Assisted Dying in Jersey

Ethical Review

November 2023

Contents

Authors, declarations and acknowledgements

This report was prepared by:

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Mullock and Huxtable had previously advised the Jersey Citizen's Jury that considered assisted dying and published its recommendations in September 2021; Mullock was one of two expert advisors to the Citizen's Jury, while Huxtable was one of three independent subject matter experts (see further here). Lemmens presented to the Citizen's Jury about the experience of the *"Medical Assistance in Dying"* law and practice in Canada. The authors were selected because they hold a range of views on assisted dying:

- Huxtable is in favour of adopting a *"middle ground"* (or compromise) position on assisted dying, which seeks to accommodate arguments for and against allowing assisted dying;[1]
- Lemmens has supported (including as an expert witness in litigation) a first Canadian law which allowed euthanasia and assisted suicide in a broad end-of-life context. He has become increasingly concerned about how assisted dying regimes develop over time, particularly when they allow direct administering of lethal medication by health care providers and have no specific terminal illness and prognosis of survival as safeguards. He is opposed to legalising the practice outside a clearly delineated end-of-life context and is concerned about the overall ability to monitor the practice;[2]
- Mullock is broadly in favour of assisted dying as a compassionate response within a carefully regulated scheme that safeguards individuals who might be regarded as vulnerable if assisted dying is permitted.[3]

All authors contributed to the background research and drafting of this Review; as lead author, Huxtable collated and drafted the report, and all authors reviewed, edited, drafted specific sections, and agreed with the final version of this report.

The authors are also grateful to the following, who provided research assistance, by gathering additional research materials:

[1] E.g., R Huxtable. Splitting the Difference? Principled Compromise and Assisted Dying. *Bioethics* 2014; 28(9): 472-480; R Huxtable. Assisted dying, ethics and the law: For, against, or somewhere in between? In S Westwood, ed., *Regulating the End of Life: Death Rights* (Routledge, 2021), 77-91.

[2] E.g., T Lemmens. Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice. *Supreme Court Law Review* (2nd) 2018; 85: 453-539; T Lemmens. When Death Becomes Therapy: Canada's Troubling Normalization of Health Care Provider Ending of Life. *American Journal of Bioethics* 2023; 23(11): 79-84.

[3] E.g., A Mullock. Overlooking the criminally compassionate: What are the implications of prosecutorial policy on encouraging or assisting suicide? *Medical Law Review* 2010; 18(4): 442-470; A Mullock. Compromising on assisted suicide: Is "turning a blind eye" ethical? *Clinical Ethics* 2012; 7(1): 17-23.

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The views expressed are those of the authors, and should not be taken to represent those of any funders, organisations or other groups or individuals with and for which they work.

Background and approach

In November 2021, the States Assembly (Parliament of Jersey) made an *"in principle"* decision that assisted dying should be permitted in Jersey, and that detailed proposals (to include all processes and safeguards on assisted dying) would be debated by the States Assembly, prior to the preparation of a draft law on assisted dying.

In April 2023, the Minister for Health and Social Services announced that: *"the Council of Ministers has agreed that the proposals considered by the States Assembly later this year should be further informed by specialists with a background in medical ethics and law, who hold a range of views on assisted dying. This external review will seek to identify the ethical and moral considerations around assisted dying, including those raised in the responses to the consultation."*

The authors were thereafter contracted by the Government of Jersey (GoJ), acting for the Minister for Health and Social Services, to undertake an ethical review, the outcomes of which are summarised in this report. The authors were provided with the following documents:

- Assisted dying consultation report (available here);
- Consultation feedback report (available here);
- Citizens' Jury report (available here);
- Phase 1 feedback report (available here);
- P95/2021 – Report and Proposition (available here and here).

The authors were asked to identify and summarise ethical arguments on key aspects of assisted dying and to map the ethical considerations across the Jersey-specific proposals. These proposals have been informed by the Jersey Assisted Dying Citizens' Jury, and two phases of public consultation. They were specifically asked to address 16 questions (see Chapter 1), as framed in discussions with the Minister and informed by the public consultation feedback.

To answer these questions, the authors drew on literature they had already compiled and, where they judged it to be appropriate, undertook further targeted searching, which was further supported by research assistants (see Authors, declarations and acknowledgements). The authors adopted various approaches to searching the literature; they did not adopt a single systematic method(s), given the timeframe for the review and their familiarity with the topic and key research in the area. However, the authors sought to ensure that the information collected and included in the report covered a range of perspectives on assisted dying.

The authors, who hold a range of views on assisted dying (see Authors, declarations and acknowledgements), worked from the basis of the States Assembly *"in principle"* decision that assisted dying should be permitted in Jersey.[4] As such, they did not engage with the general question of whether (or not) it would be appropriate to legalise assisted dying; rather, they focused on the current proposal(s) and particularly the 16 questions they were asked to address. The authors sought to consider a range of arguments (and evidence) for and against particular answers to these questions. Where there was a consensus between the authors that the ethical arguments relating to a particular provision clearly support one option over another, the authors have provided a commentary expressing and explaining that consensus. Where the arguments appear to be more

[4] The outcome of the vote is reported here: https://statesassembly.gov.je/Pages/Votes.aspx?VotingId=6441.

balanced and/or authors were not in full agreement, a commentary is provided explaining the different positions.

List of abbreviations (acronyms)

AD	Assisted dying
ALS	Amyotrophic lateral sclerosis
BMA	British Medical Association
CO	Conscientious objection
ECHR	European Convention on Human Rights
HCP	Healthcare professional
GoJ	Government of Jersey
GMC	General Medical Council
HCS	Jersey Health and Community Services department
MAiD	Medical assistance in dying
MCCD	Medical certificate of cause of death
MCFCD	Medical Certificate of the Fact and Cause of Death
NMC	Nursing and Midwifery Council
PAS	Physician assisted suicide
RCGP	Royal College of General Practitioners
US	United States (of America)

Chapter 1: Overview and summary

This chapter provides a summary of the contents of the remainder of the report. Each subsequent chapter examines a cluster of related issues and addresses specific questions about these. For each cluster of issues, the key questions guiding the review are presented here, followed by a summary of the key points made in the relevant chapter. Each summary includes cross-references to specific paragraphs in which the relevant issues are discussed in more depth.

Eligibility criteria

1. What are the key ethical considerations regarding healthcare eligibility criteria? In particular, what are the ethical considerations in relation to the following options: (a) as per current proposals – to include both "terminal illness" and "unbearable suffering" as eligibility criteria; or (b) eligibility for "terminal illness" only?
2. Are there specific ethical considerations for health eligibility criteria definitions, as proposed?
3. If the law allows for terminal illness only, then what are the ethical considerations around the following options: (a) as per consultation proposals; (b) 12 months life expectancy for all; or (c) terminal diagnosis but no timeframe for life expectancy (and requirement for current suffering)?

The proposal currently anticipates allowing AD for adults residing in Jersey who (autonomously) request this on the basis of terminal illness (Route 1) or unbearable suffering (Route 2) (2.1-2.4). This two-route approach resembles various existing AD regimes (2.5).

Route 1 (terminal illness) resembles most existing AD regimes (2.6).

There are arguments for and against a terminal illness requirement (2.7). In favour of this requirement is that it grounds the law in autonomy/self-determination and thus affords individuals the ability to control the manner and timing of their deaths, whilst offering a safeguard against expansion to more arguably problematic situations, and signalling that AD is an exceptional last resort, which may reassure some doctors and HCPs (2.8). Against this requirement is that diagnoses of terminal illness and related prognoses may not be reliable, and reserving AD for terminal illness may be considered an unacceptable restriction on self-determination, exclude those whose suffering is borne of a different cause, and be considered unjustly discriminatory (2.9).

Route 1 additionally requires the terminally ill person to have current, or a future expectation of, suffering (2.10), for which there are also arguments for and against (2.11). Arguments in favour of requiring current or future expectation of suffering include that the case for AD is typically premised on the presence of suffering, some terminally ill patients might be expected to experience suffering, and anticipating future suffering enables patients to plan (2.12). Arguments against this requirement include that suffering is too vague, too multifaceted, and too subjective to be a useful or reliable eligibility criterion, and that allowing AD on the basis of anticipated future suffering requires patients to make judgments before they can fully appreciate how their terminal illness will develop (2.13).

Route 1 additionally requires the patient to have a life-expectancy of either 12 months (for neurodegenerative conditions) or 6 months (for all other conditions) (2.14), for which there are also arguments for and against (2.15). In favour of these life expectancy timeframes is the fact that this aligns with laws elsewhere, the balance this strikes between affording the patient control and protecting people against premature death, and the clarity and specificity this gives the law, which may help to avoid any expansion of the law, such as has occurred in jurisdictions which do not specify

a life expectancy timeframe (2.16). Against the adoption of these life expectancy timeframes is the suggestion that prognoses may be imprecise or inaccurate in individual cases and (again) the limitation that timeframes place on the exercise of autonomy (2.17).

Assuming that AD will be legalised in some form, on balance we believe that the proposals regarding Route 1 (terminal illness) are ethically appropriate, for the various reasons given in favour above. There may be cause to complain that restricting AD to terminal illness deprives people who suffer outside the end-of-life context of the benefits of AD, but doing so may strike an appropriate balance between empowering and protecting people. We also recognise that diagnoses and prognoses may not be entirely precise, but are reassured that these become more accurate the closer the person is to death. (2.18). We similarly believe that the proposed timeframes are defensible, as these provide a safeguard by being more objective and measurable, and they align with laws elsewhere (2.19).

Route 2 (unbearable suffering), which focuses on incurable physical (not mental) conditions, differs from Route 1; adopting the language of a Dutch ethicist, Route 1 allows *"euthanasia to prevent a terrible death"*, while Route 2 allows *"euthanasia to prevent a terrible life"* (2.20).

There are arguments for and against an unbearable suffering route for incurable physical conditions (2.21). Key arguments in favour of this route are the fact that suffering can arise in contexts beyond terminal illness, that it may be discriminatory to restrict AD to terminal illness, and that it would respect the choices of those who seek AD who are not terminally ill (2.22). However, there are substantial arguments against this route, particularly that it makes (and reinforces) an *"ableist"* judgment about the negative value of the lives of people with disabilities. We suggest that this will impact on people with disabilities because the *"unbearable suffering"* must be due to an incurable physical condition/illness, which will almost always be regarded as a disability. There are also concerns that: *"suffering"* is too vague, multifaceted and subjective to be a useful or reliable eligibility criterion; the intolerability of suffering can change over time and be influenced by social and psychological factors; it may be discriminatory to deprive persons with disabilities and chronic illness who are not otherwise dying from equal protection against death that others continue to receive; and allowing AD as a response to unbearable suffering may lead to the expansion of AD in terms of numbers and scope (2.23). In view of these arguments and the associated data, we have serious reservations about allowing AD in such circumstances and on balance we believe that the proposals regarding Route 2 (unbearable suffering) are not ethically appropriate, for the reasons given above (2.24). Although objections to this conclusion may be anticipated, one (albeit incomplete) response is that people may still become eligible for AD under Route 1 (2.25). If the States Assembly decides to proceed with Route 2, we would additionally advise that guidance be prepared for situations in which candidates may be eligible under either route (2.26).

We conclude our analysis of Routes 1 and 2 with a briefer reflection on the notions of incurability and intolerability which (arguably) feature in both sets of eligibility criteria (2.27-2.28). These echo law elsewhere, would respect patient autonomy, and may help to signal that AD is to be a last resort (2.29). However, *"incurability"* may be hard to define and *"intolerability"* will rest on subjective judgments, which may mean that patients seek and receive AD without having tried viable options, which doctors may find difficult and which may mean it becomes more difficult to restrict the practice (2.30). We nevertheless anticipate that these concerns are less acute for Route 1, although they may need to be addressed if the States Assembly decides to proceed with Route 2 (2.31).

4. What are the key ethical arguments regarding the other eligibility criteria of: (a) Jersey resident; (b) 18 or over?

Regarding (a), the proposal is that access to AD should only be available to Jersey residents (2.32). There are arguments for and against this position (2.33). This aligns with most jurisdictions, would avoid Jersey becoming a *"suicide/death tourism"* destination, and has the most support amongst consultation respondents (2.34). However, there is a precedent for allowing non-residents access (Switzerland), this might generate income, and it might meet the needs of those who live in prohibitive jurisdictions (2.35). We suspect the case for restricting access to residents is stronger, and the States Assembly should also reflect on the appropriate duration of residency (currently proposed at 12 months) (2.36).

Regarding (b), the proposal is that access to AD should only be available to adults and not minors (<18 years) (2.37). Minors may be competent or incompetent (2.38). Although there are precedents for euthanasia for incompetent minors (2.39), we focus on competent minors, because the overall proposal focuses on patients who are capable of requesting or consenting to AD (2.40-2.41).

There are arguments for and against allowing competent minors to access AD (2.42). In favour of allowing such access: there are precedents for doing so; it may be fair, just and equitable to afford competent minors the same rights as adults in their situations enjoy; it may be legally consistent to do so; and safeguards may be introduced by additionally requiring parental consent (2.43). However, most jurisdictions do not allow minors to receive AD and those countries that do have low uptake and their laws are controversial. Furthermore, children may be said to lack the requisite autonomy and may be more in need of protection. Offering them access to AD may also create legal inconsistency (unless children were also to be given a right to refuse life-sustaining treatment). We also note that the public consultation narrowly preferred restricting access to adults (2.44). On balance, we believe that AD should be restricted to adults but, if AD for children is to be considered, the views of children themselves would need to be sought (2.45).

We additionally (c) offer brief comments on consent and capacity (2.46), which are typically needed for any medical procedure (2.47). The Jersey AD proposals would include a specific legal test for capacity, plus accompanying tools and guidance, but – as is the case with other procedures – the presumption of capacity would remain (2.48). AD presents risks and there is evidence from other jurisdictions which raise concerns about capacity assessments (2.49). We welcome the proposal to set out a specific capacity test and provide tools and guidance, but we suggest that, for AD, the presumption of capacity could be removed, and training also provided, in order to safeguard patients and best ensure compliance and consistency (2.50).

Approval routes

5. What are the key ethical arguments regarding role of health professionals in a "medical model" vs. a "non-medical model" of assisted dying?

The proposal currently depicts a "medical model" of AD, in which doctors and/or other HCPs have a high level of involvement in AD (3.1-3.4).

There are conflicting arguments about whether, in principle, doctors should be involved in AD, with reference to the nature and goals of medicine and the corresponding values and identities of its practitioners (3.7-3.9). However, these arguments appear to be less helpful than those focused on whether doctors should be involved in practice (3.10-3.11).

There are (practical) arguments in favour of doctors' involvement, which refer to the fact that doctors do provide such assistance in those countries that allow the practice, there is some support from

doctors in the UK, and some professional medical organisations have adopted a neutral position on whether the law should be changed (3.12).

There are (practical) arguments against doctors' involvement, which refer to the fact that many doctors remain opposed to AD, including some doctors in Jersey, there is a potential conflict with palliative care, and experiences in other jurisdictions reveal concerns about the welfare and protection of both patients and doctors, the impact on the doctor-patient relationship, and the time taken to provide AD (3.13).

Given the arguments for and against doctors' involvement (3.14), we welcome the plans to seek to address/ameliorate the concerns of opponents by including a conscientious objection clause and ensuring there is a good level of access to palliative care (3.15). We further suggest (before the proposals are finalised) that it would be helpful to gather additional, specific evidence from key stakeholders, including doctors and (especially if Route 2 is to be permitted) people with disabilities (3.16).

We were also asked to consider a "non-medical" or "de-medicalised" model (3.17-3.18).

A totally de-medicalised model might involve anyone other than a doctor or HCP (including someone close to the patient) or alternatively a new sort of specialist (3.19). Either of these models would have the advantage of assuaging concerns about the involvement of doctors, may make AD more accessible, and may be welcomed by patients who prefer to be assisted by someone close to them (3.20). However, involving such people might impact on personal relationships and the welfare of the assistant; it might open the door to abuse and subtle pressure within a family context; it may present conflicts of interest if providing AD is the provider's primary or sole source of income; professional input may still be needed to ensure the welfare of the patient; and no legal system appears to have adopted such a model, so there is no body of experience to inform such a proposal (3.21). On balance, total de-medicalisation does not appear to be ethically defensible (3.22).

A partially de-medicalised model could reduce the involvement of doctors to (e.g.) assessing the patient's medical condition and their competence to decide. Such a model operates in Switzerland, where right-to-die organisations provide the majority of the assistance, according to their own processes (3.23). This has the advantage of reducing the involvement of doctors and concerns about this, but their (reduced) involvement may still enable them to raise any concerns to relevant authorities (3.24). However, there may still be concerns that the patient's welfare will not be adequately protected without more medical involvement, and concerns about the potential for unjust provision, particularly if this is to be arranged by private organisations at a cost (3.25). On balance, partial de-medicalisation has some benefits but some level of medical involvement and State provision is likely to be needed (3.26).

6. What are the key ethical considerations regarding "Route 1 (terminal illness)" as proposed – i.e., approval following two doctors' assessments?

Both Routes 1 and 2 would involve at least two doctors in assessing the patient's eligibility for AD (3.27). Various jurisdictions require two doctors to be involved, and sometimes other or additional professionals (3.28).

Arguments in favour of involving two doctors include the safeguards and reassurances that doing so can offer to patients and professionals alike, by enhancing objectivity and reducing the potential for error, abuse or legal comeback (3.30). However, involving two doctors inevitably prolongs the process, imposing a burden on patients and potentially worsening their suffering, and may introduce

another subjective assessment (3.31). The arguments in favour nevertheless appear to be strongest and the risk of introducing further subjectivity may be addressed via training and/or requiring additional approval by a Tribunal (3.32). While we welcome the plan to ensure that other professionals, with relevant expertise, are involved (3.32), we suggest that thought should be given to how best to ensure that the two doctors are independent (3.33) and, while we believe the risks of *"doctor shopping"* appear to be absent or minimal, the final proposal could make explicit that both doctors must be sought from the Jersey Assisted Dying Service (3.34).

7. What are the key ethical considerations regarding "Route 2 (unbearable suffering)" – i.e., approval following two doctors' assessments, confirmed by a Tribunal?

The Route 2 (unbearable suffering) approval process would involve two doctors and a Tribunal (3.35). Prospective review processes like this have been adopted elsewhere, e.g., Spain (3.36).

Arguments in favour of involving a Tribunal include the safeguards and reassurances that doing so can offer to patients and professionals alike, by enhancing objectivity and reducing the potential for error, abuse or legal ramifications. A broadly composed Tribunal, which includes legal representation, may also somewhat address concerns about medicalisation (3.38). However, doing so would have resource implications and further prolong the process, imposing a burden on patients and potentially worsening their suffering (3.39). It may nevertheless be appropriate to involve a Tribunal, since doing so may reduce the subjectivity inherent in assessing the "unbearable suffering" of a patient and the risks associated with this (3.40).

8. What are the ethical considerations regarding the proposal of two *different* approval routes for terminal illness/unbearable suffering?

Routes 1 and 2 have different approval routes (3.41), which attract arguments in support and against (3.42). In favour of a two-track approval system is that this reflects the differences between AD in the two cases (3.43). However, some have argued that such differentiation is unjust, unequal, or inequitable, and a two-track system may also create confusion and complexity (3.44).

On balance, we believe that it is reasonable to make a fundamental distinction between AD in an end-of-life context, and AD outside the context of end-of-life. There is no injustice, inequality or inequity in treating these different cases differently. We further suggest that, to minimise possible confusion about which process to follow, training and guidance would be needed if both routes were to be introduced (3.45).

Timeframes

9. What are the key ethical considerations regarding the minimum timeframe proposed for "Route 1 (terminal illness)" – 14 days?

10. What are the key ethical considerations regarding the minimum timeframe proposed for "Route 2 (unbearable suffering)" – 90 days?

11. What are the key ethical considerations around the proposal of two *different* timeframes – i.e., 14 days for "Route 1 (terminal illness)" and 90 days for "Route 2 (unbearable suffering)"?

The two Routes have different proposed (minimum) timeframes between the request for, and the provision of, AD (4.1).

There are general arguments for and against stipulating *some* timeframe, irrespective of its proposed duration (4.2). In favour of stipulating a timeframe is that this not only provides clarity and certainty,

but also allows time for reflection and assessment, thereby providing a safeguard against premature death (4.3). Against stipulating a timeframe is that this may prolong a patient's suffering, a decision for AD is likely already to be settled, and any timeframe is bound to be arbitrary and thus hard to justify (4.4). We believe it is appropriate to specify a timeframe(s), as precision is preferable to imprecision, and doing so provides clarity, certainty, and safeguards (4.5).

There are also arguments for and against the specific proposed timeframes, i.e., 14 days for Route 1 (terminal illness) and 90 days for Route 2 (unbearable suffering) (4.6). In favour of these proposals is the fact that these timeframes align with regimes elsewhere, allow sufficient time for assessments, and rightly differ in duration, in recognition of the distinct characteristics of each Route (4.7). However, other jurisdictions do not adopt these or potentially any timeframe, neither proposal commanded support in the public consultation, and the 90-day timeframe for Route 2 may be insufficient to ensure the patient has access to sources of support that might alter their decision (4.8).

We believe that imposing specific, and distinct, minimum timeframes is appropriate, for the reasons given in favour (4.9), and that there is a case for treating the two Routes differently, such that it should be plausible to defend any charge of injustice, inequality or inequity (4.10). We emphasise that these should be considered *minimum* timeframes, in view of the gravity of the decision and the need for caution regarding any form of AD.

Turning to the specific proposed timeframes, these align with other regimes and appear to strike an appropriate balance between providing safeguards and not prolonging a patient's suffering (4.11). However, given our serious reservations about Route 2, we find it harder to conclude on what would be a sufficient and appropriate timeframe for Route 2 (4.11). Whichever route(s) is ultimately allowed, professional guidance will be needed to ensure that AD is a last resort (4.12) and, if both routes are to be allowed, to minimise possible confusion about which process to follow (4.13).

Conscientious objection and discussions with patients

12. What are the key ethical arguments regarding the right to conscientious objection, as set out in the consultation proposals? Specifically, to consider right to conscientious objection by: (a) premises owners [included in proposals]; (b) those asked to provide supporting assessments [included in proposals]; (c) those with no direct involvement in assessment, approval or delivery (e.g., receptionist booking appointment for an assisted dying assessment) [not included in proposals].

Generally, there are legal, professional and ethical arguments both in favour of, and against, allowing a HCP to conscientiously object to and thus abstain from their involvement in a particular practice (5.1-5.3). In recognition of these general arguments on each side, an ethically appropriate balance may be struck by granting HCPs a limited right to object. This would recognise the interests of both HCPs and patients, and thus allow a HCP to object to involvement in a particular practice, provided that the patient is able to access services elsewhere (5.4-5.5).

HCPs should have the right to conscientiously object to direct participation in AD, not least because AD is a controversial practice, which does not serve the usual aims of medicine to heal/cure (5.6-5.7). HCPs' right to conscientiously object should cover both their direct participation in AD and/or their provision of a supporting statement (5.11).

HCPs who conscientiously object to direct participation in AD or to providing a supporting statement should nevertheless be required not to impede a timely and efficient transfer to another HCP. This

may entail a duty to refer the patient on to a colleague, because this protects the patients' rights and interests, and aligns with the limited right to object recognised by professional organisations in other contexts. However, in line with the World Medical Association, we suggest that the professional duty could be limited to informing the patient about the presence of a CO, providing them with information about a service that can help the patient with referral, and transfer of necessary medical files (5.8-5.10).

In line with a distinction drawn in the courts between direct and non-direct participation, any right to conscientiously object should likely not extend to non-direct participation in AD. This at least means that HCPs (and, potentially, administrative staff) should not be permitted to refuse to participate in care that is unrelated to AD or administrative obligations unrelated to AD (5.12-5.13). On the same basis, drivers who transport drugs or patients for AD should also arguably not be permitted to refuse to participate (5.14).

There are compelling arguments both for and against allowing caring facilities, and those who own or manage these, to conscientiously object to AD on their premises. On balance, we suggest that the arguments in favour of allowing organisations to opt out of allowing AD are more powerful, and we note that the public consultation supports this (5.15-5.19).

13. What are the key ethical considerations regarding the discussion of assisted dying with patients, as per the proposals – i.e., law to be "silent" on the issue of raising the subject of assisted dying with patients?

The authors overall agree that, at least for Route 1, the law should neither require HCPs to initiate AD discussions with potentially eligible patients nor prohibit them from discussing AD. The ethical concerns over HCPs raising AD in a manner that would present risks to patients are important, but in the interests of honest information-sharing we agree with the GMC that this should be a matter of guidance rather than law (5.20-5.25, 5.27). Professional guidance should address concerns about the timing of information-giving and means of avoiding potential pressure. However, in keeping with our concerns about Route 2, we note that this presents additional concerns about conveying that death is a reasonable option for people with disabilities; if Route 2 is to be allowed, then there is a case for adopting a *"gag clause"* in this context (5.26).

Mode

14. Following a high-level review across the consultation proposals, are there any additional key ethical considerations? With particular consideration of: Should a person have the right to choose the mode of assisted death – i.e., self-administration vs. practitioner administration? Or should there be a presumption of self-administration?

The mode of AD may differ according to who performs the final, fatal step. "Self-administration" (sometimes labelled "assisted suicide") involves the patient taking the final step, such as taking the pills that have been provided by a doctor. "Practitioner-administration" (sometimes labelled "voluntary euthanasia") involves someone other than the patient taking the final step, such as a doctor injecting the patient (6.1). Some jurisdictions only allow self-administration, while others allow both modes of AD (6.2).

