

### **Research Space**

Journal article

Reframing assisted dying through the civil law: possibilities and challenges for the UK

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## **BMJ Supportive & Palliative Care**

## Reframing assisted dying through the civil law: possibilities and challenges for the UK

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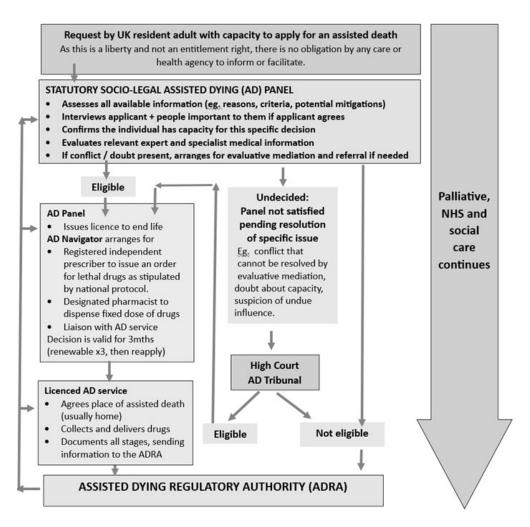
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A socio-legal, civil law model for AS/E 184x181mm (96 x 96 DPI)

#### **BMJ Supportive & Palliative Care Reviewer Responses**

Comments to the Author

I think this is worth publishing, it's an interesting take on an extremely 'live' issue.

**Response:** We are very pleased that the reviewer can see the merit in this article, which we agree is timely.

What seems to be missing is any serious engagement with counter-arguments to the claim advanced here. It would be really helpful if the authors considered what arguments might be made against this sort of scheme, and responded to them.

**Response:** We accept this criticism entirely; one of the challenges of engaging with all the possible counter arguments is the length of the Feature piece and the ability to give weight to all arguments in depth. We have attended to several counter arguments throughout, for example:

- We acknowledge the claim by some that the expansion of medical criteria is not inevitable (p.6)
- We acknowledge the opposing side that suggest structural vulnerabilities do not correlate with AS/E figures (p. 6)
- We acknowledge the possible pragmatic limitations of the model (protracted; financing the panels) p.10.
- We will also respond specifically to the points raised below:

For example, if the eligibility criteria are medical, is it possible to avoid medical involvement?

Response: Unfortunately, there is not the space to enter into this debate in the paper. In theory, the socio-legal model removes the requirement that eligibility is restricted to medical criteria, although practically speaking, this will be up to Parliament to decide those criteria at the outset. Evidence from Bills that have been introduced as well as from other global jurisdictions passing AD laws suggest that any socio-legal model would begin by restricting eligibility to 6-12 months prognosis of any terminal illness. If expansion happened this would be through the courts as UK law is largely based on case law, not just primary legislation. For example, any referrals by the panel to the High Court would decide if the criteria were to change.

However, the key difference between the socio-legal and medical models are:

a) any expansion that may take place over time would be transparent, monitored and analysed and

b) normal healthcare would be running in parallel to the socio-legal model in which medical doctors will still be treating and caring for people at the end of life.

Procedurally the processes would be kept quite separate through a socio-legal model. For example, if a patient with a terminal illness is in the healthcare system and undergoing treatment, she could request that her medical records/reports are sent to the panel (which could include prognosis if Parliament decided to restrict eligibility criteria but, again, this is not something we are aiming to influence in this paper). Importantly, the doctor would not need to be involved at this point as doctors regularly produce medical reports for various reasons (insurance etc.) and this might include the prognosis. The healthcare professional on the panel might ask for more evidence if they had concerns about the information provided and it would be up to the panel to inquire. The panel would also be assessing capacity (see below). In sum, the socio-legal model keeps medical doctors quite separate from AD provision.

It is also interesting to note the qualitative data available from Switzerland which shows that doctors do not wish to see a change in the law or a move towards a medical model- most are happy with a lay model or suggest a modified lay model like the one we are proposing which would introduce better safeguards including counselling, expertise and capacity assessment. See: Nyquist, Christina & Cohen-Almagor, Raphael & Kim, Scott. (2023). Expert Views on Medical Involvement in the Swiss Assisted Dying Practice: "We Want to Have Our Cake and Eat It Too"?. AJOB empirical bioethics. 15. 1-19. 10.1080/23294515.2023.2232796.

We have added this reference into the paper at page 12 – may we seek permission from the Editor to include this as it takes us over the footnote limit?

If the law were to specify that AD is available to terminally ill patients with capacity, who is going to carry out the capacity assessments, and who will certify that someone has a condition which is expected to lead to their death within however many months are specified?

**Response:** In terms of the latter part of the question regarding prognosis, we have responded to this above.

Regarding the question of capacity assessment: as the whole process sits outside healthcare it would not be appropriate for others to assess capacity for this decision. The panel will be comprised of people experienced in assessing capacity -and it could be completed by a health and social care worker, a social worker or a healthcare professional; it would not need to be performed by a doctor before the application stage because it is the panel that is responsible for assessing the capacity (alongside assessing other factors) on a case by case basis. We unfortunately do not have the space to detail this in the paper given the word restriction. As noted above, our model does not propose eligibility criteria as this would be up to Parliament to decide.

