to regulated VAD

Respondents' greatest support for immediate access to VAD was for a person who had finalised an advance directive that would permit VAD in their current medical circumstances (82%), even ahead of a person having unbearable suffering (80%). Most regulatory systems don't allow VAD to be included in an advance directive as a treatment decision.

Most VAD regulatory systems could not effectively manage the situation of a recently diagnosed cancer patient who is admitted to a palliative care hospital with a few weeks to live. The patient would be unwell, have insufficient time and enthusiasm to ensure

regulatory compliance and might not want to suffer a drawn-out death. In such cases, 60% of respondents supported a person's right to immediately access VAD while in palliative care, rather than enduring suffering. Adding to the trauma associated with dying, 45% said they would rather not die in a hospital with palliative care. Only 23% would not want to die at home with palliative care.

A person of advanced years (whether they are, for example, 80, 90 or 100 years old) might also want to access VAD. They might not be suffering unbearably or be terminally ill, but they might simply deem that their quality of life is unacceptable. In this situation, 58% of respondents considered a person of advanced age should have the right to immediately access VAD. In 2018, Dr David Goodall, a determined 104-year-old scientist, did just that.[1] He left Australia and travelled to Switzerland to die with nothing more serious than age-related ailments. It was his choice and he was adamant that he was making the right choice.

In addition, if VAD does not meet people's needs, 75% of respondents over 90 years old indicated that their quality of life would be improved if they had access to lethal (legal or illegal) drugs. By implication, it is possible that they could use illegal drugs to die if regulated VAD was not available to them.

They are then confronted by the cruel dilemma of when to take their drugs, best encapsulated by the maxim of 'it's always too early until it's too late'. This fear of suffering and being driven to suicide (a legal act in many jurisdictions) before they may be incapable of suiciding is reflected in a typical survey comment, 'I need to have access to suicide prior to my disability becoming advanced stage [*sic*]'.

This analysis raises the following questions.

(a) Should governments deny people the right to construct and request the implementation of VAD-relevant advance directives if they want to avoid suffering later in life?
(b) If governments have no right to prevent a person (of sound mind) from suiciding, should they be able to have others restrain people in palliative care or of advanced age from choosing to use a lethal drug to die? Both 'yes' and 'no' answers have implications.
(c) Are governments willing to accept that, in the absence of supportive VAD regulation, persons of advanced age may take matters into their own hands and use illegal drugs to suicide or travel overseas to die? In addition, should age be an eligibility criterion?
(d) If suicide is legal,[2] should it be illegal (subject to meeting conditions of it being voluntary etc) to obtain assistance with a legal act, and if so, why?

[1] David Goodall ends his life with a final powerful statement on euthanasia. Published May 10, 2018. Accessed December 28, 2020. https://www.abc.net.au/news/2018-05-10/david-goodall-ends-life-in-a-powerful-statement-on-euthanasia/9742528.
[2] Suicide is legal in many jurisdictions.

A1.5 A person's autonomy, pregnancy

Consider that 48% of respondents said that pregnancy should make a woman automatically ineligible for VAD. If a large majority of people consider that a woman has an ethical right to an abortion, then a pregnant woman who is suffering unbearably could first have an abortion and then VAD. The outcome would be the same, but she would circumvent any pregnancy objection to VAD.

If a woman has a right to determine what is best for her body and have an abortion, then a person wanting VAD should have a similar ethical right to their own body, and vice versa. That is premised on the ethical concept that a person's individual autonomy—that an individual has the right and capacity to live their life how they wish, including to determine what is right for their body—should not depend on their fertility, pregnancy status, race, age or other irrelevant attributes.

A question follows.

> Should a person's personal attributes, whether sex, sexual orientation, gender identity, ethnicity, race, age or pregnancy, mental health or other status, exclude them from the right to access VAD?

A1.6 Rights of people, including criminals

Only a small number of respondents (16%) said that convicted criminals should be ineligible for VAD. This minority considered that a criminal offence should be sufficient to deny a person a right, in this case to VAD.

A larger number (33%), but still a minority, thought that people who are subject to police investigations should be ineligible for VAD. Consider then the extreme case of a person being investigated for multiple murders and who faces a lifetime in jail but is now ill and suffering unbearably. A majority might still argue that, even if the person had refused to reveal to police where they had buried 'the other murder victims', the state would have to accede to their VAD request.

These two scenarios raise issues relating to the nature of rights, including to VAD, especially when competing rights conflict.

One issue is the following: some jurisdictions around the world have legislated death penalties (a decision by the state to kill a criminal without their voluntary consent) but ban VAD. On the one hand, a person's life can be legally ended—as punishment—by the state, on the other, some presumably consider that life must not be ended as it is perhaps too precious. This ethically irreconcilable situation occurs in many of the world's largest countries, including the USA. This theoretically results in the perverse outcome of prohibiting a terminally ill person on death row from choosing to die in advance of their death sentence.

This discussion raises the following question.

Should a person's actions through their life (criminal or otherwise), or their obligations to act responsibly in society (and answer police questions), or any other factors exclude them from any right to access state regulated VAD?