There are some similarities between self-administration and practitioner-administration (6.3). They may rest on the same justification, i.e., to respect the patient's wish and/or relieve their suffering (6.4). The assistant may have the same motivation and intention whichever mode is used, and in both cases they will play a causal role in the patient's death (6.5). There may be concerns about

doctors' involvement in either mode (6.6). Either mode might also be argued to violate the value of life (6.7), undermine protection of the vulnerable and be considered ableist (6.8), and be susceptible to abuse and errors (6.9). However, despite such similarities, there are also perceived to be differences between the two modes (6.10), and each has pros and cons.

Self-administration thus has pros and cons (6.11). Arguments in favour of self-administration include: that this may more effectively respect patient autonomy (self-rule) by better evidencing the authenticity of the patient's choice to die; that this may be less medicalised and thus require less involvement by doctors, thereby creating less tension with the traditional goals of medicine; and that this may be safe, reliable and effective according to evidence from some jurisdictions (6.12).

Arguments against self-administration include: that this would unjustly deprive those who are incapable of self-administration of being assisted in their dying; evidence from other jurisdictions that self-administering patients may endure uncomfortable deaths; concerns about whether a patient's wish is autonomous and settled; and risks to others. However, the current proposal seeks to minimise these latter two risks, since a doctor would be present and have control over the lethal substance (6.13-6.14).

Self-administration with the assistance of a loved one may help to address some of the concerns about self-administration (6.15). It could ensure that patients with disabilities who are not physically capable of self-administration are not denied the option of AD. Support to self-administer was also supported by a majority of respondents to the consultation, and is less *"medicalised"* than modes of AD directly involving doctors or other HCPs (6.16). However, this may impose burdens, pressure or other risks on loved ones and potentially also patients, and it presumes that patients will have such willing and able loved ones (6.17). On balance, this option may be appropriate, but it would require the provision of legal assurance and support to loved ones, and would still require some practitioner involvement (as, indeed, the proposal currently envisages) (6.18).

Self-administration with practitioner monitoring may help to address the latter concerns (6.19). This retains the focus on patient autonomy and is less *"medicalised"* than practitioner-administration, while ensuring a practitioner is able to ensure the welfare of the patient and potentially others (6.20). However, such practitioner involvement would require more time and participation from a doctor, and it is possible that patients may prefer not to have practitioners so involved (6.21). On balance, despite these concerns, we suggest that self-administration with practitioner monitoring may be the safest option if some form of self-administration is to be allowed in law and we note with approval that this is currently envisaged (6.22).

Alternatively, practitioner-administration may be a preferred model (6.23). Arguments in favour of practitioner-administration include evidence that patients prefer this model, the reassurance that the presence of a doctor could provide (in terms of protecting patients' welfare), and the fact that AD would not be (unjustly) restricted to those who are capable of taking the final step (6.24).

Arguments against practitioner-administration include concerns that this more directly involves doctors in ending patients' lives, may *"normalise"* and potentially expand the practice, and again requires more time and participation from a doctor. This may also make it harder for patients to withdraw or abstain from taking this final step (6.25).

There are reasonable arguments for and against self-administration and practitioner-administration (6.26). Given this, it may be appropriate to provide for both modes in law, with patients offered the choice of mode – and this would be consistent with respect for patient autonomy, which is presumably one of the goals of creating an AD law (6.27). Alternatively, it may be more prudent to

primarily allow self-administration, with practitioner-administration reserved for exceptional cases (e.g., where patients cannot self-administer), given the concerns raised regarding practitioner-administration (6.28). In any case, if self-administration is to be permitted, then practices and experiences elsewhere would need to be examined closely to ensure that the safest and most effective approach is adopted (6.29).

Appeals

15. Following a high-level review across the consultation proposals, are there any additional key ethical considerations? With particular consideration of: Should the person have a right to appeal?

The proposal allows a right of appeal to the Royal Court by eligible parties within a specified timeframe (7.1).

There are arguments for and against an appeals process (7.2).

Arguments in favour of an appeals process include that: this exists in at least one other jurisdiction, which may inform the Jersey system; this might support public confidence; it may prevent or limit under-inclusion, over-inclusion, and *"doctor-shopping"* (although the latter is not a concern under the current proposals); it may allow those with a legitimate interest to raise any concerns they may have; and it places AD within the legal domain, which may address some of the concerns surrounding a more medical(ised) process and help to ensure consistency (7.3).

Arguments against an appeals process include that: this prolongs the process and thus potentially the suffering of patients; this has resource implications for the Court system; and some patients might lose out on appeal (7.4).

On balance, it appears appropriate to include an appeals process, for the reasons given in favour. The additional time required may not be excessive, relative to the safeguards an appeals process brings, although the system would need to have the necessary resources to support to the Court and, arguably, patients who might lose on appeal (7.5). If the burdens on the Court appear to be excessive, then there are alternative models to consider, such as a review body modelled on the Consent and Capacity Board structure in Ontario (Canada) (7.6).

Certifying cause/manner of death

16. Following a high-level review across the consultation proposals, are there any additional key ethical considerations? With particular consideration of: Should the medical certificate record cause of death as per all other deaths in Jersey?

A medical certificate of cause of death (MCCD), known in Jersey as the Medical Certificate of the Fact and Cause of Death (MCFCD), will record cause of death and may also record manner of death (e.g., natural, accident, suicide) (8.1). MCCDs provide a legal record, enable claims to be settled, and provide data that is useful for planning (8.2).

Laws and practices regarding MCCD and AD differ internationally: jurisdictions variably label such deaths "natural" or "non-natural", and they differ in whether the precise manner of death (i.e., AD) is to be explicitly recorded (8.3). Many jurisdictions nevertheless require that AD be reported to a relevant authority, such as a specific commission, health department or coroner (8.4). Despite such requirements, there is evidence of under-reporting of AD (8.5).

There are opposing arguments about whether a MCCD, and the MCFCD specifically, should explicitly record AD (8.6). Various commentators argue that MCCDs should be clear and accurate, and facilitate consistency in reporting. Doing so may provide a safeguard against misunderstanding, misuse or abuse. It may also provide closure and peace of mind to patients' families. Failure to do so may lead to over- or under-estimation of the incidence of AD and undermine the accuracy of related data about AD, which may have an adverse impact on future planning and provision (8.7). The main arguments against explicitly recording AD in the MCFCD focus on the sensitivity and privacy of the information, disclosure of which may be resisted by families and/or damage relationships between patients and doctors (8.8).

The arguments for clear, consistent and accurate reporting appear to be strongest and, alongside explicitly recording AD, we are reassured that current proposals include provision for clear guidance and training for those completing the MCFCD. However, efforts may also be needed to gauge and address the potential concerns of patients and families (8.9).

Chapter 2: Eligibility criteria

Outline of the current proposal

2.1. The current proposal provides for AD to be permitted:

- On one or both of two *healthcare eligibility* bases, respectively "Route 1 (terminal illness)" and "Route 2 (unbearable suffering)"; *and*
- Provided that the person satisfies some *additional* criteria (concerning age, residency, and mental capacity).

We summarise these three sets of criteria below.

2.2. Route 1 (terminal illness):

"Assisted dying should be permitted where a person has been diagnosed with a terminal physical medical condition, that is giving rise to, or which is expected to result in unbearable suffering that cannot be alleviated in a manner the person deems tolerable and which is reasonably expected to cause the person's death within 6 months (or 12 months in the case of terminal neurodegenerative conditions)." The key elements of this basis ("route") are that the person should have:

a) A terminal physical medical condition;

b) Current, or a future expectation of, suffering; and

c) A life expectancy of 6 months, or 12 months for neurodegenerative conditions;

As an alternative to (c), we were also asked to consider whether, instead, the person should have:

- A life expectancy of 12 months, for all conditions (as is the case in Queensland, Australia); or
- No life expectancy timeframe, but current unbearable suffering (as has been proposed in a Scottish consultation).

2.3. Route 2 (unbearable suffering):

"Assisted dying should be permitted where a person has an incurable physical medical condition that is giving rise to unbearable suffering that cannot be alleviated in a manner the person deems tolerable."

The key elements of this basis ("route") are that the person should:

- Have current unbearable suffering;
- Not be required to have a terminal diagnosis; and
- Have a physical condition – a mental illness will not qualify, although the diagnosis of a mental illness would not automatically render a person ineligible.

2.4. Additional criteria:

In addition to satisfying the relevant healthcare eligibility criterion (i.e., route 1 or route 2), the person should also:

- Have a voluntary, clear, settled, and informed wish to end their own life;
- Have capacity to make the decision to end to their own life;
- Be aged 18 or over; and
- Be a Jersey resident, i.e., have been ordinarily resident in Jersey for at least 12 months prior to their first formal request.

2.5. The proposed two-route approach combines characteristics of most of the AD regimes, some of which allow AD only with a diagnosis of terminal illness, others of which are more open-ended, such as those models operating in Belgium, the Netherlands, and Canada. Of the latter, the Canadian law also distinguishes between two different tracks, with different requirements depending on the track, whereas Belgium and the Netherlands have broad requirements applicable to all AD cases, although professional practice may provide additional requirements, e.g., for AD for mental illness alone. Contrary to the open-ended models, Jersey would not allow AD for mental illness alone. Since this report is asked to also evaluate the ethical implications of only allowing AD for terminal illness, or having an approach focused on *"unbearable suffering"*, we first discuss the ethical arguments of each route separately, and subsequently discuss specific ethical implications of a combined regime.

Route 1 (terminal illness)

2.6. The majority of jurisdictions that have legalised AD introduced *"terminal illness"* as an eligibility requirement, and restrict AD to persons who have a terminal physical medical condition, with a life expectancy ranging from 6 to 12 months. Legal regimes with terminal illness as a requirement also tend to explicitly exclude mental illness as the sole basis for AD, which arguably would also be excluded implicitly. Some, but not all (e.g., California), additionally require that the terminal illness causes suffering that cannot be relieved in a manner that the person considers tolerable.[5] Canada's first law allowed AD only for persons whose natural death was *"reasonably foreseeable"*, without requiring a specific terminal illness diagnosis. Although this restriction was interpreted by some very broadly as a result of a court decision,[6] and of guidance by health profession organizations,[7] it arguably also restricted the practice to a broad end-of-life context.[8] We will briefly mention some of the concerns about the terminology adopted in the Canadian law, in order to raise some challenges as compared to requiring a terminal illness diagnosis with a specified life expectancy.

[5] S.9 (d)(4) Victoria (AUS), Voluntary Assisted Dying Act 20217, No. 61 of 2011.
[6] *AB v Canada (AG)* 2017 ONSC 3759.
[7] See T McMorrow. MAID in Canada? Debating the Constitutionality of Canada's New Medical Assistance in Dying Law. *Queen's Law Journal* 2018; 44(1):69-120 at pp.83-85.
[8] T Lemmens, H Kim, E Kurz. Why Canada's Medical Assistance in Dying Law Should be C(h)arter Compliant and What it May Help to Avoid. *McGill Journal of Law & Health* 2017; 11(1): S61-S148.

Terminal illness as a requirement

2.7. There are ethical arguments for and against a terminal illness requirement.

2.8. Ethical arguments in support of a terminal illness requirement:

- Allowing AD as a response to terminal illness *respects the autonomy* (self-determination) of those patients who wish to control the manner and timing of their deaths. Arguments in favour of AD tend, paradigmatically, to cite terminal illness (e.g., end-stage cancer) and neurogenerative diseases (e.g., motor neurone disease, the most common form of which is amyotrophic lateral sclerosis (ALS)) as situations in which patients wish to exercise some control. For example, in narratives involving challenging health conditions such as ALS, emphasis tends to be put on how offering control over dying may assuage fears of a protracted, painful, and/or terrifying dying process.[9]

- Restricting AD to terminal illness provides both an eligibility criterion for access to AD and a *safeguard against premature death*. The restriction emphasises the exceptional nature of AD, which is available only to those who meet a (measurable) eligibility criterion (i.e., terminal illness). Others, who are not dying, would not be eligible, so the restriction offers a safeguard against societal normalisation of facilitating or inducing death.

- Restricting AD to terminal illness *strikes a balance* between serving the interests of those who want some control over the dying process, and recognising the broader concerns of those opposed to AD. Such concerns include that AD: undermines the societal commitment to protecting life; runs counter to suicide prevention; runs counter to the goal of medicine (see 3.8ff); and reflects an *"ableist"* presumption that persons with a illness, disease, or disability, whether it is in the context of end-of-life or not, are better off dead than alive (see 2.23).[10]

- Focusing on terminal illness *aligns with practice worldwide*, as most cases of AD involve terminal illness, e.g., 72% in the Netherlands,[11] including in those countries where AD is permitted for other reasons.

- *Doctors may be more willing to participate in AD* if this is limited to terminal illness. There is evidence that some doctors are (or become) reluctant to engage in AD in countries where the practice has expanded in scope (i.e., beyond terminal illness) and

[9] See, e.g., the description in *Carter v Canada (Attorney General)* [2015] 1 SCR 331.
[10] See, e.g., H Braswell, R Garland-Thomson. When antidiscrimination Discriminates. *The American Journal of Bioethics* 2023; 9: 35-38.
[11] P Lewis. Should assisted dying require the consent of a High Court Judge? In BP White, L Wilmott (eds), *International Perspectives on End-of-Life Law Reform* (Cambridge University Press 2021), pp.113-144.

increased in incidence.[12],[13],[14] Restriction to terminal illness helps to limit the scope of AD (and its potential ramifications) by drawing a clear *"line in the sand"*, which may ease concerns that AD is in tension with the traditional medical commitments to curing, healing and avoiding harm (see 3.8ff). Participating in AD may also place a psychological burden on HCPs (see 3.13), so restriction to terminal illness helps limit the incidence and thereby any psychological impacts.

2.9. Ethical arguments against a terminal illness requirement:

- *Diagnosis and prognosis in terminal illness is not reliable*, e.g., some patients outlive their life expectancy. Whilst a valid concern, this may be a reason for a cautious approach, involving robust assessment, rather than excluding AD on the basis of terminal illness. Studies actually suggest that over-estimation of life-expectancy is more likely.[15] This could support requiring a longer prognosis (>6 months) as an eligibility criterion. However, survival estimates become more reliable the closer the patient is to death, e.g., in advanced cancer, *"a combination of clinical and laboratory variables can reliably predict two week and two month survival"*.[16] This could support requiring a shorter prognosis (<6 months) as an eligibility criterion.

- Limiting AD to terminal illness places an *unacceptable restriction on self-determination*. However, no jurisdiction allows AD solely on the basis of individual choice[17] – additional criteria must also be met, e.g., requiring the presence of suffering and/or a medical condition or disability (although see further 2.23).

- Limiting AD to terminal illness inconsistently and unfairly *excludes others who are suffering* from receiving AD. This argument is built on the premise that relief of suffering is the key rationale for AD, and that not allowing AD outside the end-of-life context is inconsistent with that rationale. A legal formulation of this argument holds that it is discriminatory to allow persons with terminal illness to obtain relief of suffering via AD

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[12] E.g., T Lemmens. Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice. *Supreme Court Law Review* (2nd) 2018; 85: 453-539, at p. 496 (discussing opposition of physicians, including euthanasia-specialists, to euthanasia of persons with dementia).

[13] E Payne. New changes to MAID laws are 'a bridge too far' for some—including doctors. *Ottawa Citizen*, 12 December 2022. https://ottawacitizen.com/news/local-news/new-changes-to-maid-laws-are-a-bridge-too-far-for-some-including-doctors#:~:text=While%20growing%20numbers%20of%20Canadians,is%20mental%20illness%20to%20apply. The article reports, e.g.,, that for the Ottawa-Champlain region, 80 physicians signed up to provide MAID, but only 4 agreed to take on "track 2" (patients without reasonably foreseeable death) and no one agreed to be a provider for a request based on mental illness (which will be permissible as of April 2024).

[14] See also: M Li. I Am a MAID provider. It's the most meaningful – and maddening – work I do. Here's Why. As told to Liza Agrba, *Macleans*, 13 February 2023: https://macleans.ca/society/i-am-a-maid-provider-its-the-most-meaningful-and-maddening-work-i-do-heres-why/.

[15] P Glare, et al. A systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ* 2003; 327: 195.

[16] B Gwilliam, et al. Development of Prognosis in Palliative care Study (PiPS) predictor models to improve prognostication in advanced cancer: Prospective cohort study. *BMJ* 2011; 343 :d4920.

[17] A 2020 German constitutional decision probably comes the closest to rejecting any form of state interference with an individual choice to die except for ensuring "free will". It also rejects legal restrictions on assisted suicide based on illness and suffering. Yet, the case has not yet resulted in the legal regulation of AD. Medical associations in Germany appear largely to remain opposed to any HCP involvement. For a discussion of the case, see: U Wiesing. The Judgment of the German Federal Constitutional Court regarding assisted suicide: a template for pluralistic states? *Journal Medical Ethics* 2022; 48(8): 542-546.

while prohibiting this for persons with illnesses or disabilities that are not terminal. This was the basis of the ruling (of a lower court) in Quebec, in the *Truchon* case, which held that the restriction to the broad end-of-life context in Quebec (as well as Canadian law more broadly) was unconstitutional.[18] It is worth noting that this decision was not appealed, and that the discrimination argument as a basis for legalizing AD has never been accepted by higher courts in Canada. This discrimination argument prioritises access to AD as relief of suffering as a *"good"*, seemingly prioritising it over the prevention of premature death. It has been pointed out that the right to equality and non-discrimination is not only about equal access to services, but also about equal protection. Thus, it has been argued in the Canadian context, including by 2 UN Special Rapporteurs and 1 UN Special Human Rights Expert,[19] that the Canadian law which allows AD outside the end-of-life context for persons with an irremediable disease, illness, or disability, but not for others who may want to end their lives, is discriminatory towards persons with disabilities.[20,21] It deprives them of equal protection against premature death, since laws aimed at preventing suicide and suicide prevention policies will not apply to them, whereas they continue to apply to non-disabled persons (see further 2.23).

Current or future expectation of suffering as a requirement

2.10. Route 1 (terminal illness) additionally requires *"current or future expectation of suffering"*. Here we focus on this additional requirement specifically in the context of Route 1, i.e., terminal illness; we consider suffering in the context of the more open-ended Route 2 separately (see 2.20ff). Some of the latter arguments would also apply to suffering in the context of terminal illness. However, for Route 1, we note that the suffering requirement is directly connected to the terminal illness which is the basis for the AD request, i.e., it is the terminal medical condition which results in, or is expected to give rise to, the suffering, which cannot be alleviated in a way that the person finds tolerable. The presence of intolerable suffering in Route 1 thus functions as an *additional eligibility requirement*, which further restricts access to AD to situations where suffering is present. Persons who are approaching their death but who are not or would not be suffering would arguably not qualify in the absence of intolerable suffering.

2.11. There are arguments for and against a current or future expectation of suffering criterion.

2.12. Arguments in favour of a current or future expectation of suffering criterion:

- Allowing AD as a response to terminal illness which entails (or is anticipated to entail) intolerable suffering serves the patient's interest in *avoiding suffering*. Some patients with terminal illnesses might be expected to experience suffering, e.g., arising from

[18] *Truchon v Canada (AG)*, 2019 QCCS 3792.
[19] Mandates of the Special Rapporteur on the rights of persons with disabilities; the Independent Expert on the enjoyment of human rights by older persons; and the Special Rapporteur on extreme poverty and human rights (3 February 2021), UN Doc OL CAN 2/2021 at 4: spcommreports.ohchr.org/TMResultsBase/DownLoadPublicCommunicationFile?gId=26002.
[20] I Grant. Legislated ableism: Bill C-7 and the rapid expansion of MAiD in Canada. *McGill Journal of Law & Health* 2023, forthcoming; available at: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4544454.
[21] T Lemmens, L Jacobs. The latest medical assistance in dying decision needs to be appealed: Here's why. *The Conversation* (9 October 2019). [Accessed 9 March 2023].

significant pain or significant breathing difficulties. For example, Diane Pretty had motor neurone disease and in 2001-2002 she (unsuccessfully) sought permission from the courts in England and the European Court of Human Rights for a right to be assisted in her suicide by her husband.[22] In the House of Lords, Lord Bingham noted that Mrs Pretty had an incurable *"progressive degenerative illness"*, *"has only a short time to live and faces the prospect of a humiliating and distressing death"*, so she sought *"to be able to take steps to bring her life to a peaceful end at a time of her choosing"*.[23] Allowing for AD on the basis of expected future suffering would enable patients to avoid such suffering.

- If doctors are to be involved, then allowing AD as a response to terminal illness which entails (or is anticipated to entail) intolerable suffering speaks to the professional ethical commitment to relieve patient suffering (beneficence), thereby providing a *justification for involving doctors* (and/or other HCPs) in AD. In the absence of suffering, the key justification for allowing doctors (and/or other HCPs) to be involved with ending another person's life would be missing, and concerns about the expansion of AD when it is based entirely on choice would become more prominent.

2.13. Arguments against a current or future expectation of suffering criterion:

- Suffering (whether current or future) is *too vague, too multifaceted, and too subjective* to be a useful or reliable eligibility criterion. A holistic understanding of suffering emphasises interwoven existential and physical components, and reflects a more subjective view of suffering. Objective understandings of suffering suggest that there are measurable components to suffering.[24] A more objective understanding would arguably make it more defensible to include suffering as an eligibility criterion, although it would be important to specify the measures of suffering that would be employed. However, linking the suffering to terminal illness may enhance objectivity, and avoid some of the expansions of the law seen elsewhere. In Canada, prior to the expansion of the law beyond the broad end-of-life context, AD was restricted to persons with a *"reasonable foreseeable natural death"*, whose disease, illness, or disability causes intolerable suffering that cannot be alleviated in a manner the patient finds acceptable. The concept of intolerable suffering was approached very broadly (see further discussion at 2.20ff) and subjectively even before the law was expanded beyond the end-of-life context. Arguably in part because of the absence of a specific terminal illness requirement, the concept of suffering included a variety of physical, psychological, existential, and economic sources of suffering. An explicit link to terminal illness may avoid this. But it would arguably be important to emphasise that the suffering must be *directly connected* to the disease, to avoid a broadening of the practice to situations where existential suffering, economic concerns, social factors are the main reasons why people perceive their suffering as intolerable.

- Requiring (current or future) suffering plus terminal illness is *unnecessary*. In jurisdictions where terminal illness is an additional eligibility criterion, the presence (or absence) of terminal illness largely determines whether AD is permitted. In jurisdictions

[22] *Pretty v United Kingdom* 2346/02 [2002] ECHR 427.
[23] *R (Pretty) v Director of Public Prosecutions (Secretary of State for the Home Department intervening)* [2001] UKHL 61.
[24] B Pesut, et al. What's suffering got to do with it? A qualitative study of suffering in the context of Medical Assistance in Dying (MAID). *BMC Palliat Care* 2021; 20: 174.

without such a terminal illness restriction, the intolerable nature of suffering has not played a significant role in determining whether AD is permitted (see further 2.20ff).

- Future suffering relies on *potentially unreliable predictions*, which may be influenced by others. Future suffering requires the person to make predictions about the tolerability of anticipated suffering before they can fully appreciate how the terminal illness will develop. Furthermore, allowing HCPs to raise AD as an option has the potential to influence current experiences or future expectations of the tolerability of *"suffering"* and may influence whether patients trust that other options can offer relief (see further 2.20ff). However, the terminal illness requirement may ameliorate this concern.

Life expectancy timeframe requirements

2.14. For Route 1 (terminal illness), the current proposal is to introduce a mixed life-expectancy prognosis of 6 months (for all diseases other than neurodegenerative conditions) or 12 months (for neurodegenerative conditions). We have also been asked to consider whether no specific timeframe should be stipulated.

2.15. There are arguments for and against stipulating a specific life-expectancy prognosis.

2.16. Arguments in favour of a specific life-expectancy prognosis:

- There is *legal precedent* for adopting the proposed timeframes. For example, in Victoria (Australia), only those with weeks or months to live are permitted to access AD. In the case of neurodegenerative disease (e.g., motor neurone disease, ALS), natural death should be expected to occur within 12 months, whereas for all other diagnosed terminal conditions the maximum anticipated death must be within six months.

- Providing clear timeframes offers a *more objective measure* for determining who would (not) have access to AD. Doing so reserves AD for the *"already dying"*,[25] as is the case in Victoria (Australia), which has been argued to present a principled balance between prohibition (that leaves people suffering or opting for suicide) and permissive legalisation that might fail to offer sufficient safeguards for persons in heightened situations of vulnerability (see also 2.8).[26]

- Providing clear timeframes helps to *delineate permissible practice and prevent the expansion of AD*. Some regulatory regimes without a terminal illness diagnosis appear to have difficulties delineating the practice. The developments in Canada's medical assistance in dying (MAID) regime provide an example. Before Canada's expansion of the law outside the end-of-life context, Canada restricted the practice to persons with a *"reasonable foreseeable natural death"*. This criterion was introduced without a specified life-expectancy prognosis. It still exists as a criterion to determine who has access to AD under a more easily accessible so-called *"track 1"* system, which has fewer safeguards (e.g., there is no 90-day assessment period as is required under *"track 2"*). The original criterion (*"reasonable foreseeable natural death"*) was criticised by some for being too restrictive. However, soon after its introduction, the criterion began to be

[25] C Hempton, C Mills. Constitution of the "Already Dying": The emergence of voluntary assisted dying in Victoria. *Bioethical Inquiry* 2021; 18: 265-276.
[26] Hempton and Mills (note 25).

interpreted very broadly, including in a decision of a lower court,[27] and by professional organisations.[28] As a result, some patients who had no clear terminal illness diagnosis and a life expectancy exceeding two or more years had their lives terminated through AD.[29] Canada's AD regime also rapidly expanded in terms of numbers, with the absence of a life-expectancy prognosis arguably contributing to this rapid expansion. Even before a new law introduced a second track outside the end-of-life context, in 2020, Canada had 7,595 officially declared deaths by MAID, which constituted 2.5% of the overall deaths in the country.[30] In 2021, the number of deaths was 10,064, or 3.3% of overall deaths, with only 219 of these cases covering situations in which natural death was not reasonably foreseeable.[31] In 2021, two provinces, Quebec (4.6%) and British Columbia (4.8%), had a higher percentage of officially declared MAID deaths compared to overall deaths in Belgium (2.4%),[32] and at more or less the same level as in the Netherlands (4.5%)[33], two countries that had legalised euthanasia in 2002, including outside the end-of-life context. The province of Quebec in Canada has, in addition to the federal MAID law, its own MAID legislation. Its original access criterion was *"end-of-life"*, which is arguably more constrained than *"reasonably foreseeable natural death"*[34] and more akin to *"terminal illness"*, albeit without requiring a specific life-expectancy prognosis. Quebec always had one of the highest rates of MAID deaths in Canada and now appears to be the jurisdiction with the highest rate in the world. It is estimated that, in 2023, more than 7% of persons who die will die by AD, the highest percentage in the world.[35] In the majority of cases, AD will likely have been provided under the *"end-of-life"* criterion. This vividly illustrates how the absence of a more specific and objective life-expectancy prognosis can lead to rapid expansion of the practice, even when AD is restricted to a vaguer end-of-life context.