Does it matter what patients think? le should we try to find out whether patients value the involvement of healthcare professionals in AD?

**Response**: The perspective of patients is important; however, there is no established data in this area. An early study from the mid 1990s revealed that most patients do not feel that AS/E would undermine the doctor-patient relationship; only 5% patients were concerned about this. See Graber, M.A., Levy, B.I., Weir, R.F. et al. Patients' views about physician participation in assisted suicide and euthanasia. J Gen Intern Med **11**, 71–76 (1996). https://doi.org/10.1007/BF02599581

Evidence from Australia does point to the challenges patients face when they feel they have won a legal 'right' to AS/E but then cannot access this in a timely manner due to various pragmatic issues such as finding willing and available doctors to perform it. This patient data therefore does support a model outside healthcare. See White, B.P., Jeanneret, R., Close, E. et al. The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions. BMC Med Ethics 24, 22 (2023). <a href="https://doi.org/10.1186/s12910-023-00902-3">https://doi.org/10.1186/s12910-023-00902-3</a>

We would be concerned to draw on this data in this article as there is not enough space to unpack the challenges of calling on CO and its relationship to patient access. Although it supports our socio-legal AS/E model, CO is sometimes used to discriminate against doctors (as noted above) in parts of the world where AS/E has been legalised.

However, even if patients trust doctors to perform AS/E, this doesn't resolve the normative question raised in this paper which is whether AS/E ought to be regarded as a medical issue at all – and this is challenged by the literature on medicalisation as well as the other pragmatic challenges we have raised in this paper. As the reviewer points out there is good reason to draw parallels to the abortion literature and we would point to the feminist literature that is critical of the medicalisation of abortion and the authority of doctors to make decisions in this area. See Sheldon, S. (1997) Beyond Control: Medical power and Abortion Law. Pluto Press.

We could include this sentence in the paper slotted into the paragraph at page 5:

"Alongside pragmatic critiques of medical models sit theoretical and empirical critiques of medicalisation. Medicalisation refers to the process of defining and treating non-medical issues as medical problems."

Parallels may be drawn here to the abortion debate. Feminist scholars have criticised the medicalisation of abortion in Britain through the 1967 Abortion Act, which framed abortion as a medical problem that required two doctors to assess and approve the termination of pregnancy. Likewise, applicants for AS/E typically experience terminal illness, severe and debilitating disabilities, or are elderly and infirm ..."

However, we are concerned that doing so risks reifying the existing pro-AD lobby group positions that draw these areas together in relation to other aspects of debate such as religious conservativism. We would request input from the Editor as to how relevant and useful he feels the inclusion of this additional sentence is to the overall article.

In countries where AD is lawful, is there actually evidence of a shortage of doctors willing to provide it? Ie - AD is not going to be so common that all doctors need to be willing. In countries where it's lawful, is there evidence that people cannot access it because of a lack of willing doctors?

Response: Given restrictions on # references we have omitted some of these from the publication. Reference 2 evidences this point (data from Oregon). This is based on AD reports plus online data on the number of active physicians in each jurisdiction. Most doctors only perform AD 1-2 times a year with a few individuals doing 2-3 each week. This has implications for experience and doctor shopping. Other data available is from Griffiths et al that cases in the Netherlands are stalled due to doctor procrastination), and Australia (qualitative evidence that doctor-patient relationships are undermined by access challenges). Sources here:

Griffiths, 'Euthanasia and Assisted Suicide Should be Decriminalised,' in A Alghrani, R Bennett and S Ost, eds. Bioethics, Medicine and the Criminal Law, Volume 1: The Criminal Law and the Bioethical Conflict: Walking the Tightrope (Cambridge: Cambridge University Press, 2013):13-29; p. 19, footnote 4.

B.P. White, R. Jeanneret E. Close, and L. Willmott, 'The Impact on Patients of Objections by Institutions to Assisted Dying: A Qualitative Study of Family Caregivers' Perceptions,' BMC Medical Ethics, 24 (2023): 22.

With permission from the Editor, we would be pleased to include these in the final version of the paper. However, we recognise that the # of footnotes is restricted.

The authors are claiming that a right to conscientious objection would be insufficient to protect healthcare professionals. This is a really interesting claim and I'd like to see them explore it a little more. For example, there are two other statutory CO clauses in UK law. Is there evidence that they haven't worked or are in some way problematic that could be relied upon here?