A1.7 A child's or infant's suffering

A child's or infant's suffering, as it impacts on their quality of life or well-being, is not intrinsically less than that of an adult. In reality, it could be more (or less) severe than an adult's, as a child might not understand the seriousness of their illness or nature of their medical treatment.

Nonetheless, in relation to Q7 in the survey, a minority of respondents (35%) said that a child (with guardian/doctor support) should be automatically ineligible for VAD. This means they accept that a child would suffer unbearably when adults in similar situations could access VAD. It also means that, in some circumstances at least, 65% thought that a person could be a child (having unbearable suffering) and access VAD.

As 61% of respondents (to Q4) said that being an adult is necessary for a person to access VAD (that is, a VAD eligibility criterion), 39% thought that a person can also be a non-adult (a child) and be eligible for VAD. That is, 39% thought eligibility should be extended to any person (child or adult) independent of age.

These perspectives can be compared to those for people having unbearable suffering and being terminally ill, see Figure A1.1. In these cases, the majority of respondents considered that being terminally ill, having unbearable suffering (see also section A1.1) or being a child (assumed with unbearable suffering) are sufficient to allow a person to access VAD. A minority said that a person of any age who is terminally ill (22%) or having unbearable suffering (34%) should be necessary for VAD (an eligibility criterion).

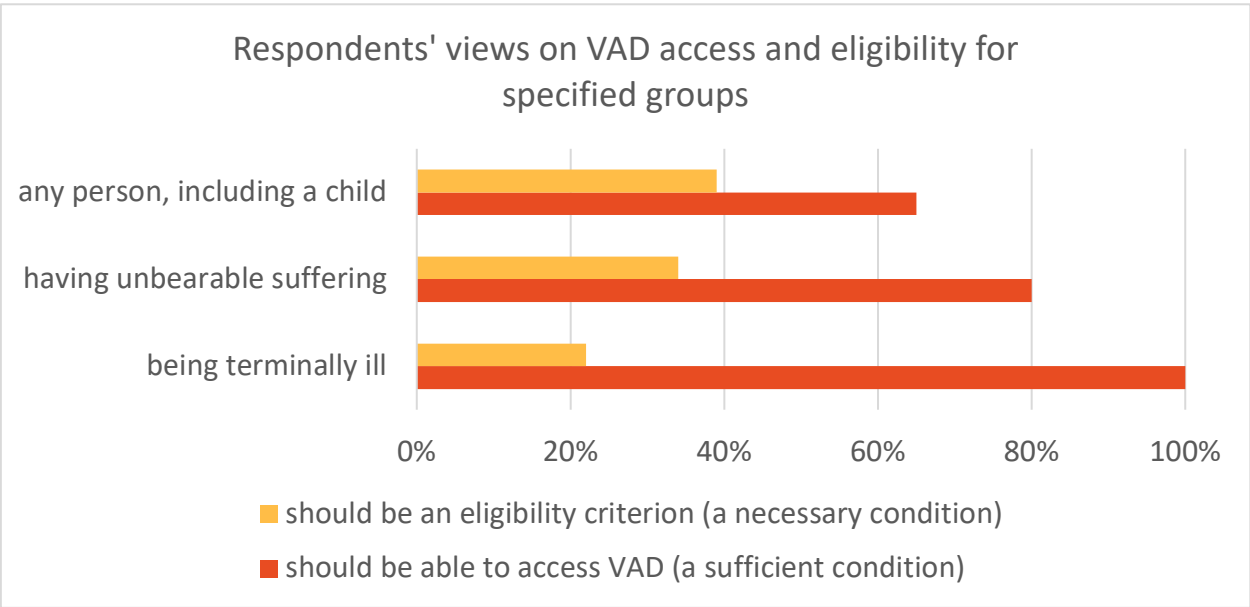

Figure A1.1. Graph of respondents' views on VAD access and eligibility for specified groups.

If the survey's majority views were manifested in legislation, then all people (adults or children) who are terminally ill or who are having unbearable suffering should be able to access VAD.

Similarly, although 26% thought a newborn infant should be ineligible, 74% considered that there may be a circumstance under which an infant might need VAD (with guardian/doctor support). Such a circumstance is a baby being born with a disease that will result, for example, in the infant's certain, traumatic and painful death within 40 days.[3]

Similar short life expectancy scenarios apply to children and adults. It is likely that existing regulatory systems would be slow to respond to such scenarios. If a person's quality of life is important, regardless of their age, regulatory systems must be responsive to their needs and their (or their guardian's) wishes.

A fundamental ethical question, and particularly for this specific issue, is the following.

> As all people can suffer, should any person, including non-adults (child or infant), be refused the option of VAD when suffering and death is inevitable in the short-term?

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[3] Cannon A. Parents resigned to allow their children to die of a rare disease. La Ronge Northerner. Published July 5, 2021. Accessed July 12, 2021. https://www.townoflaronge.ca/parents-resigned-to-allow-their-children-to-die-of-a-rare-disease/