- Providing clear timeframes *encourages regulatory compliance*. Even if prognoses can be difficult to determine, predictions can be made, based on statistical data available for most diseases.

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[27] *AB v Canada (AG)* 2017 ONSC 3759.

[28] See the discussion in: T McMorrow. MAID in Canada? Debating the Constitutionality of Canada's New Medical Assistance in Dying Law. 2018 44(1) Queen's Law Journal 2018; 44(1):69-120 at pp.83-85.

[29] R Coelho, et al. The realities of Medical Assistance in Dying in Canada. *Palliative and Supportive Care* 2023. Available at: https://doi.org/10.1017/S1478951523001025.

[30] Health Canada. Second Annual report on Medical Assistance in Dying in Canada (Health Canada: Ottawa, 2021). Available at: https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2020.html.

[31] Health Canada. Third Annual report on Medical Assistance in Dying in Canada (Health Canada: Ottawa, 2022). Available at: https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/annual-report-2021/annual-report-2021.pdf.

[32] Belgium: Federale Controle en Evaluatie Commissie Euthanasia, Persbericht: Euthansie—Cijfers van 2021 (31 March 2022) online: https://overlegorganen.gezondheid.belgie.be/sites/default/files/documents/fcee-cijfers-2021_persbericht-totaal_1.pdf.

[33] https://www.dutchnews.nl/2022/03/euthanasia-deaths-rise-again-in-2021-most-patients-had-terminal-cancer/.

[34] T McMorrow, et al. Interpreting eligibility under the Medical Assistance in Dying Law: The experience of physicians and nurse practitioners. *McGill J Law & Health* 2020; 14(1): 51–108.

[35] D Gentile, D Boily. Plus de 7 % de décès découlent de l'aide médicale à mourir au Québec. Radio Canada 23 February 2023. Available at: https://ici.radio-canada.ca/nouvelle/1956764/aide-medicale-mourir-quebec-commission-soins-fin-vie-consultation-medecins#.

2.17. Arguments against a specific life-expectancy prognosis

- *Life-expectancy predictions are not reliable*. They are based on statistical predictions, thus provide an average measurement, but it is impossible to predict whether or to what extent an individual prognosis will deviate from that anticipated average. This is often invoked to argue against any specific term, i.e., either 6 or 12 months. Yet, prognoses are used in medicine to determine other interventions, and the lack of precision does not mean that they are entirely unreliable. The argument of lack of precision can also be invoked as a reason to have an even narrower timeframe, since prognosis is easier when death is expected in a shorter timeframe.[36] However, as discussed above (2.9), medical over-estimation of survival is more likely to occur, and so reducing the timeframes might mean that people who would be eligible (e.g., because they would in fact die naturally within 6 months) would be prevented from accessing AD because their prognosis indicates they would have longer than six months to live.

- Limiting AD to people with a specific life-expectancy places an *unacceptable restriction on self-determination* (see also 2.9). Yet, in our view, once one accepts that terminal illness is a reasonable requirement to provide a clear delineation of the practice, it seems hard to argue against any specific prognosis.

2.18. Assuming that AD will be legalised in some form, on balance we believe that the proposals regarding Route 1 (terminal illness) are ethically appropriate, for the various reasons given in favour above. There may be cause to complain that restricting AD to terminal illness is unjustly discriminatory, but doing so may strike an appropriate balance between empowering and protecting people. We also recognise that diagnoses and prognoses may not be entirely precise, but are reassured that these become more accurate the closer the person is to death.

2.19. We further believe that stipulating specific timeframes is defensible. Stipulating particular timeframes can act as a safeguard, as the requirement that death must be expected within 6 or 12 months is more objective and measurable, making the law more clearly defined and easier to apply. Stipulating such timeframes may also help to prevent any expansion of the law that could arise from the absence of a specified timeframe, which would introduce more subjectivity. We nevertheless recognise that predictions of life-expectancy may be imprecise – although they reportedly become more accurate the closer the person is to death. This may be a reason for having shorter timeframes. However, on balance, we believe that the proposed timeframes are defensible. Whilst reducing the timeframe might further enhance objectivity and measurability, the 6-month requirement appears to strike an appropriate balance and also has the advantage of mirroring the law in (e.g.) Oregon and New Zealand. Given these points, we would not propose extending the timeframe, e.g., so that all terminally ill patients are eligible if their death is expected in 12 months. However, we believe, on balance, that it is appropriate to extend the timeframe to 12 months for those people who have a terminal neurodegenerative disease. This mirrors provision in Australia and the extended timeframe appears to be defensible because this enables the law to apply to people who *"due to the nature of the disease, [are] likely to see a significant deterioration in quality of life and associated potential for unbearable suffering significantly before they reach the point of having*

[36] Gwilliam et al (note 16).

six month's life expectancy".[37] As such, extending the timeframe for these individuals means that they would not unjustly or inequitably be denied the option of AD.

Route 2 (unbearable suffering)

2.20. Route 2 (unbearable suffering) would make AD available for persons with an "*incurable medical condition*", which causes "*unbearable suffering that cannot be alleviated in a manner the person deems tolerable."* This would make AD available for a broad range of physical disabilities and chronic illnesses. In contrast with Route 1 (terminal illness), life-expectancy appears irrelevant for this route; rather, *"suffering"* and *"incurable physical condition"* are the key eligibility criteria for Route 2. Some of the discussion of suffering here overlaps with the earlier discussion of suffering as a component of Route 1 (see 2.10ff). However, we discuss here the more general arguments in favour of and against suffering as arguably the key justification for AD, and thereafter we address the *"incurable physical condition"* criterion. The qualification of this route as the *"unbearable suffering"* route, and the absence of a specific life-expectancy, makes it clear that AD under this route is not seen primarily as a method to ease the dying process and to offer some control over the end-of-life stage. Rather, Route 2 provides the option of ending the lives of people with chronic illness and disability who are otherwise not dying, arguably to relieve intolerable suffering. In short, adopting the language used by Dutch ethicist Boer, Route 1 allows *"euthanasia to prevent a terrible death"*, while Route 2 allows *"euthanasia to prevent a terrible life"*.[38]

2.21. There are arguments for and against creating an unbearable suffering route for incurable physical conditions.

2.22. Arguments in favour of an unbearable suffering route for incurable physical conditions:

- Allowing AD as a response to unbearable suffering serves the patient's interest in *avoiding suffering* (see also 2.12). Significant suffering may arise not only in terminal illness, but also from an incurable physical condition.
- It may be *discriminatory* to deny AD to suffering individuals merely because they do not have a terminal illness.
- Allowing AD as a response to unbearable suffering *respects the autonomy* (self-determination) of those patients who wish to decide for themselves whether their life is no longer of the quality that merits continued living or whether their suffering is so serious that it is no longer tolerable (see also 2.8). It may be argued that people should be allowed to end their lives if and when they so desire, including with the assistance of (willing) HCPs.[39]

[37] Assisted Dying in Jersey Consultation Report (October 2022), para 19.
[38] Quoted in: A Albaladejo, Fear of assisted dying: Could it lead to euthanasia on demand or worsen access to palliative care? *BMJ* 2019; 364: l852.
[39] There is some uncertainty over whether assisting a suicide is currently unlawful in Jersey. In England and Wales, suicide has been decriminalised, but encouraging or assisting a suicide (or its attempt) remains a crime. In Jersey, although there are homicide offences which *might* apply, there is no legislation that governs suicide or which prohibits encouraging or assisting the suicide, or attempted suicide, of another person. See further: https://statesassembly.gov.je/AssemblyPropositions/2021/P.95-2021.pdf.

- Allowing AD as a response to unbearable suffering offers *a humane means of dying* to people who might otherwise be inclined to end their lives via suicide, potentially in violent circumstances, and potentially with attendant trauma for family members and others. However, there is no evidence that suicide rates reduce when AD is available. Moreover, family members may also be traumatised when someone close to them, who potentially has years to live, opts to receive AD, and there are also anecdotal reports of troubling circumstances in which people died by AD.

2.23. Arguments against an unbearable suffering route for incurable physical conditions:

- Allowing AD as a response to unbearable suffering goes *beyond the original remit of AD*. AD was originally envisaged as a means to facilitate an already approaching death and to provide some level of control over the timing and manner of one's death. Extending AD beyond this context is also linguistically awkward, since it is arguably *inaccurate and potentially misleading* to refer to "assisted dying" when, absent the fatal intervention, the person in question is not actually dying.

- Allowing AD as a response to unbearable suffering *makes (and reinforces) an "ableist" judgment about the negative value of the lives of people with disabilities*. According to a broad definition of disability, all persons applying for AD on the basis of an incurable physical condition can be defined as disabled.[40] Allowing AD on such a basis creates a societally endorsed and – if HCPs are involved – medicalised ending-of-life for disabled persons who are otherwise not dying, thereby signalling that a life with disability is less worth living, and/or more intolerable, than a life without a disability.[41,42] This signal runs counter to the emphasis on universal design, ensuring universal access to goods and services, and efforts to create norms and standards that do not disadvantage disabled persons. Furthermore, such negative signals may be amplified by HCPs and potentially influence the decisions of people with disabilities. Lower perceptions of the quality of life of persons with disabilities are already commonly documented among HCPs.[43,44,45] When AD is offered in the context of the fiduciary doctor-patient relation, with its inherent power imbalance and relationship of trust, there is a concern that the

[40] Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) provides: *"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"*: https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities. See also, e.g., https://www.ohrc.on.ca/en/policy-ableism-and-discrimination-based-disability/2-what-disability#_edn17.

[41] J Beaudry. Somatic Oppression and Relational Autonomy: Revisiting Medical Aid in Dying through a Feminist Lens. *University British Columbia Law Review* 2020; 52: 241-298.

[42] G Quinn, C Mahler, O De Schutter. Letter to the Government of Canada (3 February 2021), Reference OL CAN 2/2021. Available at: https://spcommreports.ohchr.org/TMResultsBase/DownLoadPublicCommunicationFile?gId=26002.

[43] H Janz. MAID to die by medical and systemic ableism. In J Kotalik, DW Shannon (eds), *Medical Assistance in Dying (MAID) in Canada: Key multidisciplinary perspectives* (Cham: Springer, 2023), pp. 299-308.

[44] K Fitzpatrick, DA Jones. A life worth living? Disabled people and euthanasia in Belgium. In DA Jones et al (eds), *Euthanasia and Assisted Suicide: Lessons from Belgium* (Cambridge: Cambridge University Press), pp. 133-149.

[45] The Expert Panel Working Group on Advance Requests for MAID, Council of Canadian Academies, *The State of Knowledge on Advance Requests for Medical Assistance in Dying*. (Ottawa, ON: Council of Canadian Academies, 2018). Available at: https://cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf.

perception of health care providers would influence the self-perception of disabled persons about the desirability of death compared to continue living with a disability. Moreover, allowing AD on the basis of disability may be discriminatory, since people with disabilities would be deprived of the protection against death that others enjoy, i.e., prohibitions on ending life and suicide prevention measures would no longer apply to people with disabilities.[46,47,48] A further discrimination claim may be advanced if more women than men were to come to request AD (as is the case for euthanasia for mental illness in Belgium and the Netherlands).[49]

- Suffering is *too vague, too multifaceted, and too subjective* to be a useful or reliable eligibility criterion (see also 2.13). Some jurisdictions require the doctor to agree that there is intolerable suffering that cannot be relieved, thereby imposing a *"reasonableness"* or acceptability standard,[50] which may be submitted to at least some form of evaluation; e.g., in the Netherlands, the doctor must *"emphatically understand"* or *"appreciate"* that the suffering is intolerable.[51,52] Yet, in the Netherlands and Belgium, the reasons for demanding and providing AD have become much more centred around autonomy, and thus reliant on the subjective judgment of the patient.[53,54,55] Notably, practice in these jurisdictions has increasingly allowed AD on bases other than terminal illness, which may signal a greater regard for respecting individual judgments about intolerable suffering, even when other medical interventions may offer relief. In Canada, the subjective nature of suffering has been emphasised more strongly, with wording that resembles the wording in the Jersey proposal for Route 2, i.e., suffering *"that cannot be alleviated in a manner the person deems tolerable"*. Annual reports from Health Canada show that AD has been provided there not only on the basis of physical suffering (pain), but also as a response to social factors (e.g., loneliness), psychological factors (e.g., the feeling of being a burden on others), and existential factors (see Appendix 1). Not only are many of these factors not traditionally addressed by medical

[46] K Joffe, R Lattanzio. Canada's Medical Assistance in Dying Law and the Rights to Life and Equality at International Law. In J Kotalik, DW Shannon (eds), *Medical Assistance in Dying (MAID) in Canada: Key multidisciplinary perspectives* (Cham: Springer, 2023), pp. 355-369.
[47] Grant (note 20).
[48] Lemmens and Jacobs (note 21).
[49] M Nicolini, C Gastmans, S Kim. Psychiatric euthanasia, suicide and the role of gender. *British Journal of Psychiatry* 2022; 220(1): 10-13. One explanation for this is that women have, on average, a lower *"suicide capability"*. Findings show that more women than men attempt suicide, but more men than women die by suicide. The suicide capability of men results from the choice of methods more likely to prove lethal. Offering broad access to AD may augment the number of women who die by suicide, thus diminishing their protection against premature death resulting from this suicide capability issue.
[50] J Griffiths, H Weyers, M Adams. *Euthanasia and Law in Europe* (Oxford: Hart, 2008), at pp. 91-92.
[51] The Dutch expression is that the suffering has to be "invoelbaar": see Griffiths et al (note 50), at p.90.
[52] See also: T Lemmens. Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice. 85 *Supreme Court Law Review* (2nd). 2018; 85: 453-539, at p. 532.
[53] G den Hartogh. WTL: Een potemkindorp? (WTL: A Potemkin Village?) in Laura De Vito, ed., 15 jaar Euthanasiewet (Amsterdam: NVVE, 2017) 138, at 152-54.
[54] W Lemmens. Euthanasie et autodétermination. Qui souffre veut être accompagnpé. In T Devos, *Euthanasie, l'envers du décor: Réflexions et expériences de soignants* (Éditions Mols, 2019), pp. 73-87, in particular at pp. 78-84.
[55] B Beuselingck. 2002-2016: Fourteen Years of Euthanasia in Belgium: First-line observations by an Oncologist. In DA Jones et al (eds), *Euthanasia and Assisted Suicide: Lessons from Belgium* (Cambridge: Cambridge University Press), pp. 101-113, at pp. 101-104.

practice, but some could likely be relieved by medical treatment or other, social or psychological, interventions. Accepting suffering as an access criterion, combined with the notion that it is up to patients requesting AD to determine whether it can be addressed in a manner tolerable to them, appears to open up AD on the basis of individual choice for all persons with a disease, illness, or disability, who say that they suffer intolerably.

- The perceived *intolerability of suffering can change over time and be influenced by social and psychological factors* (e.g., failures in social and disability support, wait times for care, intersecting mental health issues) that may not easily be detected by HCPs. The disability paradox refers to the gap between the negative perceptions of life with disability held by non-disabled people and the more positive perceptions held by people with disabilities themselves; prior to becoming disabled, people tend to imagine a life with disability or chronic illness as intolerable.[56],[57],[58] For example, evidence reveals that persons diagnosed with a new serious illness or injury tend to struggle significantly for some time, even experience suicidality, but this does not persist over time.[59,60] In a recent study which followed patients with spinal cord injury, more than half of the patients reported suicidal ideation during the first two years.[61] None of them thought they would have been able to make a truly informed decision in the early years following their injury, and none still wanted AD after their adjustment. This arguably reveals the danger of offering death as an option based on a suffering criterion, particularly without combination with a diagnosis of terminal illness, as perceptions of suffering can change.

- Allowing AD as a response to unbearable suffering *may lead to the expansion of AD* in terms of numbers and scope. The experience of AD regimes in Belgium, the Netherlands, and even of Canada's first law, which focused on the (already broad) concept of *"reasonable foreseeable natural death"*, reveal that regimes which offer AD outside the strict terminal illness context are confronted with much more significant expansion in terms of numbers than regimes with a terminal illness restriction.[62] Belgium and the Netherlands have also experienced a significant expansion in scope, beyond people with terminal illness, which raises concerns about normalising AD as a

[56] See The Expert Panel Working Group on Advance Requests for MAID (note 45).
[57] See also Fitzpatrick and Jones (note 44), at p.142, citing a 2001 study by Basnett which reports on a study in which 90% of quadraplegics indicated they were happy to live, while only 25% of Accident and Emergency doctors could envisage themselves living with quadriplegia.
[58] See also the examples provided by O Hartling, *Euthanasia and the ethics of a doctor's decisions: An argument against assisted dying* (London: Bloomsbury Academic, 2021), at pp.65-69.
[59] V Nafilyan et al. Risk of suicide after diagnosis of severe physical health conditions: A retrospective cohort study of 47 million people. *The Lancet Regional Health - Europe* 2023; 25: 100562.
[60] I Marini, L Villareal. The Psychosocial Aspects of Adapting to Traumatic Non-life-threatening Disability. In J Kotalik, DW Shannon (eds), *Medical Assistance in Dying (MAID) in Canada: Key multidisciplinary perspectives* (Cham: Springer, 2023), pp. 339-354.
[61] N Tchajkova et al. Inside the lived perspective of life after spinal cord injury: A qualitative study of the desire to live and not live, including with assisted dying. *Spinal Cord* 2021; 59: 485–492.
[62] D Pullman. Slowing the Slide Down the Slippery Slope of Medical Assistance in Dying: Mutual Learnings for Canada and the US. *The American Journal of Bioethics* 2023. DOI: 10.1080/15265161.2023.2201190. However, a confounding factor is that most of the regimes with terminal illness as an eligibility criterion also restrict AD to prescription of lethal medication or at least only allow physician-provided AD if the person is incapable of taking the medication themselves. In other words, both the mode of AD and the eligibility may explain lower uptake in those regimes.

response to suffering that may have intersecting physical, socio-economic and psychological components, which could be addressed differently. For example, in Belgium *"polypathology",* the presence of a variety of ailments, generally among older people, is increasingly the basis for providing euthanasia, with some arguing that it may reflect a medicalisation of ageing.[63,64,65] Some jurisdictions have expanded AD to encompass those with a psychiatric illness but, notably, jurisdictions that restrict AD to terminally illness have not expanded their eligibility criteria in such ways. Amidst (general) arguments for compassionate approaches to people with psychiatric illness,[66,67] some have also argued for allowing such people access to AD.[68] Although others have argued against doing so,[69],[70] some jurisdictions have indeed moved to accommodate AD on the basis of unbearable suffering due to a psychiatric illness (e.g., Canada, Netherlands). If such expansions were to be allowed, then the European Court of Human Rights has also signalled the importance of ensuring that safeguards are in place and are observed, otherwise the State may be found in violation of article 2, which protects the right to life.[71] In summary, allowing AD as a response to unbearable suffering may lead to the expansion of AD – but, notably, jurisdictions that restrict AD to terminally illness have not expanded their eligibility criteria in such ways.

- People with a serious condition would *still become eligible for AD* under Route 1, when their disease progresses. They would thus not be prevented from accessing AD when their natural death is approaching.

2.24. Although there are arguments for and against allowing AD for unbearable suffering arising from an incurable physical medical condition, we have serious reservations about allowing AD in such circumstances and on balance we believe that the proposals regarding Route 2 are not ethically appropriate. Aside from linguistic quibbles about the accuracy of describing assistance in such cases as instances of assisted *dying*, Route 2 raises significant concerns

[63] Kasper Raus, et al. Opinie: Komt nagenoeg iedereen van boven de 70 nu in aanmerking voor euthanasie? [Opinion: Is nearly anyone above the age of 70 now a candidate for euthanasia?] [our translation] *Knack*. 14 November 2016: https://www.knack.be/nieuws/belgie/komt-nagenoeg-iedereen-van-boven-de-70-jaar-nu-in-aanmerking-voor-euthanasie/article-opinion-776597.html.

[64] K Raus, B Vanderhaegen, S Sterckx. Euthanasia in Belgium: Shortcomings of the Law and Its Application and of the Monitoring of Practice. *The Journal of Medicine and Philosophy* 2021; 46(1) 80-107.

[65] Lemmens (note 52), at 497-498.

[66] AG Martinez, et al. The power of a label: Mental illness diagnosis, ascribed humanity and social rejection. *Journal of Social and Clinical Psychology* 2011; 30(1): 1-104.

[67] J Read, et al. Prejudice and schizophrenia: A review of the "mental illness is an illness like any other" approach. *Acta Psychiatrica Scandinavica* 2006; 114(5): 303-318.

[68] E.g., The Halifax Group. MAiD Legislation at a Crossroads: Persons with Mental Disorders as their Sole Underlying Medical Condition. *IRPP Report.* 2020: https://irpp.org/research-studies/maid-legislation-at-a-crossroads-persons-with-mental-disorders-as-their-sole-underlying-medical-condition/.

[69] See e.g. Expert Advisory Group on Medical Assistance in Dying. Canada at a crossroads: Recommendations on medical assistance in dying and persons with a mental disorder: An evidence-based critique of the Halifax Group. *IRPP Report* 2020. doi:10.13140/RG.2.2.36236.87687.

[70] S Gaind, et al. Canada's Medically Administered Death (MAD) expansion for mental illness: Targeting the most vulnerable. *World Medical Journal* 2022; 71(4): 72-82.

[71] See *Mortier v Belgium* (2022) (78017/17). The deceased died without the knowledge of her next-of-kin when an oncologist, who had not previously been responsible for the care of the deceased and was not qualified to assess her mental illness, agreed to provide AD. The European Court held that Article 2 of the Convention had been violated by the State's failure to protect the victim.

because it: makes (and reinforces) an *"ableist"* judgment about the negative value of the lives of people with disabilities; relies on perceptions of the tolerability of suffering, which may change over time and be influenced by social and psychological factors; rests on a concept – *"suffering"* – which is too vague, multifaceted and subjective to be a reliable eligibility criterion; and, given its inherent subjectivity, may lead to the expansion of AD in terms of numbers and scope.

2.25. We anticipate that our conclusion on Route 2 will be resisted particularly by those who believe it is too restrictive of autonomy, underplays the suffering that can accompany an incurable physical medical condition, and that it unjustly denies people who are not terminally ill the option of AD. One response to these counter-arguments is that people may still become eligible for AD if only Route 1 is enacted, so they are not entirely denied the option; however, we appreciate that this may offer small comfort to people who might endure suffering for years before this point is reached.

2.26. As we would advise against allowing Route 2, we will not consider in detail whether AD should be allowed on the basis of *both* Routes 1 and 2. However, if Ministers were inclined to allow both routes, it may be necessary to further clarify, and provide guidance on, situations where a person may be potentially eligible under both routes (see also 3.44, 4.13).

Incurability, intolerability, and other treatment options

2.27. Both Route 1 and Route 2 refer to *"suffering that cannot be alleviated in a manner the person deems tolerable*" and rely on the *incurability* of the underlying medical condition, explicitly in the case of Route 2 and implicitly in Route 1 (if we assume that the terminal illness is not curable).

2.28. There are arguments for and against incurability and intolerability as eligibility criteria.

2.29. Arguments in favour of incurability and intolerability as eligibility criteria:

- There is a *legal precedent* for including as an eligibility criterion that the patient is experiencing *"suffering that cannot be alleviated in a manner that the person deems tolerable"*. This phrasing echoes that adopted in Canadian law.
- Allowing the patient to determine what they find tolerable aligns with an (adult) patient's right to refuse medical treatment, which is premised on *respect for autonomy* (self-determination) and the right to bodily integrity.
- Requiring the medical condition to be incurable helps to ensure that AD is reserved for situations in which interventions short of AD have been trialled, and thereby helps to position AD as a *"last resort"*.

2.30. Arguments against incurability and intolerability as eligibility criteria:

- Patients may seek and receive AD *before other viable options are explored*. If patients can reject that which they consider to be intolerable, then AD may be sought (and granted) in situations where other health care, social and disability support measures could offer relief from suffering. As such, the legal option of AD may undermine resilience and result in the premature death of patients who are in need of – and may potentially benefit from – support.

- Building on the previous point, including intolerability and incurability as eligibility criteria may make it *difficult to restrict the expansion of AD*. However, it may be possible to restrict the practice by also including more objective criteria, such as a diagnosis of terminal illness with a specified prognosis.

- Incurability *cannot be precisely defined*, particularly when it is tethered to the individual's assessment of tolerability. The difficulties of defining *"incurability"* can be illustrated by the following questions. Is a condition incurable even when there are adequate technological or social means available to support the person in their daily activities? Does a condition become incurable if the person refuses further interventions or support measures? Is a person who loses hearing suffering from an *"incurable physical medical condition"*? Could this person argue that their condition creates suffering that cannot be alleviated when they refuse to take up (e.g.) sign language lessons or a Cochlear implant? When does the loss of limbs or paralysis become an *"incurable medical condition"*? However, concerns about the possible scope or interpretation of *"incurability"* may be addressed by restricting this to Route 1, i.e., where there it is the terminal illness that is incurable.