Response: In the UK, CO clauses protect doctors in the Abortion Act 1967 and in the Human Fertilisation and Embryology Act 1990. However, CO clauses do not protect doctors and nurses from engaging in peripheral acts (doctors will have to refer on patients etc). According to the Conscientious Objection (Medical Activities) Bill [HL] HL Bill 14 of 2017–19 there is evidence that medical professionals face discrimination in practice due to their beliefs. The CO Bill sought to establish "provisions seek to affirm as a matter of statute that no one shall be under any duty to participate in activities they believe involve the taking of human life, either in the withdrawal of life-sustaining treatment or in any activity authorised by the 1967 or 1990 Acts. Such a reform would re-establish legal protection for medical conscientious objectors and reaffirm the Article 9 rights of healthcare workers. It would give reality to the protections afforded in the Equality Act". However, this was prorogued.

https://researchbriefings.files.parliament.uk/documents/LLN-2018-0010/LLN-2018-0010.pdf
https://hansard.parliament.uk/lords/2018-01-26/debates/C4A11F08-ABCF-4EA1-AFB5-

18174224A982/ConscientiousObjection(MedicalActivities)Bill(HL)

References 3 & 4 reveal data from other countries that CO clauses don't protect against hierarchical and institutional/peer pressure, particularly for junior doctors.

See also:

M.E., Bouthillier and L.A Opatrny, 'A Qualitative Study of Physicians' Conscientious Objections to Medical Aid in Dying,' Palliative Medicine, 33(9) (2019): 1212-20.

K. Evenblij, H.R.W. Pasman, J.J.M van Delden, A. van der Heide, S. van de Vathorst, D.L., Willems and B.D. Onwuteaka-Philipsen, 'Physicians' Experiences with Euthanasia: A Cross-Sectional Survey Amongst a Random Sample of Dutch Physicians to Explore Their Concerns, Feelings and Pressure,' BMC Family Practice, 20 (2019): 177

W. Chavkin, L. Leitman and K Polin, 'Conscientious objection and refusal to provide reproductive healthcare: a White Paper examining prevalence, health consequences, and policy responses,' International Journal of Gynaecology & Obstetrics 2013, 123:541-56

Evidence from the abortion debate suggests that doctors who conscientiously object are not discriminated against in practice. See Fleming, V, Frith L, Maxwell C. Understanding the extent of and limitations to conscientious objection to abortion by health care practitioners: A hermeneutic study. PLoS One. 2024 Feb 23;19(2):e0297170. doi: 10.1371/journal.pone.0297170. However, other research into midwifery suggests that healthcare professionals feel disclosing CO is risky and possibly erodes human rights as they can be discriminated against if views on CO are made known. See Fleming, V., Frith, L., Luyben, A. et al. Conscientious objection to participation in abortion by midwives and nurses: a systematic review of reasons. BMC Med Ethics 19, 31 (2018). https://doi.org/10.1186/s12910-018-0268-3

A more fundamental legal issue is also whether CO clauses can be challenged. The United Nations International Covenant on Civil and Political Rights in Article 18(1)1, for example, affirms the right to CO, yet this is limited by Article 18(3) of this same covenant if it infringes on the fundamental rights of others. In different jurisdictions, Article 18(3) is given different weight. For example, as Schuklenk notes, the EU Court of Human Rights as well as different domestic courts have tested the right to conscientiously object, with some states being more unwavering in support of this right (e.g. US states) while others, like Sweden, do not permit CO at all. Some critics have suggested that CO and healthcare are 'incompatible' because the former does not allow medical professionals to fulfill their professional (and legal) obligations. See, for example, U. Schuklenk, Conscientious objection in medicine: accommodation versus professionalism and the public good, British Medical Bulletin, 126(1), (2018):47–56

We have added a line regarding this final point relating to legal challenge (page 5); however, we have not substantially extended this debate in the revised version because of word limitation, though feel it may be an interesting and important follow up article that explores the evidence in depth. Reference to Schuklenk omitted due to footnote restrictions but we would be pleased to include this with permission from the Editor.

I'm not sure that the authors do want to argue that assisted dying should be entirely removed from the criminal law. Presumably it would be important to ensure that there were serious penalties for ending a patient's life outside of the administrative regime that they propose? le wouldn't the criminal law continue to operate as a backstop where a patient's life is ended in

circumstances that don't fit within whatever criteria are set down in legislation?

Response: Thank you for this comment. At page 11we note: Accountability would have greater prominence if a practitioner fails to comply with the law causing a wrongful death. In such a case, in the proposed model the criminal law would clearly still be involved. However, we have added a line to emphasise the point you raise above where the criminal law would be a backstop for assisted deaths that have taken place without approval by the statutory panel. Furthermore, as the ADRA is a statutory body it would have the power and responsibility to refer individuals to the police.

I would have thought that there might be interesting analogies that could be drawn here with the legalisation of abortion in the UK in 1967. This adopted a thoroughly medicalised model, making abortion a decision for two doctors, based upon their assessment of whether termination or continuing the pregnancy is more risky for the woman's health.

**Response:** we agree and have included a reference to this regarding the feminist critiques of medicalisation and paternalism that is now at page 5.

#### More specific points

On page 1, rather than referencing a recent debate by British MPs (when? reference?), it might be better now to reference the fact that Kim Leadbeater MP is going to soon bring forward a Private Members Bill, with a commitment from the Prime Minister to devote parliamentary time to it.