- *Doctors may object* to providing AD when other treatment options remain available. Doctors may feel that providing AD to patients who refuse other options that could alleviate their suffering runs counter to the professional standard of care.[72] They may object that allowing patients to refuse treatment and opt for AD *de facto* grants them a right to insist on AD, which is inconsistent with the general legal position and with usual medical standards. In Canada, MAID providers have testified about the moral anguish of having participated in the ending of life of patients for whom they knew there were available interventions that would be highly likely to save their lives.[73] There have also been controversies in specific cases,[74] for example, when a young man with diabetes and vision loss resulting from his diabetes applied for, and obtained, initial approval for MAiD.[75]

2.31. Including incurability and intolerability as eligibility criteria has a legal precedent, would respect patient autonomy, and may help to signal that AD is to be a last resort. However, *"incurability"* may be hard to define and *"intolerability"* will rest on subjective judgments, which may mean that patients seek and receive AD without having tried viable options, which doctors may find difficult and which may mean it becomes more difficult to restrict the practice. We nevertheless anticipate that these concerns are less acute for Route 1, which links incurability and intolerability to terminal illness, and which may also involve more objective (and measurable) judgments. As such, we conclude our analysis of Routes 1 and 2 here but, if Ministers are inclined to also support Route 2, we note that these concerns about incurability and intolerability would need to be addressed.

[72] T Lemmens, M Shariff, L Herx. How Bill C-7 will sacrifice the medical profession's standard of care." *Policy Options*. (11 February 2021) https://policyoptions.irpp.org/magazines/february-2021/how-bill-c7-
[73] See: M Li (note 14).
[74] Coelho et al (note 29).
[75] "Is it too easy to die in Canada? Surprising approvals for medically assisted death -The Fifth Estate" CBC 19 January 2023 online: https://www.youtube.com/watch?v=plinQAHZRvk

Access for Residents

2.32. The proposal is that access to AD should only be available to Jersey residents, specifically those who have *"been ordinarily resident in Jersey for at least 12 months before requesting an assisted death"*.[76]

2.33. There are arguments for and against restricting access to Jersey residents (so defined).

2.34. Arguments in favour of restricting access to Jersey residents:

- The vast majority of jurisdictions that allow AD restrict access to residents.
- Restricting access to Jersey residents would avoid Jersey becoming a *"suicide/death tourism"* destination. Considerations of justice may arise if access were to be extended to non-residents. For example, if AD were to be provided as a State-run medical service, then (potentially scarce) resources might be consumed by non-residents, which might deprive residents of the opportunity (especially in view of the potentially low numbers of HCPs available and willing to deliver the service in Jersey: see 3.13).
- The majority of respondents to the consultation (47.78%) agreed that access should be restricted to Jersey residents. However, some felt that the service should be available to others with a clear link to Jersey, such as those born in Jersey who are residing elsewhere.[77]

2.35. Arguments against restricting access to Jersey residents:

- There is a precedent for allowing access to non-residents. Switzerland is apparently unique in allowing so-called *"suicide tourism"*, as some of the organisations which provide AD there allow foreign residents to become members and receive AD in that jurisdiction, e.g., over 90% of the members of Dignitas are from other jurisdictions.[78] In 2011, voters in Zurich overwhelmingly voted in favour of continuing to allow non-residents to take up this option.[79]
- Allowing access to non-residents might potentially generate income.
- Allowing access to non-residents could help residents in other, prohibitive countries, including in the mainland UK or other Channel Islands. This might convey something of a compromise, in enabling residents of these countries to nevertheless receive the service nearby.[80] However, the primary beneficiaries of this compromise would be those non-residents, whilst the *"costs"* would primarily be borne by Jersey (unless Jersey were to charge for such provision).

2.36. Although there are arguments for and against a residency requirement, we feel less able to judge whether Jersey should allow access to non-residents. On balance, we suspect not, given public opposition, the potential costs (and potential for injustice), and the fact that only one

[76] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.45.
[77] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), pp.45-46.
[78] https://www.swissinfo.ch/eng/society/membership-in-swiss-assisted-suicide-organisations-reaches-record-high/48358502 [Accessed: 8 October 2023].
[79] https://www.cbsnews.com/news/zurich-voters-keep-suicide-tourism-alive/ [Accessed: 8 October 2023].
[80] R Huxtable. The Suicide Tourist Trap: Compromise across Boundaries. *Journal of Bioethical Inquiry* 2009; 6(3): 327-336.

country worldwide appears to allow access to non-residents. We also find it difficult to comment on the appropriateness of requiring 12 months of residency, rather than a shorter or longer period. A careful analysis of the broader immigration and residency requirements would be needed to evaluate this. The Jersey department responsible for residency may be best placed to determine whether there is still a risk, even with a 12-month residency requirement, that persons will be planning a 12-month residency in Jersey in order to be able to access AD.

Access for Minors

2.37. The proposal would restrict access to AD to (eligible) adults, and would not permit access to minors, i.e., to those under 18 years of age. The question arises whether minors should be permitted access to AD.

2.38. Minors may occupy one of two groups: those with the mental capacity or competence to make the relevant decision (hereafter *"competent minors"*), and those who lack said capacity or competence (hereafter *"incompetent minors"*).

2.39. In the Netherlands, seriously ill young children may have their lives ended under *"Groningen Protocol"*.[81] Rather than AD, which is premised on consent and aligns with the older term *"voluntary euthanasia"*, the Groningen Protocol authorises *"non-voluntary euthanasia"*, i.e., ending the life of a patient who is incapable of consenting or refusing. This protocol permits physicians to end the lives of babies under the age of 12 months in exceptional circumstances, i.e., when the prognosis is hopeless and there is unbearable suffering. Although seldom used,[82] it has been reported that there are plans to expand the Groningen Protocol to children aged one to 12.[83]

2.40. We exclude incompetent minors and thus non-voluntary euthanasia from our review because the Jersey proposals explicitly require the patient to request or consent to AD, which requires them to have reached a decision voluntarily and with the requisite capacity.

2.41. We accordingly limit our focus to competent minors, i.e., those who might be capable of consenting to (or requesting) AD. In line with law in England and Wales, competent minors occupy one of two groups:

- Those under 16 years who have the competence to consent to medical treatment if they demonstrate the requisite level of understanding. In line with the leading ruling, these are sometimes referred to as *"Gillick competent*" minors or *"mature minors"*;[84] and

[81] See: BA Manninen. A case for justified non-voluntary active euthanasia: Exploring the ethics of the Groningen Protocol. *Journal of Medical Ethics* 2006; 32: 643-651.
[82] D Wilkinson. Dutch government to expand euthanasia law to include children aged one to 12 – an ethicist's view. *The Conversation* 19 April 2023. Available at: https://theconversation.com/dutch-government-to-expand-euthanasia-law-to-include-children-aged-one-to-12-an-ethicists-view-203961 [Accessed: 8 October 2023].
[83] SC de Keijzer, et al. The age limit for euthanasia requests in the Netherlands: A Delphi study among paediatric experts. *Journal of Medical Ethics* 2023; 49: 458-464.
[84] *Gillick v West Norfolk and Wisbech Area Health Authority and the Department of Health and Social Security* [1986] AC 112.

- Those of 16 or 17 years, who have the capacity to consent to medical treatment if they demonstrate the requisite level of understanding.[85]

2.42. There are arguments for and against allowing competent minors to access AD.

2.43. Arguments in favour of allowing competent minors to access AD:

- Some jurisdictions have allowed competent minors to access AD, so there are models on which such a proposal could be based, e.g., from Belgium and the Netherlands. Following legalisation of AD for adults in 2002, the law in Belgium was expanded in 2014 to allow children of any age to access AD in certain circumstances: death is close, there is terminal or incurable illness, or chronic pain.[86] The parents must consent, and there must be an assessment by a child psychiatrist, who must certify that the child possesses the capacity to understand their situation and what AD involves before access is granted. When the Dutch law was codified in 2002, it also included access to AD for children aged 12 or over on the same basis as adults.

- It would be fair, just and equitable to afford terminally ill or unbearably suffering (competent) minors the same right to AD as would be enjoyed by terminally ill or unbearably suffering (competent) adults. According to this argument, an age cut-off is arbitrary and irrelevant, because the key consideration is the presence of terminal illness and/or unbearable suffering. Just like adults, terminally ill children may suffer significant pain and distress during the dying process, and palliative care does not always provide sufficient relief.[87] While this highlights the need to improve palliative care, it also supports an argument that terminally ill (competent) children should have the same right of access as terminally ill (competent) adults. Equally, children and adults alike might experience unbearable suffering arising from a medical condition. To deny terminally ill or unbearably suffering minors an option that is available to adults in their situations would arguably amount to unjust discrimination.

- It would also be fair, just and equitable to afford competent minors the same right of choice, including for AD, as would be enjoyed by competent adults. According to this argument, an age cut-off is arbitrary and irrelevant, because the key consideration is the consent (or request) of a competent individual. Provided that the minor has the requisite (*Gillick*) competence or capacity to understand their diagnosis, prognosis, treatment options, and the nature and implications of AD, they should be permitted to exercise their autonomy over their end-of-life treatment, including a choice to access AD. To deny competent minors this option would again arguably amount to unjust discrimination.

- If there are concerns about grounding a decision for AD entirely on the consent or request of a (competent) minor, then provision could be made for additionally ensuring that consent is also provided by their parent(s). It is conceivable that there would be situations in which the child and their parent(s), as well as the HCPs caring for the child,

[85] In England and Wales, the capacity test is the same as that for adults: Mental Capacity Act 2005, ss. 2-3.
[86] Raus K. The Extension of Belgium's Euthanasia Law to Include Competent Minors. *J Bioeth Inq* 2016; 13(2): 305-15.
[87] J Wolf et al. Symptoms and distress in children with advanced cancer: Prospective patient-reported outcomes from the pediQUEST study. *Journal of Clinical Oncology* 2015; 33(7): 1928-1935.

agree that it would be appropriate to permit AD, e.g., in order to avoid a distressing death.

- If there is a case for retaining some age limits in the law, then consistency might demand that those who have attained (e.g.) the age of 16 years should enjoy the same rights as adults. For example, in Jersey the voting age is 16;[88] if 16 and 17 year olds are regarded as sufficiently mature to vote, then they are also arguably sufficiently mature to take decisions concerning AD.

2.44. Arguments against allowing competent minors to access AD:

- Restricting access to adults would be consistent with most jurisdictions that permit AD.
- The laws permitting AD for minors in Belgium and the Netherlands are not only seldom used, but also controversial. It is very rare for a child to die by AD in Belgium. For example, reports indicate that between 2016 and 2018, three children died by euthanasia.[89] The number of children accessing AD in the Netherlands has also been very low (e.g., reportedly one case involving a patient of 12-16 years in 2022).[90] Despite the low incidence, this has been one of the most controversial aspects of AD law in these countries, particularly in Belgium.[91]
- Children lack the requisite autonomy. Some argue that children lack the discernment to make such a significant decision, and further query whether a child's choice would be sufficiently autonomous, as children may be sensitive to close adults' views and potentially susceptible to pressure from them to take up AD.[92]
- Children should be protected. Even if some children may be considered to have the requisite autonomy, children are qualitatively different from adults, and such differences should be reflected in the law. There are already many decisions that the law does not permit to be made until adulthood, in view of the potential harms (e.g., smoking, consuming alcohol).[93] It may be argued that children are inherently vulnerable, and therefore should be protected from exercising their autonomy in ways that might be harmful. AD may be judged to be harmful, since it ends the individual's life, so children should be denied this option until they have reached majority. *"Everyone is potentially vulnerable in the context of MAID, including adults; however, children are in a position of compounded vulnerability in this context due to their existing childhood-related vulnerabilities (e.g., being embedded in adult-privileging power dynamics, inability to defend oneself from risk of harm)"*.[94]

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[88] https://www.vote.je/voting-in-jersey/ [Accessed: 8 October 2023].
[89] C Lane. Opinion: Children are being euthanised in Belgium. *Washington Post*, 6 August 2018. (This article cites the primary source: https://organesdeconcertation.sante.belgique.be/fr/documents/cfcee-rapport-euthanasie-2018 [Accessed: 8 October 2023].
[90] https://www.theguardian.com/society/2023/apr/14/netherlands-to-broaden-euthanasia-rules-to-cover-children-of-all-ages [Accessed: 8 October 2023].
[91] https://www.sbs.com.au/news/article/controversy-as-belgium-approves-child-euthanasia/o6oq71frz [Accessed: 8 October 2023].
[92] L Bovens. Child euthanasia: Should we just not talk about it? *Journal of Medical Ethics* 2015; 41: 630-634.
[93] Bovens (note 92).
[94] HK Singh, ME Macdonald, FA Carnevale. Considering medical assistance in dying for minors: The complexities of children's voices. *Journal of Medical Ethics* 2020; 46: 399-404.

- Allowing AD for competent minors risks creating a legal asymmetry and consequently legal inconsistency, which might entail further revisions to the law beyond the scope of the current proposals. Although existing law permits competent minors to consent to treatment, it does not, except in very exceptional circumstances, allow those under 18 to refuse life-sustaining treatment. Brazier et al suggest that, *"Adolescent autonomy is little more than a myth, for no young person under 18 – no minor – has a right to refuse treatment, at least if the treatment is life-sustaining and in their best interests*".[95] There is a limited exception to this position, which allows a refusal to stand if the impact of the unwanted treatment on the minor would, on balance, be more damaging to them than respecting their refusal. For example, in *DV (A Child)*,[96] a 17-year-old Jehovah's Witness cancer patient was permitted to refuse a blood transfusion after a previous forced transfusion caused them to suffer PTSD. If the law were to allow competent minors to consent to AD, but not generally to refuse life-sustaining treatment, the law would appear to be inconsistent. Further revisions might then be indicated, in order to address the perceived inconsistency, which are currently beyond the scope of AD proposals.

- The Jersey public consultation indicated a narrow preference for limiting access to AD to adults over 18-years-old. 39.91% agreed that assisted dying should only be permitted for those over 18, while 34.81% disagreed and 25.28% responded that they did not know.[97] (The views of children themselves were not sought.[98])

2.45. There may be objections that denying competent children the option of AD amounts to unjust discrimination and that models exist for so extending AD. However, in view of concerns about the autonomy and vulnerability of children, the public's ambivalence about extending AD to minors, and the low uptake and controversial status of child euthanasia in those jurisdictions that allow the practice, on balance we believe that, if permitted, AD should be restricted to adults. If there were to be moves to allow access to children, we further believe that the views of children themselves should be elicited, in line with the edict *"nothing about us without us"*.

Capacity and consent

2.46. Although not explicitly asked to do so, we also wish to comment briefly on the additional criteria that the person must have capacity to consent to AD and they must provide informed consent (see 2.4).

2.47. The requirements that a person must have capacity and must provide informed consent are not unique to AD: these are typically key requirements for medical interventions, and particularly for an invasion of bodily integrity, unless a recognised exception applies (e.g., in an emergency situation).

2.48. The current Jersey proposals intend to set out, in law, a specific test to assess whether a patient has decision-making capacity in relation to AD, along with accompanying tools and guidance.[99] However, in line with existing capacity legislation in Jersey, it appears that – as with

[95] M Brazier, E Cave and R Heywood. *Medicine, Patients and the Law*, Manchester University Press, 7th Edition (2023), p.493.
[96] *A Teaching Hospital NHS Trust v DV (A Child)* [2021] EWHC 1037 (Fam).
[97] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.48.
[98] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.48.
[99] Assisted Dying in Jersey Consultation Report (October 2022), pp.100-101.

other medical procedures – capacity to consent to AD would be presumed, unless there is reason to test this.[100]

2.49. AD presents risks which indicate the need for stringent requirements regarding capacity and consent:

- AD is designed to end life, so, by definition, it exposes a person to the most serious risk of irreversible harm.
- Capacity for decision-making and informed consent may be more at risk of being undermined by the unique circumstances that surround AD decisions, such as the presence of physical and emotional suffering, the potential intersection of mental illness, subtle pressures from others, and the ambiguity of the desire to die.[101]
- There is evidence, particularly in the context of euthanasia for mental illness,[102] that physicians' judgments about patients' capacity to opt for AD often differ and that they often consist of only global judgments. This raises concerns about reliance on *general* (and potentially diverse) approaches to determining capacity and ensuring consent, which have not been *specifically* tailored to AD.
- There is evidence from Canada that clinicians assessing requests for AD have mostly done so without undertaking a formal capacity assessment or, when this has taken place, by using clinical tools that have been developed for other settings.[103] The evidence also suggests that they have rarely assessed applicants for the presence of mental illness.

2.50. Given the risks presented by AD, we welcome the intention to set out, in the AD law, a specific test for assessing whether a patient has decision-making capacity in relation to AD, along with accompanying tools and guidance.[104] However, we suggest that the States Assembly should additionally consider removing the presumption in favour of capacity in the case of AD specifically, so that all applicants are routinely assessed. In terms of said assessment, we additionally suggest that (mandatory) training in assessing capacity and ensuring consent be provided, so as best to ensure compliance with the AD law and guidance and consistency in practice.

[100] https://www.jerseylaw.je/laws/enacted/Pages/L-30-2016.aspx#_Toc470685347.
[101] L Charland, T Lemmens, K Wada. Decision-Making Capacity to Consent for Medical Assistance in Dying for Persons with Mental Disorders. *Open Issue Journal of Ethics in Mental Health* 2016; 1-15.
[102] SN Doernberg, JR Peteet, SYH Kim. Capacity Evaluations of Psychiatric Patients Requesting Assisted Death in the Netherlands. *Psychosomatics* 2016; 57(6): 556-565.
[103] E Wiebe et al. Assessment of capacity to give informed consent for medical assistance in dying: A qualitative study of clinicians' experience. *CMAJ Open* 2021; 9(2): E358-E363.
[104] Assisted Dying in Jersey Consultation Report (October 2022), pp.100-101.

Chapter 3: Approval routes

Outline of the current proposal

3.1. The current proposal envisages AD as:

- Premised on a "medical model", i.e., with a high level of involvement from health and care professionals, as distinct from models operating elsewhere (such as in Switzerland) where there is a less overtly "medical model";
- Free to access;
- Provided by the Government health department (i.e., Health and Community Services), not by private providers; and
- Involving health and social care professionals in:
  - Providing assessments, including with the option to refer on to other health and care services as part of the eligibility assessment;
  - Prescribing and dispensing the assisted dying substance; and
  - Delivering AD, including the requirement that the Administering Practitioner remain with the person until their death.

3.2. The envisaged "medical model" involves nine stages, from the person's first request to after their death has occurred, key aspects of which are summarised below. Distinct approval processes are proposed for routes 1 and 2.

3.3. Route 1 (terminal illness) approval process:

- Following the person's first request, a first assessment is conducted by the co-ordinating doctor and a second assessment is then undertaken by an independent doctor;
- Following these assessments, the person must make a second request. Both the co-ordinating doctor and the independent doctor must assess the person as eligible, then the co-ordinating doctor approves (or not) the request. Unlike route 2, there is no requirement that this request be confirmed by a tribunal;
- Following approval, and preparation and prescribing, there is a final review, when consent may be confirmed, although it is envisaged that the need for this final (third) consent/request may be waived for route 1;
- The co-ordinating and independent doctors should be supported by a multi-disciplinary team, which should include a nurse, a therapist, and a social worker;
- The minimum time that must elapse between the first request and the final review at the point of provision of AD is 14 days.

3.4. Route 2 (unbearable suffering) approval process:

- Following the person's first request, a first assessment is conducted by the co-ordinating doctor and a second assessment is then undertaken by an independent doctor;

- Following these assessments, the person must make a second request that must be approved by a tribunal;
- Following approval, and preparation and prescribing, there is a final review, when consent must be confirmed and, unlike route 1, it is apparently envisaged that this final consent cannot be waived;
- The co-ordinating and independent doctors should be supported by a multi-disciplinary team, which should include a nurse, a therapist, and a social worker;
- The minimum time that must elapse between the first request and the final review at the point of provision of AD is 90 days.

Models involving doctors in assisted dying

3.5. We were asked to consider the key ethical arguments regarding the role of HCPs in a "medical model" of AD.

3.6. In AD debates, there is a *"pervasive"* assumption that doctors should be responsible for: *making decisions* about AD; *prescribing* the means; and/or *administering* the means.[105] However, there are opposing arguments about whether – in principle and in practice – doctors should be so involved.

Doctors' involvement in principle

3.7. Arguments about whether doctors should be involved in AD *in principle* focus on the nature and goals of medicine, and the corresponding values and identities of its practitioners.

3.8. Principled arguments against doctors' involvement:

- Some argue that AD is incompatible with the medical endeavour, which should (for example) aim to cure or heal patients, and thus benefit patients and avoid them coming to harm (see also 5.6).[106,107,108,109] On such accounts, doctors should not assist patients to die, since death resulting from medical intervention is *"a serious adverse outcome"* and *"not a health benefit"*.[110]

3.9. Principled arguments in favour of doctors' involvement:

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[105] F Randall, R Downie. Assisted suicide and voluntary euthanasia: Role contradictions for physicians. *Clinical Medicine* 2010; 10(4): 323-325.
[106] ED Pellegrino. The internal morality of clinical medicine: A paradigm for the ethics of the helping and healing professions. *Journal of Medicine and Philosophy* 2001; 26: 559.
[107] Randall and Downie (note 105).
[108] B Chan, M Somerville. Converting the "right to life" to the "right to physician assisted suicide and euthanasia": An analysis of *Carter v Canada (Attorney General)*, Supreme Court of Canada. *Medical Law Review* 2016; 24(2): 143, 172.
[109] O Hartling. *Euthanasia and the ethics of a doctor's decisions: An argument against assisted dying*. (Bloomsbury, London: 2021).
[110] Randall and Downie (note 105).

- Others argue that AD is compatible with the medical endeavour, since (for example) this encompasses *"helping patients to achieve dignified and peaceful deaths"*.[111] On these accounts, doctors may assist patients to die, at least *"as a last resort"*.[112],[113]

3.10. These (principled) arguments remain contested. They might not even be significantly helpful, as sometimes the nature and values of medicine (and of doctors) are described in ways that mean AD is either compatible or incompatible, *by definition*.[114]

Doctors' involvement in practice

3.11. Arguments about whether doctors should be involved in AD *in practice* focus on whether doctors support AD and would be willing to provide it. Some argue that there is support amongst medical professionals for allowing AD and there are some such professionals who would be willing to provide it. Others argue that there are many medical professionals who remain opposed to allowing AD and who would not be willing to provide it.

3.12. Practical arguments in favour of doctors' involvement:

- AD (in some form), as performed by doctors, has been provided for in law in numerous jurisdictions and thereafter has been provided by doctors.
- Studies indicate that at least some doctors in the UK support AD and may be willing to provide it: for example, the Royal College of General Practitioners (RCGP) found that 40% of its members surveyed in 2020 felt *"The RCGP should support a change in the law on assisted dying, providing there is a regulatory framework and appropriate safeguarding processes in place"*.[115]
- Although professional medical organisations have traditionally been opposed to AD, the British Medical Association (BMA) moved in 2021 to a position of neutrality, i.e., neither supporting nor opposing any proposed reforms to the law.[116]

3.13. Practical arguments against doctors' involvement:

- The 2020 RCGP consultation also found that the majority – 47% – of respondents felt that *"The RCGP should oppose a change in the law on assisted dying"*; the RCGP thereafter retained its position of opposition.[117] The BMA similarly found that the

[111] FG Miller, H Brody. Professional integrity and physician-assisted death. *Hastings Center Report* 1995; 25: 8.
[112] Miller and Brody (note 111).
[113] R Momeyer. Does physician assisted suicide violate the integrity of medicine? *Journal of Medicine and Philosophy* 1995; 20: 13.
[114] R Huxtable. Death on Demand: Proper Medical Treatment? In S Fovargue, A Mullock, eds., *The Power of 'Proper Medical Treatment': What Role for the Medical Exception?* (Routledge, 2015), 142-159.
[115] Royal College of General Practitioners. Assisted Dying (rcgp.org.uk). [Publication date not given.] Jersey-based doctors are members of the UK Royal Colleges.
[116] British Medical Association. BMA moves to neutral stance on assisted dying. [Publication date: 14 September 2021.] Jersey-based doctors may be members of BMA.
[117] Royal College of General Practitioners (note 115).

majority – 33% – of respondents felt the BMA should be opposed, although the BMA thereafter changed its position to one of neutrality.[118]

- A survey conducted by the BMA in 2020 found that the majority – 45% – of respondents would not be willing *"to actively participate in any way in the process"* of self-administration of AD drugs by eligible patients.[119]

- A 2006 (questionnaire-based) study of end-of-decisions in the UK found, relative to other countries, a lower rate of doctor-assisted dying occurring in practice and a higher rate of non-treatment decisions, which was interpreted as suggesting *"a culture of medical decision making informed by a palliative care philosophy"*.[120] Although views do appear to differ amongst these professionals,[121] palliative care professionals tend generally to be opposed to allowing AD, with a 2020 survey finding that 76% of those working in palliative medicine in the UK were opposed.[122]

- Some UK-based doctors, including some practicing in palliative care, raise concerns based on the evidence emerging from jurisdictions that allow AD:[123]

    - Professionals in Canada reportedly feel they must withhold giving medications that may cause sedation or confusion, as providing these might jeopardise the provision of AD, even if doing so might alleviate patient suffering;

    - There is reportedly an adverse impact on the doctor-patient relationship in Canada, with some patients fearing that doctors will urge AD. Such fears have been generated by recommendations – for example, from the Canadian Association of MAID Assessors and Providers – that physicians must provide information about AD to anyone who might qualify (which, in line with Canadian law, is not restricted to those who are terminally ill).[124] Persons with disabilities have expressed concerns about this;[125]

    - Clinicians in Australia describe AD as time-consuming, taking approximately 60 hours of work, which may divert time and care from other patients, and may mean eligibility for AD is not assessed to the best of the doctors' abilities. However, in this regard, we note that the proposal is that doctors who register

[118] British Medical Association. BMA physician-assisted dying survey results published. [Publication date: 8 October 2020.]
[119] British Medical Association (note 118).
[120] C Seale. National survey of end-of-life decisions made by UK medical practitioners. *Palliative Medicine* 2006; 20: 3.
[121] AV Campbell, R Huxtable. The position statement and its commentators: Consensus, compromise or confusion? *Palliative Medicine* 2003; 17: 180.
[122] Kantar, BMA Survey on Physician-Assisted Dying: Research Report. [Publication: October 2020.]
[123] A Worthington, I Finlay, C Regnard. Assisted dying and medical practice: Questions and considerations for healthcare organisations. *BMJ Supportive & Palliative Care* doi: 10.1136/bmjspcare-2022-003652. [Publication: 26 April 2022.]
[124] T Lemmens. When Death Becomes Therapy: Canada's Troubling Normalization of Health Care Provider Ending of Life. *American Journal of Bioethics* 2023; 23(11); 79-84.
[125] G Peters. Trusting a stranger with your life. When MAiD gives them a right to end it (26 August 2023): https://mssinenomine.substack.com/p/trusting-a-stranger-with-your-life; G Bartlett. Mother says doctor brought up assisted suicide option as sick daughter was within earshot. *CBC News* (24 July 2017): https://www.cbc.ca/news/canada/newfoundland-labrador/doctor-suggested-assisted-suicide-daughter-mother-elson-1.4218669.

with the Assisted Dying Service would be contracted to work part-time for this Service and part-time in their regular role. As such, the time needed to provide AD would be part of doctors' contracted hours (rather than time that must be found on top of regular commitments), so the anticipated time commitment may not present particular problems under the proposal Jersey model;

- There are concerns that, in Belgium, *"safeguards in reality often fail to operate as such"*;[126,127] similar concerns have been expressed about Canada;[128]
- Evidence from Canada and Oregon suggests that patients receiving an AD have experienced *"distressing complications and prolonged dying"*;
- A review of studies suggests that, of clinicians who have participated in AD, 30-50% *"describe an emotional burden or discomfort about their role"*, while up to 20% reportedly experience *"a lasting adverse emotional or psychological impact"*.

- There is also evidence of opposition to allowing AD from Jersey-based doctors: by November 2021, 65 medical professionals in Jersey had stated their opposition in an open letter to the Health Minister.[129] This suggests that, at that time, at least 6% of doctors registered in Jersey (65/946) were explicitly opposed to allowing AD.[130] The letter remains opens for signatures and this figure may have risen.[131] While preparing this report, we were also directed towards a 2019 survey of 71 Jersey-based doctors regarding their views on AD in various scenarios.[132] 34% of respondents believed that AD was *"always acceptable"* when the patient was terminally ill; 39% believed that AD was *"sometimes acceptable"* in other cases (e.g., unbearable suffering). However, between 31% and 41% believed AD was *"never acceptable"* and 38% indicated they would *"never"* be willing to provide AD, while 25% reported they would *"always"* be willing.

3.14. While the principled arguments appear to be inconclusive, there are compelling practical arguments for and against a *"medical model"* involving doctors in AD.

3.15. Given this, we welcome the stated plans to attempt to address and/or ameliorate the concerns of opponents, in particular:

- We welcome the inclusion of a conscientious objection clause in the current proposal and recommend its retention (see chapter 5).
- We welcome the inclusion, in the current Jersey proposals, of the statement that *"it is envisaged that the report and proposition will ask States Members to agree, in principle, that legislation permitting assisted dying should not be brought into force until the*

[126] Raus et al (note 64).
[127] T Lemmens. Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice. *Supreme Court Law Rev* (2nd). 2018; 85: 453-539.
[128] J Kotalik. Medical Assistance in Dying: Challenges of Monitoring the Canadian Program. *Canadian Journal of Bioethics* 2020; 3(3); 202-209.
[129] Medical professionals open letter urges against allowing assisted dying in Jersey | ITV News Channel. [Publication date: 23 November 2021.]
[130] Jersey medical practitioners register (gov.je) [Accessed: 16 August 2023.]
[131] Our Duty of Care Jersey – healthcare professionals opposing the intentional killing of patients by assisted suicide or euthanasia. [As of 16 August 2023, this letter remains open to signatures.]
[132] http://www.dignitas.ch/images/stories/pdf/umfrage-eolcjersey-4insight-2.pdf [Accessed: 16 October 2023.]

Assembly is satisfied that all Islanders can access good palliative and end-of-life services".[133] We further welcome the intention to secure additional funding *"for investment in palliative care and end-of-life services"*.[134] Evidence and arguments from other jurisdictions confirm the importance of not adopting AD in isolation, but instead doing so alongside efforts to ensure, for example, that there is appropriate input from palliative care specialists and that there is good quality palliative care available to all citizens.[135] There are lessons to learn from experience in the Netherlands, where it has been queried whether support for AD would have been so widespread at the time it was introduced had there been the levels of palliative care that are currently available.[136] The Dutch health system was encouraged to invest in palliative care in response to concerns that *"once you legalize euthanasia, palliative care will get worse"*.[137],[138] The Austrian approach to AD may also provide a model, as two doctors must assess a request for AD, one of whom must be a specialist in palliative medicine.[139] Belgium's approach might be considered as well. Although a so-called *"palliative care filter"* was proposed but ultimately not included in the legislation, a separate law introduced a right to palliative care.[140] Significant investments were also made in the years following the adoption of the euthanasia law.[141] However, such input would need to be voluntary, and we recognise that some such professionals may refuse to participate, and indeed that some patients may be resistant if these specialists prefer to recommend treatment or care other than AD. However, as noted, we are reassured that there are plans to ensure the availability of palliative care and we further welcome the recent announcement of a palliative and end-of-life care strategy for adults in Jersey,[142] and we hope that a similar strategy will be in place for children and young people.

3.16. Beyond such steps, we further suggest *gathering further, specific evidence*, which may help to tip the balance in one or other direction. It may be felt that sufficient evidence has already been gathered. However, gathering the detailed views of those likely to be most intimately involved in providing AD should help to indicate the extent to which the proposed law commands support and would be workable in practice in Jersey:

- Once the detailed proposals have been refined, we suggest that the views of Jersey-based doctors could be sought again (e.g., via a survey or other means), to ascertain levels of support for AD as proposed and their willingness to participate in AD as

[133] Assisted Dying in Jersey Consultation Report (October 2022), para 12, 338.
[134] Assisted Dying in Jersey Consultation Report (October 2022), para 342.
[135] Some authors have argued for a national law on palliative care in Spain, which they believe should have preceded or accompanied Spain's legalisation of AD: TR Velasco Sanz, et al. Spanish regulation of euthanasia and physician-assisted suicide. *Journal of Medical Ethics* 2023; 49: 49-55.
[136] A Albaladejo, Fear of assisted dying: Could it lead to euthanasia on demand or worsen access to palliative care? *British Medical Journal* 2019; 364: 1852.
[137] Albaladejo (note 136).
[138] A Brinkman-Stoppelenburg, M Boddaert, J Douma, A van der Heide. Palliative care in Dutch hospitals: A rapid increase in the number of expert teams, a limited number of referrals. *BMC Health Serv Res* 2016 Sep 23.
[139] New law allowing assisted suicide takes effect in Austria - BBC News. [Publication date: 1 January 2022.]
[140] Wet betreffende de palliatieve zorg (14 June 2002) online: <https://www.ejustice.just.fgov.be/cgi_loi/change_lg_2.pl?language=nl&nm=2002022868&la=N>.
[141] P Vanden Berghe et al. Assisted Dying: the Current Situation in Flanders: Euthanasia Embedded in Palliative Care. In DA Jones et al (eds), *Euthanasia and Assisted Suicide: Lessons from Belgium* (Cambridge: Cambridge University Press), p.67 at p.79.
[142] https://www.gov.je/news/2023/pages/PalliativeAndEndOfLifeCareStrategyForAdultsinJerseyLaunched.aspx.

proposed. We note that there were specific engagement sessions with HCPs during phases 1 and 2 of the consultation, the proposals have been developed with a Professional Leads Working Group (comprising, *inter alia*, the Medical Director, Chief Nurse, and other leading professionals in Jersey),[143] and doctors' views were previously sought in the 2019 survey.[144] However, further consultation on the specific proposal before it is made law would help to indicate the extent to which non-Jersey doctors (or other HCPs) may be needed. If the results were to indicate that there is insufficient support amongst Jersey-based doctors to ensure that AD would be workable by (only or primarily) involving Jersey-based doctors, then distinct ethical considerations would arise. These ethical considerations concern the appropriateness of introducing a system that would depend significantly on the input of non-Jersey doctors. We anticipate that, at present, doctors from outside Jersey are already likely to be routinely involved in care and treatment on Jersey (e.g., specialists coming to Jersey to provide particular treatment or services). However, if a significant number of Jersey-based doctors were opposed to the proposal to allow AD and/or their participation therein, but this were nevertheless rolled out, then this might have consequences for the integrity and functioning of the health service. We are, however, reassured, that there are plans in place to consult doctors and other HCPs before any proposal is made law.

- Irrespective of any right to conscientiously object (chapter 5), others who are envisaged to participate in AD (whether directly or indirectly) could also be surveyed about their willingness to participate, once the detailed proposals have been refined. These could include HCPs, such as nurses and pharmacists, as well as other individuals and organisations (such as caring facilities, administrators, and drivers) that would play a role in the provision of AD (see also chapter 5). Again, we are reassured that there are plans in place to consult HCPs before any proposal is made law.

- It would also be important to seek the views of people with disabilities on Jersey, once the detailed proposals have been refined, particularly with regards to some of the recommendations that may be of particular concern to them (e.g., if Route 2 is to be adopted), or where arguments have been made that rely on an alleged need to support their choices and offer them specific options in the AD context. We note, however, that in addition to the wider public consultation exercises, the views of people with disabilities have already been sought, including in dedicated consultation meetings, which were run in collaboration with Enable Jersey, a charity that supports islanders with disabilities and promotes equality and the rights of such persons.[145] The findings to date may be considered sufficient to indicate the views of people with disabilities on Jersey; evidence from other jurisdictions may also provide a sufficient indication of any concerns that would need to be addressed. However, it would seem appropriate to seek their views on the final specific proposals, particularly if route 2 is included as this appears to offer assisted dying options particularly or exclusively to them.

[143] https://www.gov.je/Caring/AssistedDying/pages/assisteddying.aspx#anchor-6 [Accessed: 16 October 2023.]
[144] http://www.dignitas.ch/images/stories/pdf/umfrage-eolcjersey-4insight-2.pdf [Accessed: 16 October 2023.]
[145] https://www.enablejersey.org/ [Accessed: 16 October 2023.]

Models not involving doctors in assisted dying

3.17. We were also asked to consider the key ethical arguments concerning a "non-medical model" of AD, i.e., a more-or-less "de-medicalised" model.

3.18. There are two "non-medical" options to consider, "total de-medicalisation" and "partial de-medicalisation".

Total de-medicalisation

3.19. "Total de-medicalisation" would not involve doctors in the provision of AD. Total de-medicalisation could take one of three forms:

- A model in which *anyone, including someone close to the patient*, may be legally entitled to provide AD. This sort of practice is sometimes labelled "mercy killing" or "compassionate killing".[146] Although mercy killers do not always face the full force of the criminal law in those jurisdictions in which AD is not lawful,[147] no legal system appears to have adopted a model that explicitly sanctions "mercy killing" as such (although see further 3.23ff).

- A model in which AD is provided by a *new sort of specialist, professional, or technician*. Brazier has discussed the possibility of creating a new specialty of *"thanatology"*: *"A licensed thanatologist (death-bringer) could … lawfully end the person's life in an approved manner. Regulations made under the statute would prescribe (inter alia) … what training thanatologists should receive... Doctors and nurses would not figure in the picture at all. One of the anxieties expressed about active euthanasia, the 'brutalisation' of caring professionals, is countered"*.[148] Randall and Downie have expressed such reservations about involving doctors, and they agree that AD could be placed within the legal (not medical) domain, with *"technicians"*, rather than doctors, providing the assistance.[149] This sort of model also appears not to have been adopted by any legal system.

- Some have proposed ways in which persons with a well-considered desire to die can be *provided with the tools to end their own life*. This would not involve anyone else, beyond providing the tools to do so.[150]

3.20. Arguments in favour of total de-medicalisation:

[146] R Huxtable. *Euthanasia, Ethics and the Law: From Conflict to Compromise* (Routledge, 2007), chapter 2.
[147] Huxtable (note 146).
[148] M Brazier. Euthanasia and the Law. *British Medical Bulletin* 1996; 52(2): 317-325, 322-323. Brazier thanks her colleague Stuart Donnan "for introducing me to the novel concept of a profession of thanatologist" (ibid, 324).
[149] Randall and Downie (note 105).
[150] E.g., B Chabot. *Uitweg: een waardig levenseinde in eigen hand* (Amsterdam: Nijgh & Van Ditmar, 15ed, 2022).

- Entirely removing doctors (or other HCPs) from the provision of AD would avoid potential conflicts with the assumed role of the doctor (3.8) and concerns that have been expressed about involving doctors in AD (3.13).[151]
- It is conceivable that patients might prefer to be assisted by someone close to them, rather than a doctor (or, indeed, another sort of professional).
- It may make AD much more easily accessible.

3.21. Arguments against total de-medicalisation:

- No legal system appears to have adopted a totally de-medicalised model, which means there is no body of experience to inform such a proposal.
- If doctors are not involved at all, then there may be risks that the patient's medical condition (diagnosis, prognosis, and/or treatment options) and their competence to decide will not be adequately assessed.
- Conflicts of interest concerns inevitably arise when professionals gain their income from providing a practice that has such an explicit risk profile. This becomes even more prominent when it is their only or primary source of income and their sole professional focus is on ending life.
- It is possible that, without professional involvement to the end, the procedure might *"fail"* and cause the patient to die in suffering or to otherwise experience an undignified death (see also 6.13).
- If the model were to involve non-professionals, including people close to the patient, then this may negatively impact on personal relationships and/or the well-being (including the mental health) of those who assist.
- If people close to the patient are allowed to be involved, then there may be risks of abuse.

3.22. Given the risks, especially of possible harm(s) to patients, total de-medicalisation does not appear to be ethically defensible. Some level of doctor involvement seems to be merited, which a model of *partial* de-medicalisation might provide.

Partial de-medicalisation

3.23. "Partial de-medicalisation" reduces the involvement of doctors, although they would still play a role.[152] Randall and Downie recognised that doctors may still need to be involved, e.g., in confirming the patient's medical condition and their competence to decide.[153] Swiss law and practice effectively adopts such a model. Article 115 of the Swiss Penal Code holds that assisted suicide is a criminal offence if carried out for self-interested reasons. As Ost notes, *"there is no medicalised construction of the circumstances in which assisted death can be*

[151] See also: L Thomas, Demedicalisation: Radically reframing the assisted dying debate. *British Medical Journal* 2020; 371; m2919.
[152] See also: N Preston, S Payne, S Ost. Breaching the stalemate on assisted dying: It's time to move beyond a medicalised approach. *British Medical Journal* 2023; 382: p1968.
[153] Randall and Downie (note 105).

permissible" – assisted suicide may be performed, irrespective of who the assistant is, provided that the patient is competent to decide, and the assistant has no selfish motivation.[154] A doctor will need to prescribe the fatal drug, assess the patient's competence and their medical condition, but doctors need not otherwise be involved. Typically, a volunteer from a right-to-die organisation undertakes the other tasks (e.g., collecting, storing and mixing the drugs, and providing them to the patient for them to consume), according to the processes of the relevant right-to-die organisation. These volunteers tend to be members of the clergy, social workers, or nurses, who are trained for the role (e.g., in counselling). As such, in practice, the Swiss model involves doctors to a degree but largely relies on *"professional non-medics"*.[155]

3.24. Arguments in favour of partial de-medicalisation:

- Limiting the involvement of doctors (or other HCPs) in the provision of AD would reduce potential conflicts with the assumed role of the doctor (3.8) and may ameliorate concerns that have been expressed about involving doctors in AD (3.13). These concerns might be further addressed, not only by ensuring that doctors have a right to conscientiously object to participation (chapter 5), but also by requiring that only those who expressly choose to opt-in will be involved in the process. When doctors remain largely disconnected from the procedure itself, they may also be able to flag concerns to relevant authorities and provide protection. They could then arguably maintain their core focus on the health and well-being of the patient.

3.25. Arguments against partial de-medicalisation:

- In Switzerland, doctors are involved in assessing the patient's medical condition and competence to decide, but concerns have been expressed about the robustness of the process, amidst reports that vulnerable patients have been assisted to die.[156]
- There may still be risks that the patient will endure suffering or an undignified death, if there is no doctor present throughout the process to address any complications that might arise (see further 6.13). However, it may be possible to reduce these risks by ensuring that those who are present with the patient at the end have the requisite skills and knowledge to assist.
- The Swiss model relies on private provision by right-to-die organisations, including Dignitas. Such provision carries costs, estimated to be £10,000 for Dignitas.[157] This may be unjust, as only those who can meet the costs would be eligible for AD. However, it may be possible to adapt the model so that the service is provided by the State, rather than private providers, and we endorse the proposal that AD would be free to access and provided by a Government health department (i.e., Health and Community Services), rather than private providers.

3.26. Partial de-medicalisation appears to be more ethically defensible than total de-medicalisation, because such a model retains a role for the doctor (thereby protecting the interests of

[154] S Ost. The de-medicalisation of assisted dying: Is a less medicalised model the way forward? *Medical Law Review* 2019; 18(4): 497-540.
[155] Ost (note 154).
[156] M Leidig. Dignitas is investigated for helping healthy woman to die. *British Medical Journal* 2006; 331: 7526.
[157] https://www.theguardian.com/society/2023/jun/27/assisted-dying-dignitas-has-helped-540-british-people-die-mps-told [Publication date: 27 June 2023.]

patients), but limits this (thereby reducing concerns about doctors' involvement). However, such a model would still require robust regulation, to ensure that providers have the necessary skills and knowledge and that eligibility for AD is appropriately monitored and enforced, and may require State provision, to avoid unjust access and provision. We suggest that, whatever model is preferred, some level of involvement by doctors is likely to be needed.

Approval following assessments by two doctors

3.27. The proposed Route 1 (terminal illness) approval process would involve two doctors, who would (inter alia) confirm that the patient is terminally ill (see 3.3). The proposed Route 2 (unbearable suffering) approval process would involve two doctors, as well as a Tribunal, confirming (inter alia) that the patient is suffering unbearably (see 3.4).

3.28. Various jurisdictions require two HCPs, usually doctors, who are independent of one another, to assess the patient's eligibility for AD, with regard to (e.g.) the patient's diagnosis, prognosis, and mental capacity to make the decision. For example, in Oregon, the Netherlands, Belgium, Canada and New Zealand, two HCPs must confirm that the patient meets the eligibility criteria. In most of these jurisdictions, the two HCPs must be doctors, but in Canada they may instead be nurse practitioners. The two HCPs should be independent of one another and Oregon law further specifies that one of the doctors must have primary responsibility for the patient's care, while the other must be a specialist in the patient's condition. Additional professionals may also sometimes be involved: e.g., in Belgium, a third doctor must be consulted if the patient's death is not expected in the short term,[158] while in New Zealand, a psychiatric opinion must be obtained if there are doubts about a patient's competence.[159] In Belgium and the Netherlands, the opinion of the second doctor (or third when the request relates to mental illness) is not binding. In Canada, both physicians must agree that the eligibility criteria are fulfilled, but there is no explicit prohibition on asking another physician until a second approval has been received. The Quebec End-of-Life-Care Commission has recently felt the need to remind physicians that *"shopping"* for a second opinion is not appropriate, but it is unclear if any consequences might flow from doing so.[160]

3.29. There are arguments for and against involving two (or more) doctors in assessing the patient's eligibility for AD.

3.30. Arguments in favour of involving two doctors in assessment:

- Involving two doctors may provide support to, and help to safeguard, patients. The involvement of a second professional may enhance objectivity and reduce the risk of misinterpretation, mistakes or abuse by a single professional. It may also lead some patients to reconsider their request for AD. From their interviews with patients with psychiatric conditions in Belgium who had requested AD, Verhofstadt et al found that

[158] There are also additional procedural safeguards in Canada for assessing the eligibility of someone whose death is not reasonably foreseeable.
[159] BMA, Physician-assisted dying legislation around the world, August 2021. https://www.bma.org.uk/media/4402/bma-where-is-pad-permitted-internationally-aug-2021.pdf [accessed 1 October 2023].
[160] J Serebin. Quebecers no longer seeing doctor-assisted deaths as exceptional, says oversight body. *Toronto Star* (15 August 2023): https://www.thestar.com/politics/quebecers-no-longer-seeing-doctor-assisted-deaths-as-exceptional-says-oversight-body/article_5861b771-4670-5f59-afb3-943e243c8cb8.html.

engagement with the process enabled some patients *"to reconsider alternatives towards life, and also to attempt new treatment options"*.[161]

- Involving two doctors may also provide safeguards for, and reassurance to, the professionals themselves, by reducing the likelihood of errors and the risks of being legally called to account.

3.31. Arguments against involving two doctors in assessment:

- Involving two doctors inevitably prolongs the process from the point of request to the provision of assistance in dying, imposing a burden on patients and potentially worsening their suffering. Most of Verhofstadt et al's participants described a *"long and exhausting assessment procedure"*, which they viewed *"as a medical favour that they had to plead for"*, rather than designed to support *"a self-chosen death"*.[162] (Note, however, that as they were patients with psychiatric conditions, these individuals were required to engage with at least three doctors.)

- Rather than enhance objectivity, involving two doctors may just add another layer of subjectivity, by adding another professional to the process, who may interpret the patient's situation differently. However, adding a Tribunal (see 3.35ff) and/or training for doctors may help to reduce such subjectivity (although this is likely to remain to some extent, especially if AD is to be allowed on the basis of "unbearable suffering"; see 2.23).

- It may be queried whether or what extent the two doctors would be *"independent"*, as is proposed, given that Jersey has only 946 registered doctors, presumably many of whom know or work with one another.[163]

3.32. Although involving two doctors would inevitably lengthen the AD process and potentially burden the patient, doing so appears to be appropriate as this may provide safeguards for, and assurances to, both patients and professionals. The risk that this would merely add another subjective assessment may be partially addressed through the provision of training and/or requiring additional approval by a Tribunal. We also endorse the fact that provision has been made in the proposals to ensure that other professionals, who have the requisite expertise, will be involved in helping to assess a patient's eligibility in situations where the assessing doctors require such input,[164] e.g., a psychiatrist, geriatrician, psychologist or specialist social worker may assist in determining the patient's decision-making capacity.[165]

3.33. However, thought should be given to whether or to what extent it would be possible to ensure that the two doctors are *"independent"* and how the requisite independence might be achieved.

3.34. We also believe that the risk of *"doctor shopping"* (3.28) is absent (or at least significantly reduced) under the proposed Jersey model, since the Jersey Assisted Dying Service – i.e., a single, State-run service – would provide patients with a central point of entry to assessing

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[161] M Verhofstadt, et al. The impact of the euthanasia assessment procedure: a qualitative interview study among adults with psychiatric conditions. *BMC Psychiatry* 2022; 22: 435.
[162] Verhofstadt et al (note 161).
[163] Jersey medical practitioners register (gov.je) [Accessed: 16 August 2023.]
[164] Assisted Dying in Jersey Consultation Report (October 2022), para 155, 156.
[165] Assisted Dying in Jersey Consultation Report (October 2022), Appendix 1, p100, para 23.

doctors, and an appeals procedure would provide an avenue for challenging a refusal or approval (see further chapter 7). We understand that patients who are deemed ineligible by the Coordinating Doctor would have a right to a second opinion at this stage (after which, if approved, their eligibility would be assessed by an Independent Doctor or, if not approved, they would be denied AD as ineligible). This right to a second opinion aligns with the position regarding treatment generally,[166] and we assume that the second opinion doctor must also be registered with the Jersey Assisted Dying Service. If that assumption is correct, then the risks of *"doctor-shopping"* appear to be minimal or absent. However, we would welcome assurance that our assumption is correct and, for the avoidance of doubt, suggest that any final proposal should make it explicit that the second opinion must also be sought from within the Jersey Assisted Dying Service, so as to avoid *"doctor shopping"*.

Approval following assessments by two doctors and a Tribunal

3.35. The proposed Route 2 (unbearable suffering) approval process would (inter alia) involve two doctors, as well as a Tribunal, confirming that the patient is suffering unbearably (see 3.4).

3.36. Various jurisdictions have reporting requirements, which usually involve *retrospectively* notifying a relevant authority that an assisted death has taken place (see also 8.3). However, some jurisdictions require *prospective* review and approval by a relevant authority, in addition to those doctors or other professionals that are involved in assessing eligibility. For example, in Spain, an Evaluation Commission *"is required to carry out a verification of the requirements prior to the procedure, not just a posteriori, as in other laws"*; specifically, two members of the multidisciplinary Commission – a doctor and a lawyer – must verify that the process has been followed correctly.[167]

3.37. There are arguments for and against involving a Tribunal in assessing the patient's eligibility for AD.

3.38. Arguments in favour of involving a Tribunal in assessment:

- Involving a Tribunal, as well as two doctors, helps to further safeguard patients and guarantee that eligibility criteria are met. Commenting on the Spanish system, Velasco Sanz et al note that the presence of these *"three filters"* can *"ensure that the person is being well cared for and that their decision is deliberate, free and voluntary"*.[168] Such forms of prospective review – adopted also in New Zealand and Colombia – aim *"to increase compliance with each jurisdiction's specific safeguards and legal criteria as well as to protect vulnerable patients"*.[169]

- The involvement of a Tribunal may enhance objectivity and reduce the risk of misinterpretation, mistakes or abuse by the professionals involved. There may be

[166] In its response to the consultation, the GMC felt that it may be *"unnecessarily inflexible"* to *"limit a patient's right to a single second opinion only"*, which it also judged to be out of line with its guidance in this are: see Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.82.
[167] TR Velasco Sanz, et al. Spanish regulation of euthanasia and physician-assisted suicide. *Journal of Medical Ethics* 2023; 49: 49-55.
[168] Velasco Sanz et al (note 167).
[169] S Riley. Watching the watchmen: Changing tides in the oversight of medical assistance in dying. *J Med Ethics* 2023; 49(7): 453-457.

particular risks associated with allowing AD on the basis of "unbearable suffering" (see 2.23), which a Tribunal may help to ameliorate.