**Response:** we have now updated the paper to reflect the new Bill.

The authors claim that healthcare professionals are expected to be involved in MAiD in Canada, but there is a right to conscientiously object to participate in its provision. It would also be good to refer to evidence for the claim that in Canada MAiD is treated like any other healthcare option (the right to conscientious objection would suggest that it is not).

**Response:** The Canadian MAID legislation only provides protection on the basis of conscientious objection from administering or prescribing lethal substances to end life, but no other aspects of participation in MAID are protected. The Canadian government's Model Practice Standard for Medical Assistance in Dying (MAID) requires involvement of health care professionals in two direct ways: 1) it recommends that health care professionals raise MAID as an option to all potentially eligible persons (unsolicited) and 2) if unwilling to provide MAID themselves, a practitioner must make an effective referral to someone who will end a person's life. The Model Practice Standard applies the expected standard of practice for any other healthcare therapy to MAID.

Refs: <u>https://www.canada.ca/en/health-canada/services/publications/health-system-services/model-practice-standard-medical-assistance-dying.html</u>

https://policyoptions.irpp.org/magazines/february-2021/how-bill-c7-will-sacrifice-the-medical-professions-standard-of-care/

I'm not sure about the terms civil and socio-legal. I think it might be better to refer to this as an administrative system. Civil law often refers to disputes between individuals, and is contrasted with criminal or public law. I don't think the authors are recommending that this should be a matter of private resolution. I'm also not sure what they mean by socio-legal in this context. I think they are referring to an administrative mechanism.

**Response:** we accept the point raised. We do think that the civil law is a commonly used term and it reflects where this model sits i.e. tribunals are part of the civil law. We also feel that use of the term 'socio legal' in the model is an important way of emphasising the importance of explicitly addressing social vulnerabilities/social safeguarding in the model – something that other models (including Leadbeater's Bill) doesn't effectively address.

There are some typos/oddities to correct.

On page 1, " members of the British Isles have thus far resisted legalising AD" sounds odd - do the authors mean members of UK parliaments/assemblies?

Response: this has been reworded.

Also on page 1, I think the authors mean imminent, not immanent.

Response: thank you for picking this up – change made!

On page 2, they say " Data identifying that typical AS/E recipients are older ... " Older than who?

Response: clarified median age of 74 from the data used.

This sounds a bit odd: "Health, social and palliative care: these services would continue unchanged. Anyone with a wish to die would be given all help to resolve those issues. " Maybe reword, or specify what issues.

Response: reworded.

# Reframing assisted dying through the civil law: possibilities and challenges for the UK

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#### **Abstract**

If assisted dying is legalised in the British Isles, the authors propose that a socio-legal, civil law model is the most pragmatic, socially nuanced and ethical mode of regulation. It offers choice to end life, while ensuring social safeguarding of vulnerable persons. It also enables healthcare professionals and organisations to focus on healing and care, while protecting them from legal changes to which they may object.

#### **KEY MESSAGES**

#### What is already known on this topic:

- Existing medical models of assisted dying reveal challenges in safeguarding individuals, monitoring and reporting the process.
- Embedding assisted dying into healthcare creates pressures on already exhausted healthcare professionals and organisations.

#### What this study adds:

- A socio-legal civil law model transfers the decision to a statutory panel, and the process with licensed teams outside healthcare. Health and palliative care would continue in tandem but separated from the decision and the process.
- Would be overseen by a statutory regulatory authority, modelled on the UK Parole Board.

#### How this study might affect research, practice or policy:

- This model resolves many of the problems inherent in the medical model, providing a protective social safety valve for patients and removing the prospect that assisted deaths become part of 'normal' medical practice.
- A socio-legal model protects patients, healthcare professionals and organisations from unconscious bias in clinicians

## Reframing assisted dying through the civil law: possibilities and challenges for the UK

#### Introduction

The tide of assisted dying legal change is turning. A swathe of global northern countries have implemented some form of legal change to permit either assisted suicide or euthanasia (AS/E) and parts of the UK have followed. Since Jersey's 2024 approval of assisted dying, Kim Leadbeater's Private Member's Bill proposes to legalise assisted dying in England and Wales for terminally ill adults with less than 6 months to live. Given this current context, this article focuses not on the question of 'if' or 'when' assisted dying may become legalised in Britain, but 'how' such legal change may come into being.

In this Feature piece we argue that that a significant hurdle for prospective legal change will be how to involve doctors and healthcare in the process. Although UK medical organisations have changed their policy positions on assisted dying to 'neutral', this does not indicate universal medical acceptance of assisted suicide or euthanasia, and wide differences of opinion and ongoing concerns surrounding its possible legalisation remain.

There is a spectrum across legalised jurisdictions to the extent to which AS/E is medicalised and embedded in healthcare. At one end is Canada where some view AS/E in the same way as any other care option, and healthcare individuals and organisations are expected to be involved. At the other end of the spectrum is Switzerland where nearly all assisted deaths take place outside of healthcare, although healthcare professionals remain involved in the process. Other jurisdictions such as Oregon and Australia lie along that spectrum.

Some jurisdictions have or are proposing both assisted suicide (AS) and euthanasia € (such as Jersey and the Isle of Man), while others have or are proposing assisted suicide only (England, Wales and Scotland). This article does not address which form of assisted dying possible legislative change in Britain should take, though we acknowledge this to be an important, albeit different, question.

Alternatives to the medical model have been proposed for over 20 years, usually involving the courts as the primary decision-makers. The increasing pressures on the courts and concerns over how the law might be incorporated pragmatically into AS/E regulation have prevented any serious consideration of an alternative. This article begins by presenting the evidence concerning the challenges of medical AS/E models before detailing an alternative civil, socio-legal model.

### The challenges with medical models of assisted dying

The implementation and regulation of any AS/E regime requires a group of people willing to enact it. Most jurisdictions that have legalised AS/E rely on doctors (and sometimes nurse practitioners) to take a lead role in its delivery. Although some healthcare professionals openly support AS/E, global data reveals that finding doctors willing to enact legislation is challenging.¹ While the 2020 BMA survey revealed a significant proportion of British doctors supportive of assisted suicide (48%), this sits alongside significant opposition (41%) or neutrality (10%). Fewer doctors support euthanasia (only 35%), and fewer still are willing to prescribe assisted dying drugs (24%).² Specialisms of palliative care, oncology, respiratory medicine, and geriatric medicine along with general practice, are least supportive; yet, when legalised, these groups are typically tasked with AS/E assessment and provision.

Although conscientious objection (CO) clauses could be built into a medical model to permit doctors to opt out of AS/E delivery, this would not overcome the barrier of finding sufficient numbers of willing doctors to provide it in the first instance. For example, only around 2% of doctors in Oregon prescribe AS/E drugs. CO clauses also present other challenges. First, they only apply to those directly involved in AS/E and not to doctors assessing a patient, nurses caring for an individual, pharmacists preparing lethal drugs, or to organisations. Most medical models require objecting practitioners to make a referral to another doctor. Second, reliance on CO fails to address institutional hierarchies and peer pressure.<sup>3</sup> Hierarchical pressure may be particularly concerning for junior doctors who rely on senior doctors for career progression. CO clauses can also be legally challenged: some have even argued that healthcare provision is incompatible with CO because the latter may prevent doctors from fulfilling their legal as well as professional obligations. These issues may explain why the BMA ethics committee recently suggested that any AS/E process should be an opt-in approach for doctors through a separate service.<sup>4</sup>

Alongside pragmatic critiques of medical models sit theoretical and empirical critiques of medicalisation. Medicalisation refers to the process of defining and treating non-medical issues as medical problems. Applicants for AS/E typically experience terminal illness, severe and debilitating disabilities, or are elderly and infirm, groups who are often marginalised or stigmatised. It is important to separate requests for AS/E from persons who are medically suffering, and requests from persons who are suffering due to social marginalisation; sometimes medicalisation blurs this boundary by treating social suffering as a medical problem to be resolved through medical solutions. Sociologists of disability, for example, argue that disability is medicalised, treating disability almost exclusively as an illness, rather than because of structural barriers and systemic ableism.<sup>5</sup> Medical models may not only permit structural vulnerabilities (SVs), but can sometimes unwittingly reinforce them. Systemic ableism cannot be separated from appeals to AS/E that may come from disabled people who are marginalised by socio-structural barriers and whose disabilities are medicalised as personal problems that can be 'treated' through AS/E.<sup>6</sup> Huxley et al, who were asked to give an ethics review of Jersey's assisted dying proposals, scrutinised the inclusion of a route for those with "unbearable suffering",

"which will almost always be regarded as a disability," citing "ableism" as a significant ethical issue.<sup>7</sup> Canada has also witnessed increasing reports of disabled people being offered unsolicited Medical Assistance in Dying (MAiD), and their Human Rights Commissioner has identified this as a priority review area.<sup>8</sup> AS/E medicalisation may thus risk institutionalising unconscious discrimination.

Because of the increasing tendency to medicalise non-medical issues, medical models cannot sufficiently protect against the expansion of AS/E criteria to areas that may be better supported outside of healthcare, such as disability, 'tiredness of life' and mental illness, evident in Benelux nations and Canada. Although some argue that expansion of eligibility criteria is not inevitable this is not supported by the evidence. Oregon has not expanded from assisted suicide to euthanasia because Federal Law prohibits this, but they have expanded eligibility through broadening of practice patterns to include non-terminal illness such as those who refuse treatment and anorexia, allowing non-residents to access assisted suicide and removing the reflection period in a guarter of patients.<sup>9</sup>