- Involving a Tribunal may provide further safeguards for, and reassurance to, HCPs. Involving a Tribunal may ameliorate the potential emotional and ethical burden of HCPs, by providing reassurance that they are acting appropriately in line with the law. Such involvement may also reduce the likelihood of errors and the risks of being legally called to account.

- A broadly composed Tribunal, which includes members that are not doctors, may somewhat address concerns about excess medicalisation (see 3.13ff). Including lawyers may also address arguments that AD should be placed more squarely within the legal domain (see 3.19).

3.39. Arguments against involving a Tribunal in assessment:

- Involving not only two doctors but also a Tribunal inevitably prolongs the process from the point of request to the provision of assistance in dying, imposing a burden on patients and potentially worsening their suffering. Commenting on Spain, Velasco Sanz et al note that *"this excess of guarantee has also been criticised for being excessively complex and for exceedingly prolonging the time until the procedure is performed (at least 40 days), bearing in mind that, according to the experiences of other countries, many of the applicants are in an end-of-life situation"*.[170]

- Creating and running a Tribunal has human and financial resource implications (e.g., costs to recruit, train and reimburse members, and to set up, run and monitor processes, etc.). The value of doing so should be balanced against the anticipated volume of Route 2 cases that might arise annually – if numbers are expected to be low (if Route 2 is offered at all), then it may be queried whether creating and running a Tribunal is an appropriate use of public funds. Furthermore, a low caseload may raise doubts about whether its members will have sufficient work to build up and retain the requisite skills and knowledge.

- Involving a Tribunal would neither eradicate subjectivity nor ensure total unanimity and consistency, as it is possible (for example) that tribunal members may have different views on whether a patient is unbearably suffering.

3.40. Although involving two doctors and a Tribunal would require resources and inevitably lengthen the AD process and potentially burden the patient, doing so appears to be appropriate as this may provide safeguards for, and assurances to, both patients and professionals. In particular, a Tribunal may reduce the subjectivity inherent in assessing the *"unbearable suffering"* of a patient under Route 2 and the risks associated with this, although it would not eradicate this.

Requiring two different approval systems

3.41. We were also asked to consider the proposal for having two different approval routes for terminal illness (Route 1) and unbearable suffering (Route 2), respectively. For reasons set out in the discussion of eligibility (chapter 2), the authors have significant ethical reservations

[170] Velasco Sanz et al (note 167).

about allowing AD on the basis of unbearable suffering. What is discussed here is whether, if the decision is nevertheless made to allow AD on these two bases, it is reasonable to make a distinction between two routes.

3.42. There are arguments for and against having a two-track approval system.

3.43. Arguments in favour of having a two-track approval system:

- The main argument in favour of having a two-track approval system is that this reflects the differences between the two types of cases, including their different risk profiles. For Aristotle, formal justice requires that like cases should be treated alike, which entails that different cases may be treated differently.[171] As previously detailed (chapter 2), there are significant, qualitative differences between AD as a response to terminal illness and AD as a response to unbearable suffering, which a two-track system would seem to reflect. These differences raise additional concerns about the risks to individuals and the broader impact on the societal valuing of the lives of older people and people with disabilities who are not approaching their deaths. For such reasons, the authors have serious reservations about Route 2. The position that it is reasonable to only allow Route 1 logically supports a principled distinction between the two routes. Here we engage simply with the question of whether it is appropriate to have two different routes, if both were to be allowed.

3.44. Arguments against having a two-track approval system:

- Some respondents to the consultation rejected the two-track approval system on the basis that it may be considered unjust, unequal, or inequitable; e.g., the Channel Islands Humanists believe *"that the two routes are unnecessary and discriminatory"*, and End of Life Choices Jersey consider the distinction to be *"cruel, discriminatory and irrational"*.[172]

- The existence of two approval routes may create complexity and confusion over which Route to follow. Questions might also arise in relation to patients who would appear to be eligible under either Route (see also 2.26, 4.13).[173]

3.45. On balance, we believe that having distinct approval Routes reflects the fact that the two Routes concern qualitatively different situations, involving different considerations and assessments, and presenting distinct risks. For such reasons, it is plausible to argue that there is no injustice, inequality or inequity in treating these different cases differently. We recognise, however, that the presence of two Routes creates the potential for confusion, so we suggest that, if Route 2 were to be permitted, professionals (and potentially others) would at least need training and guidance on which Route to follow in which circumstances.

[171] Aristotle, *Nicomachean Ethics*, V.3. 1131a10-b15; *Politics*, III.9.1280 a8-15, III. 12. 1282b18-23.
[172] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.91.
[173] See Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.44.

Chapter 4: Timeframes

4.1. The two Routes have different proposed (minimum) timeframes between the request for, and the provision of, AD: 14 days for Route 1 (terminal illness) and 90 days for Route 2 (unbearable suffering).

4.2. There are general arguments for and against stipulating *some* timeframe, irrespective of its proposed duration.

4.3. Arguments in favour of stipulating a timeframe:

- The main such argument is that having a timeframe creates *"a suitable 'cooling-off period'"*, which provides a safeguard, e.g., by allowing time to ensure that the patient is eligible and has made a considered and enduring decision, and that other options can be adequately explored.[174]
- Furthermore, specifying precise timeframes has the advantage of providing clarity and certainty to patients and professionals alike.

4.4. Arguments against stipulating a timeframe:

- Some have expressed concerns about prolonging a patient's suffering, including some respondents to the consultation.[175]
- Others suggest that there is essentially no need to confirm the autonomy of the patient's decision, as they are likely already to have reflected sufficiently and have reached a stable decision; for example, Dignitas made this point in its response to the consultation.[176]
- Furthermore, Glover has referred to arguments which claim that, in some situations, *"a cut-off point anywhere […] is bound to be arbitrary and so hopeless to justify"*.[177] He gives the example of speed limits, and asks *"how can a speed limit of thirty miles an hour possibly be defended as better than one of twenty-nine or thirty-one miles an hour?"*[178]

4.5. We suggest that it is appropriate to specify some timeframes, because doing so can provide a safeguard, clarity and certainty. Glover also helps to explain why specifying a timeframe(s) of some duration is appropriate. In response to the question he posed about speed limits, Glover suggests that there may be discernible differences in safety outcomes, such that it may be possible to propose a range of safe speeds. As such, he concedes that the precise limit that is chosen within the given range may be somewhat arbitrary. Yet, choosing a precise limit may still be appropriate because *"blurred limits are less effective than precise ones"*.[179] (We would add that failing to specify a limit may also leave too much to the discretion of individuals, such that some would travel too slowly and others too fast, either of which may present concerns about safety.) Such reasoning would seem to apply here, i.e., the choice of any particular timeframe may be somewhat arbitrary, but precision may be preferable to imprecision. As for

[174] A Samuels, Assisted dying. *Medico-Legal Journal* 2022; 90(1): 49-51.
[175] E.g., Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.73.
[176] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.73.
[177] J Glover, *Causing death and saving lives* (Penguin, 1977), p.166.
[178] Glover (note 177), p.166.
[179] Glover (note 177), p.166.

which precise timeframes should be adopted, Glover implies that the choice of a particular timeframe may be justified if it occupies the range of timeframes within which safety (eligibility, autonomy, etc.) can be best assured, balanced against other relevant considerations (e.g., prolonging the suffering of the patient). These observations lead us to consider the specific timeframes that have been proposed for a Jersey AD law.

4.6. There are arguments for and against the specific timeframes proposed for Routes 1 and 2.

4.7. Arguments in favour of the proposed timeframes:

- The proposed 14 day timeframe for Route 1 (terminal illness) is, as the consultation noted, *"in line with legislation in the US, Spain, Austria and the proposals set in the UK assisted dying Bill and Scottish consultation"*.[180] This (shorter) duration appears to allow *"sufficient time for all assessments to be completed, and time for the Assessing Doctors to be confident that the request for an assisted death is enduring, whilst not unduly extending any suffering and uncertainty for the person"*.[181]

- The proposed 90 day timeframe for Route 2 (unbearable suffering) is, as the consultation noted, *"in line with legislation in Canada and Austria"* (although, regarding Canada, please see further 4.8).[182] This (longer) duration recognises that the situation of Route 2 candidates *"is fundamentally different from a person who has a terminal illness"* (i.e., Route 1) and the extended timeframe appears to allow *"time for additional assessments and opinions to be sought and confirmation that the request is enduring, as well as time to ensure that all other options for the person have been explored in terms of treatment, pain relief and the provision of any other services that may be able to alleviate the person's suffering"*.[183]

4.8. Arguments against the proposed timeframes:

- Some other jurisdictions do not adopt the proposed minimum timeframes or indeed any minimum timeframe, so there are precedents for taking an alternative approach. For example, there is no minimum timeframe in Canada, Belgium, the Netherlands, and New Zealand. The consultation report suggested that the rationale for these jurisdictions not requiring a minimum timeframe is *"that by the time a person makes a formal first request, they have already carefully considered their decision and the minimum timeframe can prejudice those who request an assisted death when they are already very close to the end of their life"*.[184]

- The overall response to the consultation did not show majority support for the proposed 14 day timeframe for Route 1 (terminal illness).[185] Some, such as the Association of Palliative Medicine, felt this was too short to ensure that any decision was appropriately informed;[186] others felt this was too long and may prolong a patient's suffering; and others felt that 14 days would strike the appropriate balance.

[180] Assisted Dying in Jersey Consultation Report (October 2022), para 76.
[181] Assisted Dying in Jersey Consultation Report (October 2022), para 76.
[182] Assisted Dying in Jersey Consultation Report (October 2022), para 76.
[183] Assisted Dying in Jersey Consultation Report (October 2022), para 76.
[184] Assisted Dying in Jersey Consultation Report (October 2022), para 76.
[185] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.72.
[186] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.73.

- The overall response to the consultation showed clear disagreement with the proposed 90 day timeframe for Route 2 (unbearable suffering).[187] Most respondents preferred a shorter timeframe, to avoid prolonging a patient's suffering, with some suggesting it would be just to use the same timeframe as for Route 1. Other respondents preferred a longer timeframe, e.g., to enable access to mental health support or palliative care.

- The 90-day timeframe may not be sufficient to alleviate concerns that persons with disabilities may be unduly induced to end their lives in circumstances in which a (potentially reversible) loss of hope, which may arise from familial, economic or social circumstances, contributes to their request for AD. In the Canadian context, the 90-period period has been described as *"grossly inadequate"*, since wait times for specialised health care – such as specialised pain treatment and mental health care, and obtaining disability support and access to specialised long-term-care or support for home care – significantly exceed the 90-day period.[188,189]

4.9. We believe that imposing specific, and distinct, timeframes is appropriate. Timeframes have the advantage of providing clarity and certainty (see 4.5). We appreciate that a patient's suffering might be prolonged by the imposition of minimum timeframes, but we believe this could be defensible in view of the reassurance and safeguards they might offer. Imposing minimum timeframes appears to offer a balance between access to AD and protection (e.g., ensuring there is time for reflection and further assessments/treatment). We emphasise that these should be considered *minimum* timeframes, in view of the gravity of the decision and the need for caution regarding any form of AD.

4.10. Having two *distinct timeframes* for the different Routes reflects the fact that the two Routes concern qualitatively different situations, involving different considerations and assessments, and presenting distinct risks. Different judgments may accordingly be required in each case, for which different processes and checks are merited. As previously discussed (chapter 2), Route 1 (terminal illness) requests appear to be more amenable to objective measurement and may be more pressing, given the limited life expectancy of the patient, which supports a shorter timeframe; in contrast, Route 2 (unbearable suffering) requests may be associated with more subjective judgments and require more careful assessments, which supports a longer timeframe. For such reasons, it is reasonable to argue that there is no injustice, inequality or inequity in treating these different cases differently, whether by only allowing AD in one of the cases (Route 1) or by allowing this in both cases but then imposing different access criteria and timelines.

4.11. Turning to the *specific timeframes* that have been proposed, these may be supported as they mirror some existing regimes, and appear to strike an appropriate balance between providing safeguards and not prolonging a patient's suffering. However, we note that these proposals did not command significant support from respondents to the consultation. Moreover, the Canadian evidence suggests that a 90-day timeframe for Route 2 may be insufficient, unless (at a minimum) access to other sources of support can be expedited (see 4.8). However, we find it difficult to propose a timeframe that could assuage our serious concerns about Route 2.

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[187] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.75.
[188] T Lemmens, L Krakowitz-Broker. Why the federal government should rethink its new medical assistance in dying law. CBC (10 November 2020) online: https://www.cbc.ca/news/opinion/opinion-medical-assistance-in-dying-maid-legislation-1.5790710.
[189] Coelho et al (note 29).

4.12. The proposals for specific timeframes should also be considered in connection with an important issue around potential treatment options and options for relief of suffering, which we discussed in relation to eligibility (chapter 2). Route 2 contains as a key access criterion the *"incurable"* nature of a condition that causes *"intolerable suffering"*. Route 1 specifies that it is for *"suffering that cannot be relieved in a manner that the person finds tolerable"*. Both formulations raise questions about whether AD can be offered when treatment or support options are available and there is a reasonable expectation that the person requesting AD can still be successfully treated and/or receive sufficient support that will make their experience tolerable. In the discussion around eligibility, evidence is provided of how much time it may take to learn to cope with the challenges of a newly acquired chronic illness or disability and to build resilience. Any specific timeframes prescribed by law should be seen as a minimum, as is indeed proposed. Particularly when persons are not approaching their deaths, professional guidance should be developed to ensure that adequate efforts are made to ensure that AD is truly a last resort, and not a solution to situations of suffering which may be temporary or addressed by some other means.

4.13. We further appreciate that the presence of two Routes with different timeframes creates the potential for confusion, and questions might also arise in relation to patients who would appear to be eligible under either Route (see also 2.26, 3.44).[190] To address such concerns, we suggest that professionals (and potentially others) would at least need training and guidance on which Route to follow in which circumstances.

[190] See Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.44.

Chapter 5: Conscientious objection and discussions with patients

General arguments for and against a right to conscientiously object

5.1. Before considering the question of conscientious objection (CO) in relation to AD, it is useful to understand the broader context of CO and the existing legal, professional and ethical principles that apply to health care provision. The main arguments in favour of, and against, allowing CO by HCPs are summarised below.

5.2. Arguments in favour of allowing CO:

- Respects Article 9 of the European Convention on Human Rights (ECHR), which protects religious freedom and conscience: *"Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief and freedom, either alone or in community with others in public or private, to manifest his religion or belief in worship, teaching, practice and observance."* This right is subject to limitations prescribed by law and necessary in the interests of public safety, public order, health or morals, or for the protection of the rights and freedoms of others.

- Compatible with professional ethical guidance provided by the General Medical Council (GMC).[191] The GMC supports a broad right to conscientiously object.[192] This allows doctors to *"practise medicine in accordance with their beliefs"* and to *"choose to opt out of providing a particular treatment because of [their] personal beliefs and values, as long as this does not result in direct or indirect discrimination against, or harassment of, individual patients or groups of patients."* As with article 9 ECHR, this means that the right to refuse to provide a treatment is subject to limitations prescribed by law, e.g., in The Equality Act 2010. This approach has been supported by the British Medical Association (BMA).[193] We also note that the GMC (and NMC) expressed its support for the inclusion of a CO clause within the Jersey law on AD;[194]

- Compatible with professional ethical guidance provided by the Nursing and Midwifery Council (NMC). The NMC supports only a limited right to object under statutory principles (provided in the Abortion Act 1967 and Human Fertilisation and Embryology Act 1990). Code 4.4 states that nurses and midwives must notify colleagues, managers and patients that they have a CO to a particular procedure, and they must arrange for a suitably qualified person to take responsibility for the care of the patient.[195] We also note that the NMC (and GMC) expressed its support for the inclusion of a CO clause within the Jersey law on AD;[196]

[191] Jersey-based doctors are regulated by the GMC.
[192] General Medical Council. Personal Beliefs and Medical Practice. [Accessed 22 September 2023.]
[193] E.g., British Medical Association. Expression of doctors' beliefs. [Note that this document, which appears to date from 2016, was not found on the BMA website and it is possible that it has been superseded by subsequent guidance.]
[194] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.54.
[195] Nursing and Midwifery Council. Conscientious objection by nurses, midwives and nursing associates. [Accessed 22 September 2023.]
[196] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report (April 2023), p.54.

- Respects the personal moral integrity and autonomy of individuals, and thus avoids placing them in a distressing position in which they are forced to behave contrary to their values and/or beliefs.[197]

5.3. Arguments against allowing CO:

- Personal values should not influence the care provided by doctors and nurses because this opens the door to *"idiosyncratic, bigoted, discriminatory medicine"*;[198]
- Patients may struggle to access treatment if CO is permissible, because they may find it difficult to find doctors willing to provide the treatment.

5.4. In light of these arguments, the law could adopt one of three positions: first, an *absolute right to object*, in recognition of the arguments in favour; second, *no right to object*, in recognition of the arguments against; or, third, a *limited right to object*, in recognition of the arguments on each side.[199] Section 4 of the Abortion Act 1967 provides an example of the third option, in recognising a right to refuse to participate in abortion treatment, which this is limited because a doctor may not excuse themselves if a woman is at risk of death or grave permanent injury.

5.5. Generally, allowing a limited right to object appears to strike an ethically appropriate balance, since it seeks to balance the interests of both the HCP and the patient by allowing professional refusal, provided that the patient is still able to access services elsewhere and is not abandoned.[200]

Conscientious objection to direct participation in assisted dying

5.6. Turning to AD specifically, it has been suggested, for example by Wicclair,[201] that CO to (direct provision of) AD is easy to justify because AD is a controversial practice. The argument is that, if a treatment falls outside the central aim of medicine (to heal/cure), there is greater scope for respecting the moral convictions and personal integrity of HCPs because the patient is not directly harmed by a refusal.[202] This argument, that AD falls outside the traditional goals of medicine, is compelling because assisted dying is not curative and, rather than aiming to extend or improve life, it serves to end life.[203] Thus a refusal to provide AD does not harm the patient according to the usual goals of medicine, and some HCPs, as outlined in chapter 3, believe that AD is incompatible with the provision of healthcare (3.8).[204] It can also be argued that this differentiates CO in the context of AD from the abortion context, since the objection

[197] MR Wicclair. Is conscientious objection incompatible with a physician's professional obligations? *Theor Med Bioeth* 2008; 29: 171-185.
[198] J Savulescu. Conscientious Objection in Medicine. *BMJ* 2006; 332: 294.
[199] J Cantor, K Baum. The Limits of Conscientious Objection: May Pharmacists Refuse to Fill Prescriptions for Emergency Contraception? *N Engl J Med* 2004; 351: 2008.
[200] MR Wicclair. Preventing conscientious objection in medicine from running amok: A defense of reasonable accommodation. *Theor Med Bioeth* 2019; 40: 539-564.
[201] MR Wicclair. Conscientious Objection in Medicine. *Bioethics* 2000; 14(3).
[202] This position has previously been supported by two of the authors of this report: R Huxtable, A Mullock, Voices of Discontent? Conscience, Compromise and Assisted Dying. *Medical Law Review* 2015; 23(2): 242-262.
[203] E.g., LR Kass. Neither for Love nor Money: Why Doctors must not Kill. *Public Interest* 1989; 94: 25.
[204] Kass (note 203).

there is not focused directly and primarily on protecting the wellbeing of the patient and respecting their own life.

5.7. In recognition of these specific arguments, as well as the more general arguments for protecting conscience (5.2), we believe that any law to allow AD should also permit a HCP to conscientiously object to direct participation. In all jurisdictions where AD is lawful, HCPs have the right to conscientiously object. In some jurisdictions, the HCP is removed from any obligation to be involved or participate (e.g., Switzerland, Belgium, and the Netherlands). In other jurisdictions, the right to conscientiously object nevertheless carries an obligation to refer the patient on to another colleague or organisation that is willing and able to assist (e.g., Oregon, New Zealand, and some Canadian provinces, such as Ontario).[205,206] In others, the right does not necessarily exclude the HCP from an obligation to communicate their objection and to cooperate to some (minimal) extent, e.g., through a timely transfer of medical records, and to the provision of basic information.[207,208,209,210] This alerts us to the important question of whether Jersey HCPs who choose to conscientiously object should have an obligation to refer the patient to a colleague who is not conscientiously opposed to participating.

Conscientious objection and the obligation to refer

5.8. Arguments against an obligation to refer:

- Some may be concerned that, by referring a patient to a colleague, they will remain complicit in a practice to which they object (sometimes called the *"dirty hands"* problem).[211]
- There are other options that facilitate patients' access to a physician who may be willing to provide the practice, such as an obligatory publication of information in the office of

[205] For an overview of the various formulations in Canadian provinces, some requiring *"effective referral (or transfer"*, others only relevant information to enable a timely transfer, see: S Czajkowski, S Murphy, EC Goligher. Freedom of Conscience and Medical Assistance in Dying—Clinical Perspective. In J Kotalik, D Shannon, eds, *Medical Assistance in Dying (MAID) in Canada: Key Interdisciplinary Perspectives* (Cham: Springer 2023), pp. 423-441, in particular the table at pp. 425-428.

[206] See also: D Ross, D Warren. The Importance of Conscience as an Independent Protection. J Kotalik, D Shannon, eds, *Medical Assistance in Dying (MAID) in Canada: Key Interdisciplinary Perspectives* (Cham: Springer 2023), pp. 399-421.

[207] For the Netherlands, see: J Griffiths, H Weyers, M Adams. *Euthanasia and Law in Europe* (Oxford: Hart, 2008), at pp. 107-8 (discussing a recommendation of the Royal Dutch Medical Association to provide basic information, but also pointing out that institutions sometimes require effective referral from their physicians).

[208] For Belgium, see Section 14 of the Euthanasia Law: *"No physician can be compelled to participate in euthanasia. [But the physician] must inform, in a timely fashion, the patient or the potential persons of confidence while explaining his/her reasons… The physician... must communicate, when asked by the patient or the person of confidence, the patient's medical records to the physician designated by the patient or the person of confidence*". For a translation of the Euthanasia Act, see: DA Jones et al (eds), *Euthanasia and Assisted Suicide: Lessons from Belgium* (Cambridge: Cambridge University Press), p.314.

[209] But, regarding Belgium, see also the discussion in: E Montero. The Belgian experience of Euthanasia since its legal implementation in 2002. In DA Jones et al (eds), *Euthanasia and Assisted Suicide: Lessons from Belgium* (Cambridge: Cambridge University Press), pp.38-41, noting growing pressure on institutions and physicians who object.

[210] Regarding some of the Canadian provinces that have an obligation to provide information or information about a central service, see: Zajkowski et al (note 205).

[211] DP Sulmasy. What Is Conscience and Why Is Respect for It so Important? *Theor Med Bioethics* 2008; 29: 135.

objecting physicians (e.g., containing information about a hotline or government information site), rather than requiring the objecting doctor to identify a specific individual.

- The World Medical Association recently reiterated its objection to obliging physicians to effectively refer patients to a physician who is willing to provide AD, although it indicates the obligation to provide information.[212],[213]

5.9. Arguments in favour of an obligation to refer:

- An approach that requires HCPs who conscientiously object to refer to another colleague avoids the risk that a patient will struggle to access assisted dying, and consequently feel abandoned;
- Requiring objecting HCPs to refer would accord with the GMC and NMC ethical guidance (5.2), which instructs members who are conscientiously objecting to arrange for a colleague to take over care if the patient is unable to arrange this for themselves;
- We also note that, if the Jersey proposal includes a requirement that all HCPs involved in providing assisted dying must undertake specialist training (as outlined in the approach indicated), there would be a clear delineation between HCPs willing and qualified to participate and those who are unwilling and/or unable to participate. Provided that sufficient numbers of HCPs choose to undertake the training in order to opt-in to providing assisted dying (see 3.12-3.13), it might be unproblematic for conscientiously objecting HCPs to refer on to a colleague who has opted in.

5.10. In recognition of these specific arguments, as well as the more general arguments for a limited right to object (5.1-5.5), we suggest that in the interests of supporting patients while simultaneously respecting the moral integrity of HCPs who conscientiously object to direct participation in AD, there should be an obligation to inform patients about the fact of a CO, provide patients with general information about accessing AD and how to locate a willing HCP, i.e., in terms of the current proposals, a document or similar directing patients to the Jersey Assisted Dying Service.[214] The objecting HCP should thereafter transfer the relevant medical files as necessary. This obligation to pass on general information should not, however, compel a HCP to directly refer to a specific colleague willing to participate in AD unless the objecting HCP feels that such direct referral is compatible with their ethical stance.

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[212] World Medical Association. WMA Declaration on Euthanasian and Physician-Assisted Suicide: Adopted by the 70th WMA General Assembly, October 2019 (23 November 2021): https:// www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/.

[213] See also: WMA Declaration of Venice on End of Life Medical Care (revised by the 73rd General Assembly, October 2022): https://www.wma.net/policies-post/wma-declaration-of-venice/

[214] This appears to be in line with the recommendation from the World Medical Association: *"The physician must immediately and respectfully inform the patient of this objection and of the patient's right to consult another qualified physician and provide sufficient information to enable the patient to initiate such a consultation in a timely manner"*: WMA International Code of Ethics (revised by the 73rd General Assembly, October 2022): https://www.wma.net/policies-post/wma-international-code-of-medical-ethics/. As discussed in Ross and Warren (note 206), pp.402-403.

Conscientious objection to providing the supporting statement

5.11. When a doctor is asked to provide a supporting statement for a patient seeking AD, this clearly falls within the realm of direct involvement in facilitating AD, and so we suggest that the considerations detailed above (5.6-5.7) apply equally to HCPs involved directly in any aspect of AD. Therefore, doctors asked to provide supporting statements should be permitted to exercise the right to conscientiously object in the same way as other HCPs who are asked to be directly involved in AD.

Conscientious objection to non-direct participation in assisted dying

5.12. For those who work in healthcare, non-direct participation is generally viewed as treatment and/or care that is not linked to AD, i.e., care that a patient requires irrespective of any choice to seek or have AD, and/or administrative duties not directly related to the paperwork required for AD. In relation to HCPs, this question has been considered by the UK Supreme Court in a case involving abortion and indirect care provided by two midwives (*Doogan*). [215] The court interpreted "participation" to mean only direct involvement in the procedure, and so it was held that the midwives did not have a right to conscientiously object to administrative or health care obligations that were not directly related to the abortion.

5.13. One of the criticisms levelled at the *Doogan* decision is that it failed properly to consider the right to freedom of conscience (etc.) under Article 9 ECHR. However, the limited evidence available from cases that have reached the European Court of Human Rights (e.g. *Pichon and Sajous v France*,[216] which involved pharmacists refusing to supply contraceptive medication) suggests that the European Court agrees with the approach in *Doogan* on the basis that personal beliefs should not take precedence over professional obligations. We see, therefore, that in relation to HCPs, a legal and ethical distinction has been drawn between *direct* involvement and *non-direct* involvement, and so the proposal (to allow CO only for direct participation) accords with that position. What constitutes direct involvement may be open to interpretation.

5.14. A related concern was raised in the public consultation regarding non-medical facilitation of AD, such as a driver delivering fatal drugs for the purposes of AD or transporting a patient for AD, and whether they should have a right to refuse to be involved. In either of these examples, the driver might have concerns about *"dirty hands"* (5.8). However, whilst their involvement may be a necessary element of the AD process (in transporting the drugs and/or patient), the nature of their involvement might be considered more akin to non-direct participation (5.12-5.13). Moreover, in the case of the driver transporting the patient, the principles of medical confidentiality indicate that they should not be made aware of a patient's medical treatment because such information has been deemed by the courts to be *"obviously private"*.[217] Consequently, the details of AD, assuming it is lawful only as *"medical treatment"*, should not be shared with anyone not directly involved in the medical care of that person, and so there appears to no strong justification for extending any right to conscientiously object to such indirect work.

[215] *Greater Glasgow Health Board v Doogan and Another* [2014] UKSC.
[216] *Pichon and Sajous v France* ECtHR 2001 X-381.
[217] *Campbell v Mirror Group Newspapers* [2004] UKHL 22.

Conscientious objection by caring facilities

5.15. We were asked to consider whether organisations or individuals that run caring facilities (such as care homes) should be permitted to prevent assisted dying on the premises (hereafter summarised as "CO by caring facilities"). While the right for HCPs to conscientiously object to direct participation in AD is protected in all jurisdictions allowing AD, the question of organisational CO is much less settled. In relation to organisations or non-HCPs, such as those who own or manage residential care home premises in which AD might take place, there are broadly two approaches: either the law states that only HCPs have the right to conscientiously object (e.g., New Zealand), which means that the law does not expressly allow for non HCPs to conscientiously object, or the law states that HCPs *and* organisations may refuse to participate (e.g. Canada). In Switzerland, the law is silent because their approach allows a less medicalised form of assisted dying under an exception to their criminal law, and so the law was not created with assisted dying in mind.

5.16. Arguments in favour of allowing CO by caring facilities:

- Article 9 ECHR is not compromised, and regardless of whether or not such an article 9 claim would be recognised by a court, moral and/or religious integrity is respected and maintained. This may be viewed as being particularly important for any care providers with a religious affiliation.
- The right to refuse to support AD in an organisation is a matter of institutional self-governance; an unwillingness to allow AD on the premises might involve practical and logistical issues beyond questions of conscience.[218]
- Organisations can be upfront about their position in order to enable individuals who anticipate that they might wish to seek AD to avoid placing themselves in a position where access would not be possible on the premises.
- Individuals who are opposed to AD can choose care options that carry no risk of unwanted exposure to AD, e.g., if they feel distressed that AD might be offered in their place of residence (home), and/or are concerned that an organisation allowing AD will offer this in a way that encourages it. Allowing CO for institutions enables such individuals to choose a *"safe space"* in which to live or receive care at a time of significant vulnerability.
- The majority of respondents (58.7%) to the public consultation expressed support for allowing the owners of premises to refuse to allow AD within their organisation.

5.17. Arguments against allowing CO by caring facilities:

- Some individuals might be prevented from accessing AD, which might be distressing for them. For example, some evidence from Canada shows that some patients have effectively been prevented from accessing AD because the faith-based caring facility in

[218] P Shadd, J Shadd. Institutional Non-Participation in Assisted Dying: Changing the Conversation. *Bioethics* 2019; 33: 207-214.

which they resided created logistical obstacles, which made it difficult or impossible to arrange AD.[219]

- Some individuals will only be able to access AD if they arrange to be moved to a different venue, which means they would be denied the comfort of dying at *"home"* in a familiar setting. For example, in Canada it has been reported that in two organisations providing AD, 9.5% and 15% of patients were *"transferred"* there to access AD because their caring facilities refused to allow AD.[220]

- Organisations offering professional residential care and medical services have an ethical obligation to allow AD if it is lawful. Personal beliefs should not be permitted to interfere with an individual's choice to seek and obtain AD.

5.18. A related concern, regarding the funding of residential care homes, was raised in the public consultation. There is evidence that, in some jurisdictions which allow AD where there is no right of institutional objection, such as Canada, organisations that have refused to allow AD on their premises have suffered detrimental public funding consequences.[221,222] We therefore note that, if Jersey law were not to provide a right for care homes and similar organisations to conscientiously object, this may raise ethical issues about coercion if funding were to be withheld on that basis.

5.19. There are compelling arguments for and against allowing objections by caring facilities. On balance, we suggest that the arguments in favour of allowing organisations to opt out of allowing AD are more powerful, and we note that the public consultation clearly supports this position.

Discussing assisted dying with patients

5.20. We were also asked to consider what (if anything) the law should say regarding HCPs discussing AD with patients. The law could adopt one of three options: first, the law could place an express obligation upon HCPs to initiate a *discussion* with every patient who might be eligible; second, the law could be *silent* on the issue of HCPs raising the subject of AD with patients; and, third, the law could *prohibit* a HCP from initiating a discussion about AD.

5.21. The first option, which would *require* HCPs to initiate AD discussions with potentially eligible patients, would clearly conflict with the ethical principles supporting the right of HCPs to conscientiously object (5.2), and so we suggest that it would be unethical to place upon all HCPs an obligation to initiate a discussion about AD. Concerns have also been expressed about the promotion of such discussions in Canada, which at least the leading organisation of MAID assessors and providers considers to be a *"professional obligation"*; according to Kim, *"Even when MAID [medical assistance in dying] is legal, it should be an exception to the practice of*

[219] E Close, R Jeanneret, J Downie, J. et al. A qualitative study of experiences of institutional objection to medical assistance in dying in Canada: ongoing challenges and catalysts for change. *BMC Med Ethics* 2023; 24: 71.
[220] Close et al (note 219).
[221] T Carpenter, L Vivas. Ethical arguments against coercing provider participation in MAiD in Ontario, Canada. *BMC Medical Ethics* 2020; 21: 46.
[222] See also the suggestion of pressure in Belgium: Montero (note 209).

medicine, not something to be taken into its very bosom".[223] Consequently, we hereafter focus on the question of whether the law should remain silent or prohibit the initiation of discussion.

5.22. In most jurisdictions where AD is lawful, the law is *silent*, allowing HCPs to exercise professional discretion over whether or not they raise the topic of AD. Alternatively, however, the law could expressly *forbid* HCPs from initiating a discussion about AD before a patient has asked about it. This approach has been adopted in New Zealand and the Australian province of Victoria, where section 8 of the Voluntary Assisted Dying Act 2017 (Vic) provides a *"gag clause"*. This position reflects a concern that, by raising AD, a HCP might be seen to be encouraging it, which might influence a patient who would not otherwise have considered AD. Indeed, depending on the way that a HCP might raise the option of AD, a patient might interpret this as a recommended option, and/or they may feel that their life is no longer as valued by that HCP, and/or that they are a burden and therefore ought to seek AD (see also 2.23). Patients' hope and resilience may be undermined by a perceived recommendation of AD, particularly when they receive this information at the same time as receiving a bad diagnosis.

5.23. The conflicting concern is that if HCPs must not mention AD, some patients who would wish to discuss AD will either not be aware that it is permissible, or they might worry that it would be inappropriate to ask about AD because it is a sensitive and contentious matter. Critics of the approach in Victoria have argued that this clause infringes upon the professional and ethical obligations of doctors.[224] This argument suggests that doctors have a duty to inform patients of all clinical options, and to be honest.

5.24. In response to the public consultation, the GMC expressed a view that the law should be silent because a gag clause would prevent doctors from exercising judgement and/or having open discussions that are beneficial for the patient. Both the GMC and the NMC suggested there should be guidance about how to manage conversations about AD with patients and the NMC suggested that such conversations should be carefully documented. Pullman's research into practice in Canada confirms the need for such guidance and documentation, since *"how [a] professional interacts with the patient can do much to influence the patient's decision, irrespective of [any] intent to be non-directive"*.[225]

5.25. The authors overall agree that, in an end-of-life route (i.e., Route 1), the law should neither require HCPs to initiate AD discussions with potentially eligible patients nor prohibit them from discussing AD. The ethical concerns over HCPs raising AD in a manner that would present risks to patients are important, but in the interests of honest information-sharing we agree with the GMC that this should be a matter of guidance rather than law (5.20-5.25). Professional guidance should address concerns about how to avoid potential pressure and about timing of providing information.

5.26. Route 2 raises additional concerns over explicitly introducing AD as an option. When a person is not approaching their natural death, offering AD would convey to the person (who may potentially have years or decades of life remaining) the message that death is a reasonable option for them. Many people with disabilities would consider this to be offensive, as it would

[223] S Kim. In Canada, MAID has become a matter of ideology. *The Globe and Mail*, 25 February 2023.
[224] B Moore, C Hempton, C Kendal. Victoria's Voluntary Assisted Dying Act: Navigating the section 8 gag clause. *Med J Aust* 2020; 212(2).
[225] Pullman (note 62).

convey a message that death is a reasonable option for persons faced with a disability or chronic illness. There is a heightened concern about how this may impact on resilience. For such reasons, it would appear to be appropriate to prohibit in law offers for AD to persons who are not approaching their deaths.

5.27. In conclusion, the ethical value of open and honest information-sharing, to empower patients to make informed decisions about their care, supports the position of legal silence outlined in the proposal. A gag clause would prevent HCPs from exercising their honest professional judgement in the best interests of the patient. We agree with the GMC and NMC that this requires professional guidance. We also suggest that the mandatory training for HCPs expecting to participate in AD should cover this issue to minimise any risk that raising the option of AD might be interpreted by a patient as encouraging or recommending it. However, if Route 2 is to be allowed, then it appears appropriate to adopt a gag clause in this context, i.e., beyond the end-of-life context.

Chapter 6: Mode

Defining "self-administration" and "practitioner-administration"

6.1. The mode of AD may differ according to who performs the final, fatal step:

- Self-administered AD is sometimes termed "assisted suicide" (AS) or, if a doctor is involved, "physician-assisted suicide" (PAS). Here, the patient takes the final, fatal step, e.g., the patient consumes the lethal drugs that have been supplied or prescribed by a doctor following the patient's request.
- Practitioner-administered AD is sometimes termed "voluntary euthanasia". Here, someone other than the patient takes the final, fatal step, e.g., a doctor lethally injects the patient at their request.

6.2. Some jurisdictions only allow AD in the form of self-administration (e.g., some US States, Switzerland, and Victoria in Australia). Other jurisdictions allow both self-administration and practitioner-administration, and patients are able to choose which option they prefer (e.g., Netherlands, Canada, New Zealand). In Belgium, the position is more complicated as the law only explicitly prescribes practitioner-administration, although the federal euthanasia control and evaluation commission appears to have *"read into"* the law that prescription of lethal medication for self-administration is also permitted.[226]

Similarities between self-administration and practitioner-administration

6.3. There are various arguments about the different respective merits of self-administration and practitioner-administration (see below, 6.11-6.25). Before we reflect on these, we note some of the areas of similarity between the two modes, which have been mentioned by both supporters and opponents of AD.

6.4. *Justification*. Subject to some further observations below, the presumed ethical justifications are the same for both modes, i.e., to respect the autonomous wish of the patient and/or act to relieve their suffering. For many supporters, this means that either or both self-administration and practitioner-administration can be supported in principle

6.5. *Motivation, intention, and causation*. In both modes, a second party is motivated to assist in ending the patient's life (in order to respect their autonomous wish and/or relieve their suffering), intends to bring about this outcome, and plays a necessary causal role in bringing about that outcome. Given these similarities, some opponents of AD claim that the assumed distinction between self-administration and practitioner-administration is of little ethical significance.[227]

[226] See H Nys. A Discussion of the Legal Rules on Euthanasia in Belgium Briefly Compared with the Rules in Luxemberg and the Netherlands. In DA Jones et al (eds), *Euthanasia and Assisted Suicide: Lessons from Belgium* (Cambridge: Cambridge University Press), p.7, at p.10.
[227] J Keown. *Euthanasia, Ethics and Public Policy: An Argument Against Legislation* (Cambridge University Press, 2002).

6.6. *The role of the doctor*. If doctors are to be involved in the provision of AD, then their involvement in either mode may generate concerns about whether such participation aligns with the professional ethical obligations of doctors (see further 3.8ff).

6.7. *The intrinsic value of life*. Since both modes of AD involve deliberately bringing about the death of a patient, both may be judged to violate the intrinsic value of human life, and in doing so may violate religious objections to AD (e.g., as described in terms of *"the sanctity of human life"*)[228,229,230] AD may also confront human rights-based objections that emphasise the protection of life as a key obligation, which is also a key justification for the human rights objections to the death penalty.[231]

6.8. *Protecting the vulnerable*. Sometimes concerns are expressed about the risk of vulnerable patients feeling under real or imagined pressure to undergo AD, e.g., to relieve perceived burdens on those close to them or the wider health system.[232] There are also concerns about *"ableism"*, i.e., discrimination against people with disabilities (see also 2.23). Even if these concerns may be more pronounced with practitioner-administration, these risks may be present in both modes of administration, so – whichever mode is preferred – robust processes will be needed, at least to ensure that the patient has reached their decision voluntarily prior to administration occurring.

6.9. *Abuse and errors*. Either mode may be susceptible to risks of abuse and errors, which again will require robust processes in order to protect patients.

6.10. Despite such apparent similarities, there are also perceived to be differences between self-administration and practitioner-administration, which may incline Parliamentarians to support one or other mode.

Self-administration

6.11. The main arguments in favour of, and against, adopting a model of AD which allows (only) for self-administration are summarised below.

6.12. Arguments in favour of self-administration:

- Evidence from the Netherlands suggests that some HCPs feel that self-administration more effectively respects patient autonomy (self-rule), because, in requiring the patient to take the final, fatal step, self-administration more clearly indicates the authenticity of

[228] L Gormally. Euthanasia and Assisted Suicide: 7 Reasons Why They Should Not be Legalized. In D Dickenson, M Johnson, J Samson Katz (eds), *Death, Dying and Bereavement* (2nd edn, Sage, 2000), 286-90.
[229] Catholic Church England and Wales. Opposition to legalisation of assisted suicide a matter of human reason as well as religious faith [Publication: 18 May 2023.].
[230] However, some people with faith do not oppose AD and some resist the use of religious arguments: e.g., TA Boer. Why Using Religious Arguments in the Euthanasia Discussion is Problematic. *Revista Latinoamericana de Bioética* 2021; 21(1): 127.
[231] This is sometimes formulated as some secular form of the *"sanctity of life"*, e.g., in *Rodriguez v British Columbia (AG)* [1993] 3 SCR 519, the Canadian Supreme Court recognized the concept of sanctity of life as a fundamental part of the Charter of Rights and Freedoms.
[232] E.g., CJ McPherson et al. Feeling like a burden to others: A systematic review focusing on the end of life. *Palliative Medicine* 2007; 21(2): 115.

the patient's wish and choice to die.[233] This may, in turn, offer greater protection against potential risks of abuse or mistakes.

- When comparing data from Canada and Oregon, the evidence suggests that more patients who receive lethal medication to self-administer end up not taking the medication,[234] as compared with patients who were approved for AD by HCP-administered injection but who did not go through with the final procedure.[235] This potentially indicates that subtle pressure may be perceived to come from direct physician involvement. This could also be one of the reasons why many more patients die with AD in regimes that allow HCPs to administer AD.

- Self-administration may be viewed as a less *"medicalised"* form of AD, requiring less direct involvement by HCPs, because the patient takes the final, fatal step. This may be an argument in favour of self-administration, rather than practitioner-administration, if there are concerns about doctors' involvement in AD given tensions with the traditional goals of medicine (see also 3.8ff).

- Emerging evidence from the US suggests that self-administration (in the form of PAS) may be safe, reliable and effective. More specifically, a review of data from the Medical Assistance in Dying programmes in Washington and Oregon supports the *"overall safety and reliability"* of the lethal medications used within these programmes.[236] Furthermore, in Washington, between the period of 2009-2017, there were no recorded cases where intervention from emergency medical services was required after the patient ingested the lethal drug.[237]

6.13. Arguments against self-administration:

- Not every patient will be capable of self-administration. Noting that the ethical justifications of AD tend to be the same whichever mode of AD is envisaged (6.3-6.10), it may be argued that it is unjust to deny patients with disabilities the option of AD if the mode adopted in law is not one of which they can physically avail themselves.

- Some evidence suggests that self-administration (in the form of PAS) may not guarantee the patient a comfortable death. Concerns have been expressed about the *"failure"* of PAS, particularly when the fatal drugs are orally ingested, and the consequent negative impact on the patient's dying process. A 2019 review of the Medically Assistance in Death Programme in Canada 2019 found that there were a number of *"major*

[233] PSC Kouwenhoven et al. Euthanasia or physician-assisted suicide? A survey from the Netherlands. *European Journal of General Practice* 2014; 20(1): 25.
[234] Oregon Health Authority, Public Health Division. *Oregon Death with Dignity Act 2022 Data Summary* (8 March 2023): https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year25.pdf.
[235] In Canada, on average, only 2% of requests that were approved were subsequently withdrawn. Nearly all deaths in Canada were by lethal injection by physician or nurse-practitioner. See: Health Canada, Third Annual Report Medical Assistance in Dying Canada 2021 https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2021.html#table_7.1
[236] L Al Rabadi et al. Trends in Medical Aid in Dying in Oregon and Washington. *JAMA Network Open* 2019; 2(8): 1, 5.
[237] Al Rabadi et al (note 237).

challenges" when the oral route is taken related to palatability, effectiveness and absorption of the medication, which can often result in *"either prolonged time to death, or failure to cause death"*.[238] Evidence from other jurisdictions also reveals the potential for a prolonged period between the patient ingesting the lethal drugs and their death, during which time they may experience *"distressing"* symptoms.[239,240] These findings suggest that oral self-administration may not guarantee the patient a comfortable death.[241,242]

- If the patient is allowed to self-administer (e.g., alone in a private residence), then it may not be possible to guarantee that the patient's wish is autonomous and settled. We recognise, however, that self-administration need not happen alone or in a private residence; instead, self-administration could be restricted to particular healthcare settings and/or the patient could be supervised or otherwise attended prior to or during their self-administration. In this regard, we are reassured that the proposal requires the administering practitioner to be present for a final review and to remain near the patient during self-administration.

- Self-administration may potentially present risks to others, e.g., if the patient is allowed to take the lethal drugs to a private residence, where others may be able to access the drugs. However, as noted above, we are reassured that the proposal requires the presence of the administering practitioner, who would have custody of the lethal substance, which should help to minimise such risks.

6.14. The arguments in favour of, and against, self-administration appear to be balanced. In favour of self-administration are the suggestions that this mode best confirms the autonomous wish of the patient and the data indicating that this may be safe, but against this is the potentially unjust denial of the option of AD to those patients with disabilities who are not physically capable of self-administration. (We note that the risks that self-administration may present to the patient and/or others are minimised by the proposed requirement that an administering practitioner will remain with or near the patient and will have custody of the lethal substance.) As the remaining arguments are balanced, the following sections consider two variations on self-administration.

Self-administration with the assistance of a loved one

6.15. Self-administration with the assistance of a loved one may help to address some of the concerns about self-administration, if someone close to the patient is willing and able to support the patient (e.g., to bring the cup containing the lethal agent to their lips).

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[238] C Harty et al. Oral medical assistance in dying (MAiD): Informing practice to enhance utilization in Canada. *Can J Anaesth* 2019; 66(9): 1106, 1108.
[239] Harty et al (note 238).
[240] A Worthington et al. Efficacy and safety of drugs used for 'assisted dying'. *British Medical Bulletin* 2022; 142(1): 15.
[241] B White, L Willmott. A Model Voluntary Assisted Dying Bill. *Griffith Journal of Law and Human Dignity* 2019; 7(2): 1, 7.
[242] E Emanuel et al. Attitudes and practices of euthanasia and physician assisted suicide in the United States, Canada and Europe. *Journal of American Medical Association* 2016; 316(1): 79, 86.

6.16. Arguments in favour of self-administration with the assistance of a loved one:

- This would help to address some of the concerns about unjustly denying the option of AD to those patients with disabilities who are not physically capable of self-administration.
- The majority of respondents to the consultation supported this position (50.33% in favour). Most of the respondents who were in favour felt that this should ultimately be the patient's decision.
- Self-administration with the assistance of a loved one is less *"medicalised"* than either practitioner-administration or self-administration with practitioner-monitoring, which may address concerns about doctors' involvement in AD (see also 3.8, 3.13).

6.17. Arguments against self-administration with the assistance of a loved one:

- Loved ones may perceive such involvement to be a burden or feel pressure to participate in AD when they do not wish to do so, either of which may have a negative impact on the relationship between the patient and the loved one, and/or on the well-being or grief of the loved one. They may struggle with the trauma of having been actively involved in the ending of the life of their loved one.
- This mode assumes that patients who may need such assistance would have access to a loved one who is willing and able to support them.
- There may be concerns about abuse or (conscious or unconscious) pressure, due to the burdens associated with care giving, or other interests of family members, which might be particularly acute (e.g.) for older persons or those who need high levels of care;[243]
- Self-administration may potentially present risks to others, e.g., as those loved ones who support the patient (and potentially others) may have access to the lethal substance. (However, related to the points noted above, this risk is reduced in the proposal, since it requires an administering practitioner to supervise; see further 6.19ff).

6.18. On balance, if self-administration is to be lawfully available, then it seems appropriate to offer the patient the option of having a (willing and able) loved one to be present and potentially even to assist. However, the loved one who assists would need to be provided with appropriate support, including assurance that their involvement is legally permitted and access to counselling or other supportive services. Moreover, in view of the potential risks presented by access to the lethal drugs and the need to provide for those who do not have loved ones willing and able to support them, it seems appropriate to also or instead involve a HCP in the process, as discussed in the next section.

[243] Such concerns were raised by various participants in a House of Commons debate on a proposed AD law, e.g., by Joan Ryan (col.661), Cheryl Gillan and Caroline Spelman (col. 663), Yasmin Qureshi (col. 664), Lyn Brown (col. 669), Fiona Bruce (col. 670), Nadine Dorries (col. 677), Liam Fox (col. 680), Nick Herbert (col. 686): House of Commons Hansard Debates for 11 September 2015, https://publications.parliament.uk/pa/cm201516/cmhansrd/cm150911/debtext/150911-0001.htm#15091126000003.

Self-administration with practitioner monitoring

6.19. Self-administration with practitioner monitoring may help to address the concerns about self-administration, whether with or without the support of a patient's loved one, and provide a compromise position between self-administration and practitioner-administration. This could, for example, require a practitioner to remain with or near the patient while they self-administer and until their death, which is what is currently proposed.

6.20. Arguments in favour of self-administration with practitioner monitoring:

- The emphasis on patient autonomy remains, since AD still involves self-administration, thus indicating the authenticity of the patient's wish and choice to die.
- Self-administration with practitioner monitoring is less "medicalised" than practitioner-administration.
- Self-administration with practitioner monitoring may reduce risks to the patient, as (where the need arises) the practitioner could step in to ensure that the patient experiences a dignified death, with minimal suffering.
- The presence of a practitioner might reduce any anxiety experienced by those family members or friends who may be present.

6.21. Arguments against self-administration with practitioner monitoring:

- Practitioner-administration arguably requires more time and participation of the doctor, which would reduce the time they have for other duties and patients. However, for reasons discussed above, we note that this should not be a concern under the current proposals (see 3.13).
- Depending on the other commitments of the doctor (and the wider health service), self-administration with practitioner monitoring may need to be scheduled to occur at a particular time, which could reduce the degree of choice and control that the patient has over the timing of AD.
- Patients may not wish (or need) to have practitioners present. In Oregon, the presence of a HCP when the patient takes lethal medication is optional. In the majority of cases, patients choose not to have a HCP present. The numbers of cases in which HCPs were present at the time of death also appear to be diminishing, *"80% [of cases] during the first decade (1998 to 2007) and 30% during the second (2008 to 2017)"*.[244] This reduction may indicate that patients do not want practitioners to be present and might not need them to be. If it is not necessary for practitioners to be present, this may be a waste of resources.