Because disability, tiredness of life and mental illness can also be driven by SVs such as poverty, inadequate access to housing, care, finance, education, employment, reasons for requesting AS/E must be scrutinised. Some might argue that SVs are not an issue in AS/E requests or, if they are, that medical doctors are sufficiently trained to consider these. Evidence can respond to both challenges. First, claims that there are no SVs with AS/E recipients in Canada have been strongly challenged as misrepresenting reality.<sup>10</sup> It is true that conflicting evidence relating socio-economic drivers to AS/E exists: some Swiss<sup>11</sup> and American<sup>12</sup> data links higher socio-economic status (SES) groups to AS/E applications and Canadian data correlates patients with low SES with restricted MAiD access. 13 Conversely, the recent Canadian MAID Death Review Committee Report, 14 which has collated data from coroner reviews of every reported MAID death in Ontario, corroborates earlier academic research revealing correlations between illness, disability and marginalisation. Report data specifically reveals correlations between material resources (poverty) and MAID recipients, including social and housing vulnerability. Qualitative Canadian data also reveals poverty can be a driver for MAiD, and that AS/E requests come from vulnerable persons with limited social care networks and economic pressures. 15 Contextualising and interpreting data is key. Data identifying that typical AS/E recipients are over the age of 70, white, middle-class males diagnosed with cancer is sometimes used to undermine SV claims. 12, 13 In Oregon, longitudinal data reveals that these categories shift over time; cancer diagnosis is a declining category, from 80% in the first 5 years to 64% in 2022; changes in health funding from private to predominantly government; an increase in the percentage of patients feeling a financial burden and a reduction in the physician-patient relationship by two thirds. 12 Second, although some doctors may aspire to integrate SVs in AS/E requests, integrating SV fully into the medical curricula and into practice has proven challenging, 16 and attention to SVs may be undermined by possible unconscious discrimination.

## Alternative models for assisted dying

Given the pragmatic and theoretical issues with medical models of AS/E, some academics and practitioners have proposed a 'demedicalised model'. Preston et al cite the Swiss model as the only (partially) de-medicalised model of AS/E.<sup>17</sup> Indeed, qualitative data from Switzerland suggests that doctors do not wish to see a change in the law or a move towards a medical model. 18 However, the Swiss model remains complexly bound with medicine and cannot easily overcome the problems identified in this paper. Swiss AS, for instance, is decentralised, overseen by non-profit organisations, and regulated through a combination of laws, professional codes of conduct and social mores. Moreover, the Swiss model does not address the empirical and conceptual issue of medicalisation which requires a more robust social support filter to account for SVs. In addition, its outsourced AS/E services are not monitored and produce no detailed reports or research. In the qualitative study cited above, some Swiss doctors suggested they would prefer to see a modified lay model, which would introduce better safeguards including counselling, expertise and capacity assessment. The UK is not considering a devolved regulatory infrastructure and has thus far expressed most interest in considering a medical model, arguably because this is the most well established elsewhere; any prospective de-medicalised model like we are suggesting would require more central and statutory oversight.

In attending to concerns regarding medical models, Preston et al<sup>17</sup> proposed that AS/E requests are regulated instead through the civil law. They propose a statutory multidisciplinary oversight board, comprising a healthcare professional, a lawyer and an ethicist, that would review AS/E requests (and thereby grant or deny them). There is good reason to expand this board to include a social care worker, welfare officer and psychologist to widen the net of the duty of care towards applicants, and to give social and legal legitimacy to an individual's decision that is more meaningful and safeguarded than a decision behind closed doors by one or two healthcare professionals of variable experience. The Irish Joint Committee on Assisted Dying have recommended that AS/E should be entirely separate from palliative care.

A key feature of the proposed civil law model is that it is prospective. Some legal scholars have already written on the merits of such a prospective or 'ex ante' model of regulation. Prospective models license activities before they take place. Because prospective models provide better safeguards through transparency and accountability, they tend to involve higher costs, so they must be justified as necessarily measures to protect against undesirable outcomes. The first part of this paper has addressed why medical models do not provide sufficient safeguarding. What follows is an overview of a possible prospective socio-legal civil law model of AS/E.

Figure 1: A socio-legal, civil law model for AS/E

#### A socio-legal, civil law model for AS/E (see Figure 1)

There are two key elements of the AS/E process: the decision and the assisted death itself. We propose that neither need to be within healthcare. The decision would be moved to a statutory, multidisciplinary socio-legal panel, and the assisted death moved from healthcare to certified providers.

Assisted Dying Regulatory Authority (ADRA): This would be a statutory body that oversees the process of AS/E. It would appoint the socio-legal panels and AS/E navigators (see Figure 1 above). It would also monitor all decisions made by the panels, license the AS/E services, designate secure, regional pharmacies, certify licensed prescribers and ensure drug use and disposal is recorded. In addition, the ADRA would ensure the AS/E services record and analyse the death process, collate and analyse all data, reporting at least annually. Finally, the ADRA would have a review process in case of disagreement with a panel's decision. The body would be responsible to the parliament and legal authority in the relevant jurisdiction. In the UK, a well stress-tested model exists for such a body, the Parole Board.

Statutory socio-legal panel: As a minimum this would consist of an individual with at least 10 years' experience in law and who would be legally accountable to their jurisdiction's legal authority; a social worker or psychologist with 10 years' experience; a healthcare professional with at least 10 years' experience in end-of-life care decisions. Finally, an administrator would document the process. None of the panel could be employed by, have any financial / commercial relationships with, or act in a voluntary capacity for, any agency providing the assisted death. Such statutory separation of the decision from the assisted death is a key safeguard that is not present in current medical models (see Table 1 below).

The panel would evaluate the need and understanding of the individual and order specialist reports. If the patient is considered eligible the panel would issue a license to end life, authorise the release of the AS/E drugs, and ensure that the details of the decision are recorded. The latter is a key difference with medical models where the decision is rarely monitored or recorded. Despite their statutory requirements, panels would ensure that their hearings are as informal as possible. They would also travel to a patient's setting if required and hear applications urgently.

The AS/E process: this would be managed in two ways:

AS/E navigators would be appointed by the ADRA to ensure the correct process is followed once an assisted death has been authorised. They would liaise with the local AS/E service to ensure that drugs are dispensed, collected and that any unused drugs are recorded and disposed of. They would ensure that all relevant data is collected, collated and returned to the ADRA.

AS/E services would be licenced by the ADRA but run separately by existing AS/E charities. They may include healthcare professionals who have volunteered for this role, but who have no links of any sort with the AS/E panels, AS/E navigators or the ADRA. Each service would liaise with the individual about the pace of the assisted death and support the patient and family in taking or administering the drugs. The service would be responsible for documenting the assisted death and sending the information to the ADRA.

Health, social and palliative care: these services would continue unchanged. Anyone with a wish to die would continue to be treated, with the option of also pursuing a request for an assisted death through the socio-legal model proposed.

Numbers and costs: Assuming a rate of 1% of assisted death would result in 6900 assisted deaths each year in the UK, including 630 in Scotland and 170 in Northern Ireland. Estimates are that 11 AS/E panels would be needed and approximately 50 panel members. Based on Parole Board numbers, an additional 120 staff would be needed. Based on costs seen in Canada, this would cost around £10 million for the UK. Against this would be savings in care. Each assisted death in Canada is estimated to save the equivalent of £7,700, which would result in savings for the UK of £53 million. Cost analysis discussions can be deeply uncomfortable but are an unfortunate pragmatic reality. A civil law model would distance doctors from any possible speculations over utilitarian calculations made about end-of-life care, allowing physicians to continue to uphold their professional responsibility to ensure that patient safety and alleviation of suffering are prioritised through the comprehensive utilisation of all available health and social resources.

*Drugs:* an independent prescriber would be certified by the ADRA to issue a prescription for the lethal drugs; they must be independent of any AS/E panel and the ADRA. The prescription would be according to a nationally agreed and approved protocol. The ADRA would designate secure pharmacies staffed by pharmacists who have individually agreed to dispense AS/E drugs. These arrangements assume that relevant drug regulatory authorities have approved both the drugs and doses to be used.

Table 1: comparison of the socio-legal and medical models

Factor	Socio-legal model	Medical model
Decision-makers	Multi-disciplinary expert	Single doctor,
	panel	no expertise expected (or two
		doctors, as with the current
		model for abortion provision)
Assessing social vulnerability	Expertise within expert panel	No expertise expected

Decision process	Open, transparent,	Isolated, never monitored
	documented	
Separation of decision + process	Statutory separation	No separation
Oversight	Statutory authority	Often absent
Assisted death process	Licensed AD service	Isolated professionals
Drugs	Statutory monitoring	Left to individuals
Reporting	Statutory, detailed reports	Dependent on individual doctors
Impact on healthcare	Minimal	Large impact

### Discussion

The statutory separation between an AS/E decision and the assisted death is key to safeguarding patients, providing greater legitimacy. Healthcare professionals who want to participate in AD provision would be better protected with a prospective socio-legal model because the requests for death are regulated and approved *before* they take place. This is fundamentally different to most existing medical models where reviews take place after the patient has died. It would safeguard, as well as avoid the adversarial criminal law model in UK jurisdictions. Prosecution remains a possibility in other jurisdictions where, even when assisted death is decriminalised, doctors may be subject to criminal investigation after a death.<sup>20</sup> The BMA has affirmed a solution like the socio-legal model, suggesting that "eligibility for assisted dying could be decided by a panel, committee or ombudsman....to protect doctors from litigation, [and] better protect patients from coercion"<sup>4</sup> Accountability would have greater prominence if a practitioner fails to comply with the law causing a wrongful death. The criminal law would thus continue to operate as a backstop in such cases where a patient's life is ended in circumstances outside those approved by the statutory panel. As the ADRA is a statutory body it would have the power and responsibility to refer individuals to the police.

Critics may argue that a socio-legal civil law model would be too protracted to deal effectively with AD requests. In reality, people resolved to seek an assisted death do so long before the last days of life, often many months or even years before the assumed death. The socio-legal panels could consider and respond to cases deemed urgent. Hypothetical stress-testing of the civil-law shows that it is possible to cover all the UK with a small number of panels that could, if necessary, travel to the person's care setting. Despite their statutory responsibilities, such panels can ensure encounters make the person and those close to them feel safe and at ease.