6.22. Although there are also arguments for and against self-administration with practitioner, we suggest that on balance it may be safest to offer this option if some form of self-administration is to be allowed in law. We note with approval that this is what is envisaged under the current proposals.

[244] K Hedberg, C New. Oregon's Death With Dignity Act: 20 Years of Experience to Inform the Debate. *Annals of Internal Medicine* 2017; 167(8): 579, 580.

Practitioner-administration

6.23. The main arguments in favour of, and against, adopting a model of AD which allows (only) for practitioner-administration are summarised below.

6.24. Arguments in favour of practitioner-administration:

- When both options are available, practitioner-administration appears to be preferred by patients. Evidence indicates that patients are much more likely to choose practitioner-administration, rather than self-administration. For example, while self-administration is allowed in all Canadian jurisdictions except Quebec, Medical Assistance in Dying Provision was made on 10,064 occasions in 2021, but there were *"fewer than seven deaths from self-administered MAID"* across the country, and this figure is consistent with previous years.[245] The experience in Canada and also in the Netherlands suggests *"that where given choice between self and practitioner administration, the large majority of persons appear to elect physician administration"*.[246]

- Practitioner-administration necessarily means that a practitioner will be present throughout the AD process, and thus capable of ensuring that the patient's wish is autonomous and settled, that access to the drugs is controlled, and that any complications can be addressed.

- Practitioner-administration may serve the interests of justice, in providing equality of opportunity. Self-administration may be unjust as not every patient will be (physically) capable of self-administration, which means that some patients may be denied the option of AD (see 6.13); however, practitioner-administration does not require the direct participation of the patient in administering the fatal drug, so may be an option available to all eligible patients.

6.25. Arguments against practitioner-administration:

- Some perceive a morally significant distinction between undertaking the act of administering fatal medication to another person, and (merely) providing the means by which the person can do this for themselves. As such, some believe that practitioner-administration more directly implicates the doctor in causing death.[247]

- Practitioner-administration arguably requires more time and participation of the doctor, which would reduce the time they have for other duties and patients. However, for reasons discussed above, we note that this should not be a concern under the current proposals (see 3.13).
- Depending on the other commitments of the doctor (and the wider health service), practitioner-administration may need to be scheduled to occur at a particular time,

[245] Health Canada, Third Annual Report on Medical Assistance in Dying in Canada 2021 (July 2022), pp.18-19. [Accessed 22 September 2023.]
[246] K Braun, Self-administration or practitioner administration? The scope of future German assisted dying legislation. *Medical Law Review* 2023; 31(1): 141, 156.
[247] See e.g. R Cohen-Almagor. An Argument for Physician-Assisted Suicide and Against Euthanasia. *Ethics, Medicine and Public Health* 2015; 1(4): 431-441.

which could reduce the degree of choice and control that the patient has over the timing of AD.

- Instead of reflecting a neutral exercise of patient preference, the much higher overall uptake of AD in jurisdictions where HCP-administration is permitted, combined with the nearly exclusive use of HCP-administration in those jurisdictions, is seen by some as a reflection of a normalisation of providing death as a form of medical therapy.[248] This raises a concern about the expansion of AD in situations where other options to relieve suffering are available.[249]
- Involving a doctor may make it harder for patients to withdraw or abstain from taking this final step.

Reflections on the choice of mode

6.26. There are reasonable arguments in favour of, and against, each mode (self-administration and practitioner-administration).

6.27. If the States Assembly considers the arguments about the two modes to be balanced, then it may judge it appropriate to provide for both modes in law, with patients offered the choice of mode. If the (or a) central goal of the proposed law governing AD is to respect patient autonomy, then allowing patients the choice of mode of AD would also be consistent with this goal.[250]

6.28. However, the States Assembly may prefer on balance to primarily allow for self-administration, and to reserve practitioner-administration for *exceptional* cases.[251] Practitioner-administration seems to raise more concerns, in view of: reports of significant increases over time in those jurisdictions that allow this; potential impacts on the overall role of HCPs; and the low number of cases in which patients withdraw their request when practitioners are involved in administration, when compared with the numbers of those who decide not to self-administer a prescribed drug (see 6.12). Self-administration may therefore be the more prudent approach. However, in view of concerns about equal access for those who may physically be unable to self-administer, practitioner-administration could be reserved for these sorts of exceptional cases.

6.29. Finally, if self-administration is to be allowed, then experiences elsewhere (discussed at 6.13) suggest that the different drugs and methods used in different jurisdictions would need to be examined closely to ensure that the safest and most effective approach is adopted.

[248] Lemmens (note 124).
[249] See, e.g., the reference to such concerns arising in Canada, as cited by Worthington et al (note 123), discussed in 3.13.
[250] White and Willmott (note 241).
[251] This is the strong preference of one of the report authors.

Chapter 7: Appeals

7.1. An appeals process is proposed, the key elements of which are set out in the consultation.[252] In summary, an appeal may be made to the Royal Court, between 48 hours and 28 days since the final (dis)approval was issued under either Route 1 or Route 2 (by the coordinating doctor or the Tribunal, respectively). The grounds of appeal relate to perceived procedural irregularities or determinations regarding the patient's residency, capacity and/or autonomous choice. An appeal may be brought by the patient, someone on their behalf, or anyone that *"the Court is satisfied has a special interest in the care and treatment of the person, such as a family member"*; an appeal may not be brought by unconnected third parties, such as lobbyists that are opposed to AD.[253] The Court must make its decision within 7 days of receipt of application, and the Court's decision will be final.

7.2. There are arguments for and against an appeals process.

7.3. Arguments in favour of an appeals process:

- An appeals process exists in Western Australia, on which elements of the Jersey proposal are based, so there is a precedent, which may inform the Jersey system.[254]
- An appeals process may, as suggested in the consultation, *"help support public confidence"*.[255] The majority of respondents to the consultation (60.75%) agreed that there should be provision for appeals to the Court.[256]
- An appeals process can help to prevent or limit *under-inclusion*, i.e., can help to ensure that people who should be eligible for AD are not excluded from access. Once the decision has been made to provide access to AD (on some basis), it is appropriate to ensure that eligible candidates can gain access. An appeals process can help to ensure that potentially eligible patients would be not prevented from accessing AD due to (e.g.) the reluctance of a doctor or a doctor's overly narrow interpretation of the eligibility criteria.
- An appeals process can help to prevent or limit *over-inclusion*, i.e., can help to ensure that people who should not be eligible for AD are not given access. Given the irreversible and fatal nature of AD, it is appropriate to ensure that there is sufficient protection against errors in the approval process. Experience in other jurisdictions, particularly those with broader and vaguer access criteria, reveals that even among HCPs who are willing to assess and approve people for AD, there are often significant differences in the interpretation of eligibility criteria. Doctors with a more flexible approach to eligibility may more easily approve requests for AD and attract patients who are not approved by others. They may also do so in areas that are more controversial, and thus drive the practice in different directions. This has been identified as a concern, for example, in the expansion of the practice of euthanasia for mental illness in the Netherlands and Belgium. In Belgium, for example, one psychiatrist was associated with up to 50% of the country's psychiatric euthanasia cases in a 4-year period, between

[252] Assisted Dying in Jersey Consultation Report, October 2022, para 234-253.
[253] Assisted Dying in Jersey Consultation Report, October 2022, para 245.
[254] Assisted Dying in Jersey Consultation Report, October 2022, para 239.
[255] Assisted Dying in Jersey Consultation Report, October 2022, para 235.
[256] Assisted Dying in Jersey: Phase 2 Consultation Feedback Report, p.93.

2007-2011, a period when psychiatric euthanasia appears to have expanded.[257],[258],[259] Chabot mentions the role of the specialised End-of-Life clinic in offering euthanasia for cases refused by other physicians.[260] Some physicians in Canada have also publicly confirmed a high number of cases in which they have been involved, some of these in controversial circumstances.[261,262]

- An appeals process enables family members, HCPs, or others with a legitimate interest to request a review before the person's life is ended. Family members or others may be concerned about the approval of a request for AD by their loved one. Loved ones may doubt the patient is eligible due to (*inter alia*) concerns about their capacity for decision-making, depression, or social factors potentially unknown to the assessors. In some jurisdictions, family members who disagree with the eligibility of their loved one whose life will be terminated have no formal process for questioning the approval prior to the patient's death. In one Canadian case, a mother felt that her only option to prevent the death of her 23-year son with diabetes-related vision loss, who was approved for and scheduled to die by MAID, was a public letter-writing campaign to put pressure on the physician not to go ahead with the procedure.[263] An appeals procedure would allow interested family members to request a review before the person's life is ended. Equally, doctors or other HCPs may have concerns about an approval of their patient by another HCP. An appeals process would offer a higher level of scrutiny, enabling concerned HCPs to raise their concerns and have them reviewed before the person's life is terminated.

- An appeals process, involving the Court, may prevent or reduce *"doctor shopping"* for approval. As such, a formal appeals process could prevent or reduce patients who have been deemed ineligible from taking their requests to other physicians. As noted above, some doctors may be overly flexible and liberal in their interpretations of eligibility and attract a high number of requests from people who have been refused by other doctors who considered them to be ineligible. Experience in other jurisdictions, such as Belgium, the Netherlands, and Canada,[264] suggests that this form of doctor-shopping occurs and is a concern.[265] However, as discussed previously (3.34), this concern is limited or absent under the current Jersey proposals.

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[257] S Claes, et al. Euthanasia for psychiatric patients: Ethical and legal concerns about the practice. *BMJ Open* 2015: http://bmjopen.bmj.com/content/5/7/e007454.responses#euthanasia-for-psychiatric-patients-ethical-and-legal-concerns-about-the-belgianpractice.

[258] M De Hert, et al. Improving Control Over Euthanasia of Persons With Psychiatric Illness: Lessons from the first Belgian Criminal Case Concerning Euthanasia. *Frontiers in Psychiatry* 2022; 13.

[259] Lemmens (note 12), p.489.

[260] B Chabot. Worrisome culture shift in the context of self-selected death. *NRC Handelsblad* (16 June 2017). Translation: https://trudolemmens.wordpress.com/2017/06/.

[261] A. Raikin. No Other Options (16 December 2022): https://www.thenewatlantis.com/publications/no-other-options.

[262] See examples in Coelho et al (note 29), p.5.

[263] Canadian Broadcasting Corporation, The Fifth Estate. Is it too easy to die in Canada? Surprising approvals for medically assisted death (19 January 2023): https://www.youtube.com/watch?v=plinQAHZRvk.

[264] Lemmens (note 124).

[265] See previous references and Chabot (note 260).

- An appeals process, in which the Court is involved, places AD more squarely within the legal domain, which may address some of the concerns surrounding a more medical(ised) process (see 3.8, 3.13, 3.19).

- An appeals process may, over time, contribute to consistency in decision-making, since it may guide physicians in future cases about the boundaries of eligibility as determined by the court.

7.4. Arguments against an appeals process:

- An appeals process inevitably inevitably prolongs the AD process, potentially worsening the suffering of patients and imposing a burden on them (and potentially other parties). At the upper end, the proposal states that an appeal may be made 28 days after the final decision was made in Route 1 or Route 2, with the Court then required to rule within 7 days. As such, if (e.g.) someone close to the patient were to appeal against a decision approving that patient for AD, this could, at the upper end, potentially add 35 days to the process.

- An appeals process has human and financial resource implications (e.g., costs to the Court system, in terms of setting up and running this new process, which would need to be completed within a fairly tight timeframe of 7 days).

- An appeals process would inevitably mean that some patients who had been granted access to AD, and thus had their hopes raised, would thereafter be denied access, which may be a source of distress or suffering.

7.5. On balance, it appears appropriate to include an appeals process, involving the Court, as there is a precedent for this, it may help build public confidence, it may prevent or limit under-inclusion and over-inclusion, and it places AD within the legal domain, which may assuage some of the concerns about a medicalised process. The AD process would be prolonged, but arguably not excessively so, at least relative to the safeguards an appeals process brings, but the system would need to have the resources to support the process and, arguably, those patients who might lose out as a result of an appeal.

7.6. If it is felt that the resource implications would pose too great a burden on the Court, there may be alternative appeals models to consider. For example, an appeals process could be modeled on the Consent and Capacity Board structure in Ontario (Canada).[266] Amongst other functions, this administrative body acts as an appeal board for various decisions, including findings of incapacity, involuntary treatment, admission to a care facility, and review of a substitute decision-maker's compliance with the rules of substitute decision-making. The boards work relatively informally, and are able to meet at short notice. The interested parties present their case, and the board's decision is binding, unless one of the parties appeals to the Court. Such a model would divert some work away from the Court, although it could remain as a final point of appeal. If adapted to AD, as some authors have proposed,[267] the board could (e.g.) consist of three to five members, including a lay member, a HCP, and a member with

[266] Consent and Capacity Board (Ontario). About us: https://www.ccboard.on.ca/scripts/english/aboutus/index.asp.

[267] The consent and capacity board was proposed as a model for all 'MAID' reviews in Canada. See: D Baker, G Sharpe, R Lauks. Federal and Provincial Responsibilities to Implement Physician-Assisted Suicide. *Health Law in Canada* 2016; 36(3): 148.

legal knowledge. Depending on the type of AD that would be legalised, specific specialists (e.g., rehabilitation specialist, pain specialist), and social workers, may also be considered key members of such an appeal board.

Chapter 8: Certifying cause/manner of death

Law and practice on certifying cause/manner of death

8.1. A medical certificate of cause of death (MCCD) states a person's *cause of death* alongside other key details (e.g., name, age, place of death, significant medical history).[268] The MCCD may also describe the *manner of death*, i.e., provide *"a description of the circumstances of how the death occurred with the usual manner of death categories including natural, accident, suicide, homicide or undetermined"*.[269] In Jersey, the relevant certificate is the Medical Certificate of the Fact and Cause of Death (MCFCD).

8.2. MCCDs have value and influence in various contexts. They can constitute a legal record of a person's death, which may be relevant to, e.g., settling estates, pensions and insurance claims, and establishing genealogy. MCCDs may also provide useful statistical data, e.g., on population health or mortality trends, which can inform planning.[270] Despite their value, there is evidence of errors in MCCD reporting internationally.[271]

8.3. In those countries which allow AD, practice varies internationally with regard to what the MCCD should record, and how MCCDs are actually completed, following an assisted death. In 2018, Brown et al reviewed the processes and practices operating in various countries and provinces.[272] Their headline findings included:

- In Canada, practice varies, with the underlying illness, disease or disability often recorded as a cause of death, and with the death often recorded as *"natural"*, although some provinces and territories additionally record, explicitly, that MAiD (i.e., AD) was provided.
- In the Netherlands and Switzerland, death is recorded as *"non-natural"* and the precise manner of death (i.e., AD) is also recorded.
- In some American States, the underlying illness is recorded as the cause of death and the manner of death is recorded as *"natural"*; in some States (e.g., Oregon, Vermont, and Washington), there may be no reference to the death arising from AD.
- In Belgium, AD is not apparent on the MCCD.

[268] Guidance for doctors completing medical certificates of cause of death in England and Wales, 25 March 2022. https://www.gov.uk/government/publications/guidance-notes-for-completing-a-medical-certificate-of-cause-of-death/guidance-for-doctors-completing-medical-certificates-of-cause-of-death-in-england-and-wales-accessible-version [accessed 1 October 2023].
[269] J Brown, L Thorpe, D Goodridge. Completion of Medical Certificates of Death after an Assisted Death: An Environmental Scan of Practices. *Healthc Policy* 2018; 14(2): 59-67.
[270] Brown et al (note 269).
[271] Brown et al (note 269).
[272] Brown et al (note 269). They reviewed all Canadian provinces and territories, selected American states, and Belgium, the Netherlands and Switzerland.

8.4. Whether or not AD is specifically certified as cause or manner of death, many jurisdictions require AD to be reported to a relevant authority,[273] e.g.:

- In Canada, all written requests for MAiD (i.e., AD) must be reported to the relevant health department (at provincial, territorial or federal levels, depending on location).
- In the Netherlands, AD must be reported to the coroner, who will inform one of five regional review committees, which will check compliance with the law (with non-compliance referred to the public prosecutor).
- In Belgium, AD must be reported to the Federal Control and Evaluation Commission, which will check compliance with the law (with non-compliance referred to the public prosecutor).

8.5. Whatever the precise reporting requirements, there is evidence from some jurisdictions of under-reporting of AD. In Belgium, for example, evidence suggests that only 60% of the euthanasia cases are reported to the Federal Control and Evaluation Committee.[274] In 2018, Cohen et al undertook a *"[m]ortality follow-back survey using a random sample of death certificates"* in Belgium, and found that MCCDs *"substantially underestimate the frequency of euthanasia as a cause of death"*.[275] In the Netherlands, at least 20% of cases of AD are not reported.[276] Under-reporting in these countries may be partly due to clinicians believing that their actions did not amount to AD (e.g., because they used drugs typically associated with symptom relief or sedation in end-of-life care).[277],[278] Under-reporting may also be driven by ignorance of what the law requires, failures to have observed all aspects of the law, fears of legal redress, and perceived administrative burdens.[279]

For and against recording assisted dying as a cause/manner of death

8.6. The question arises whether the MCFCD in Jersey should record the cause and/or manner of death in a way that expressly accounts for the fact that a patient was assisted in their death. There are arguments for and against this proposition.

8.7. Arguments in favour of recording AD in the MCFCD:

- Researchers who have studied MCCDs in relation to AD internationally have argued that, given their importance and value, MCCDs should be clear and accurate, and facilitate consistency in reporting. Following their international comparison, Brown et al suggested that *"striving for consistent application of cause and manner of assisted death*

[273] BMA, Physician-assisted dying legislation around the world, August 2021. https://www.bma.org.uk/media/4402/bma-where-is-pad-permitted-internationally-aug-2021.pdf [accessed 1 October 2023].
[274] Raus et al (note 64).
[275] J Cohen, et al. How accurately is euthanasia reported on death certificates in a country with legal euthanasia: a population-based study. *Eur J Epidemiol* 2018; 33: 689-693.
[276] A van der Heide A, et al. End-of-life practices in the Netherlands under the Euthanasia Act. *N Engl J Med* 2007; 356: 1957-65.
[277] T Smets, et al. Euthanasia in patients dying at home in Belgium: Interview study on adherence to legal safeguards. *British Journal of General Practice* 2010; e163-170.
[278] See also: Raus et al (note 64).
[279] Cohen et al (note 275).

reporting is important for accurate, sensitive and […] consistent statistical reporting".[280] Following their study of Belgian practices, Cohen et al also called for accuracy, recommending that MCCDs may need modification and that doctors may need clear guidelines concerning the reporting of ADs.[281] Some recommend that MCCDs should record the underlying medical condition as cause of death, with AD recorded as manner of death.[282]

- Maintaining accurate and consistent records of cause and/or manner of death may provide a safeguard against misunderstanding, misuse or abuse, which may be further enhanced by requiring that reports be made to a relevant authority, such as a monitoring committee.[283],[284] The obligation to report may reinforce doctors' understanding of the law governing AD and motivate them to remain up-to-date on, and practice in accordance with, the relevant requirements and standards.[285] It may also clarify for doctors those behaviours that amount to AD (and should be recorded as such), and those that are not (such as symptom relief or palliative sedation).[286] Furthermore, maintaining clear records can help to identify failures to observe the law and thereafter with the assignation of legal liability or culpability.[287]

- Failure accurately to reflect that a patient's death involves AD may lead to over- or under-estimation of the incidence of AD and undermine the accuracy of related data about AD, which may have an adverse impact on future planning and provision (e.g., allocation of health resources). Here, a parallel may be drawn with suicide (and related) statistics. Some coroners in England and Wales reportedly issue *"open"* or *"accidental"* verdicts *"in the belief that this avoids adding to a family's distress"*.[288] Official data accordingly combines *"suicide"* and *"open verdict"* deaths, in an effort to gauge the incidence of suicide.[289] The accuracy of the data was further questioned in light of evidence that, from 2001 to 2009, coroners in England and Wales were increasingly using (free text) *"narrative verdicts"*, rather than more specific *"short form"* verdicts (e.g., *"suicide"*, *"accident"*, *"open"*).[290] Although they allow coroners to raise matters of public concern, the rise in narrative verdicts exacerbated concerns about *"the underestimation of suicide"* and impacts on related data (e.g., evaluations of suicide prevention activity and research into the drivers of suicide).[291] Similar concerns might

[280] Brown et al (note 269).
[281] Cohen et al (note 275).
[282] J Downie, K Oliver. Medical Certificates of Death: First Principles and Established Practices Provide Answers to New Questions. *Canadian Medical Association Journal* 2016; 188(1): 49-52.
[283] T Smets, et al. The medical practice of euthanasia in Belgium and The Netherlands: Legal notification, control and evaluation procedures. *Health Policy* 2009; 90(2-3): 181-7.
[284] T Smets, et al. Reporting of euthanasia in medical practice in Flanders, Belgium: Cross sectional analysis of reported and unreported cases. *BMJ* 2010; 341: c5174.
[285] HM Buiting, et al. Physicians' labelling of end-of-life practices: A hypothetical case study. *J Med Ethics* 2010; 36(1): 24-9.
[286] Buiting et al (note 285).
[287] Downie and Oliver (note 105).
[288] D Gunnell, K Hawton, N Kapur. Coroners' verdicts and suicide statistics in England and Wales. *BMJ* 2011; 343: d6030.
[289] Gunnell et al (note 288).
[290] Gunnell et al (note 288).
[291] Gunnell et al (note 288).

arise if official data – such as is recorded on death certificates – does not explicitly refer to AD.

- MCCDs can *"provide closure, peace of mind and documentation of cause of death to family members"*.[292] Although there is some sensitivity around recording *"suicide"* as cause of death,[293] it may be queried whether there would be significant similar concerns around explicitly recording AD as manner of death (but see 8.8, below).

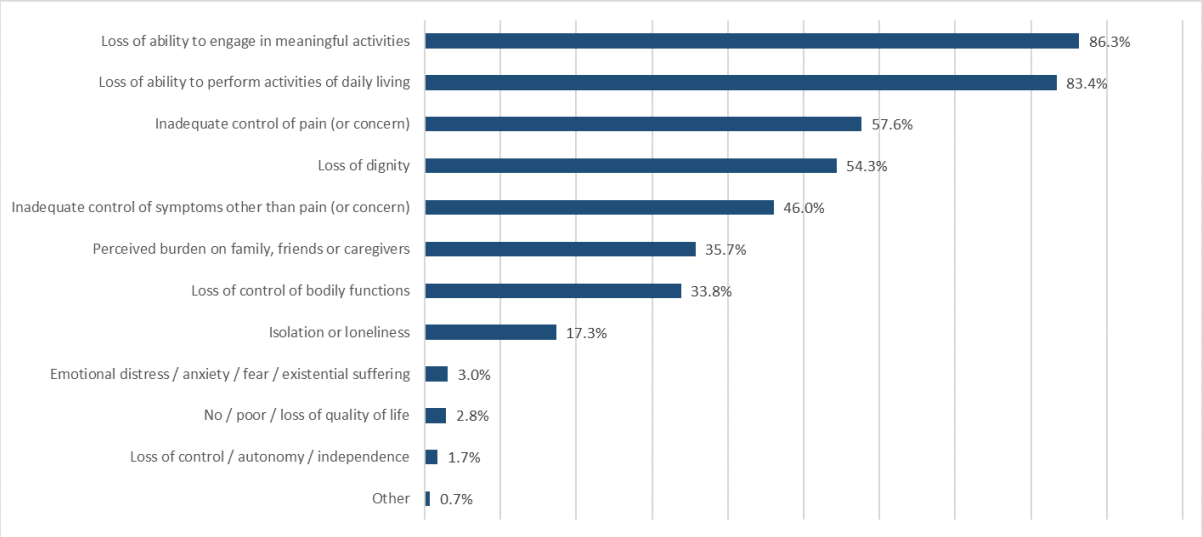
8.8. Arguments against recording AD in the MCFCD:

- MCCD *"may reveal sensitive information about deceased individuals including cause, manner and location of death and significant medical history"*.[294] This may generate concerns about breaching the privacy of the patient, damaging relationships between patients and doctors, and families may have reservations about explicitly (and publicly) recording that death was assisted (but see 8.7, above).[295],[296]

8.9. The arguments for clear, consistent and accurate reporting appear to be strongest, so the provision of AD should be explicitly recorded in some way. We are reassured that the proposed Jersey model will require the MCFCD to be completed by a specially trained and registered doctor,[297] which should enhance consistency and reduce the risks of incomplete or inaccurate reporting, and that instances of AD must be routinely reported to the Jersey Assisted Dying Service. However, the potential concerns of patients and families should be explored; for example, it may be appropriate to anonymise and aggregate data for public dissemination, so that individuals cannot be identified, provided that relevant agencies can still have appropriate access to any data they need (e.g., to investigate any legally questionable instance of alleged AD, to measure the incidence of AD, and/or to plan future provision and practice).

[292] Brown et al (note 269).
[293] Gunnell et al (note 288).
[294] Brown et al (note 269). They cite: JR Boles. Documenting Death: Public Access to Government Death Records and Attendant Privacy Concerns. *Cornell Journal of Law and Public Policy* 2012; 22(1).
[295] Buiting et al (note 285).
[296] Downie and Oliver (note 105).
[297] Assisted Dying in Jersey Consultation Report (October 2022), para 305.

Appendix 1: Nature of Suffering of Those Who Received MAID, 2021 (Canada)



This chart represents MAID deaths where the report was received by Health Canada by January 31, 2022. For 2021, this represents 9,950 MAID deaths. Providers were able to select more than one reason when reporting; therefore, the total exceeds 100%.