The socio-legal model would also be mandated to balance SV assessments with autonomy claims. It would not be used to block applications for AD, an important concern in any legalised system premised on choice. A socio-legal model would foreground and mitigate against the possibility of structural coercion, something that Canada's MAiD model has not robustly built into its assessment process. It would also recognise autonomy as fundamental to healthcare decisions, ensuring that requests can be heard so long as social support filters remain strong. The social support filter of an oversight board also enables a sound evidence base to exert pressure on governments and policy makers that will strengthen social care provision. It would collect and review demographic data on assisted deaths including applications that are denied or permitted. A statutory authority would also better protect against the prospect of economic calculations placed on the value and quality of an individual's life.

#### Conclusion

Using doctors and healthcare organisations to deliver AS/E gives the impression of respectability and safety. However, evidence reveals that a medical model presents challenging regulatory issues, both for patients, doctors, vulnerable citizens, and the broader healthcare sector: (1) it ignores professional objections to involvement, which has distorted clinician roles; (2) it fails to robustly address SVs to safeguard vulnerable persons, and; (3) having assisted dying as part of healthcare frames it as a treatment and thus subject to health economics. A prospective, socio-legal, civil law approach potentially has several key benefits that would mitigate these challenges: (1) it provides a better social support filter which gives greater legitimacy for the applicant's decision and considers alternate solutions, (2) it reduces the problem of having doctors recommending death as a treatment to address gaps in access to health and social services or due to unconscious bias regarding perceived quality of life, and (3) it protects doctors from institutional pressures, possible personal moral conflicts, and potential prosecution for a criminal offence to overstretched clinical teams responsible for day-to-day care provision. If assisted dying is a question of 'when, not if' then it is also incumbent upon us to carefully, and pragmatically, consider the question of 'how'.

#### a. Contributor statement

JD is a sociologist specialising in bioethics and socio-legal studies. CR is a retired palliative care medicine physician and the main contributor to www.kadoh.org.uk, a website propounding that assisted dying should not be part of healthcare. AP is palliative medicine physician and past president for the Association for Palliative Medicine of GB and Ireland. LH is Professor of Palliative Medicine and former President of the Canadian Society of Palliative Care Physicians. RC is an independent family medicine physician in Canada. JD and CR were the primary authors of this article and AP, RC and LH contributed to the article development. JD wrote the first draft, which was revised by CR, and subsequently circulated to AP, RC and LH for final revisions. JD is the guarantor.

#### b. Competing interests

We have read and understood <u>BMJ policy on declaration of interests</u> and have the following interests to declare:

CR is the main contributor to <a href="www.kadoh.uk">www.kadoh.uk</a> (this is an information website only with no membership or affiliations). CR does not belong to any campaign group for or against assisted dying. <a href="mailto:ln March">ln March</a> 2024 he was invited onto the content group for the Nuffield Bioethics project on assisted dying.

RC and LH are recognised and respected experts in their fields who have spoken and published widely on assisted dying. They have both been invited as expert witnesses to testify at several parliamentary committees studying MAiD legislation in Canada.

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AP speaks as a recognised expert in palliative medicine and is a past president of the Association for Palliative Medicine. She has never been a member of the *Our Duty of Care* group or other campaign groups for or against assisted dying.

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#### e. Ethics approval

No ethics approval.

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## Reframing assisted dying through the civil law: possibilities and challenges for the UK

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#### **Abstract**

If assisted dying is legalised in the British Isles, the authors propose that a socio-legal, civil law model is the most pragmatic, socially nuanced and ethical mode of regulation. It offers choice to end life, while ensuring social safeguarding of vulnerable persons. It also enables healthcare professionals and organisations to focus on healing and care, while protecting them from legal changes to which they may object.

#### **KEY MESSAGES**

### What is already known on this topic:

- Existing medical models of assisted dying reveal challenges in safeguarding individuals, monitoring and reporting the process.
- Embedding assisted dying into healthcare creates pressures on already exhausted healthcare professionals and organisations.

#### What this study adds:

- A socio-legal civil law model transfers the decision to a statutory panel, and the process with licensed teams outside healthcare. Health and palliative care would continue in tandem but separated from the decision and the process.
- Would be overseen by a statutory regulatory authority, modelled on the UK Parole Board. How this study might affect research, practice or policy:
- This model resolves many of the problems inherent in the medical model, providing a protective social safety valve for patients and removing the prospect that assisted deaths become part of 'normal' medical practice.
- Such Aa socio-legal -model protects patients, healthcare professionals and organisations which exposes patients to from unconscious bias in clinicians

#### **Contributors and sources**

JD is a sociologist specialising in bioethics and socio-legal studies. CR is a retired palliative care medicine physician and the main contributor to www.kadoh.org.uk, a website propounding that assisted dying should not be part of healthcare. AP is palliative medicine physician and past president for the Association for Palliative Medicine of GB and Ireland. LH is Professor of Palliative Medicine and former President of the Canadian Society of Palliative Care Physicians. RC is an independent family medicine physician in Canada. JD and CR were the primary authors of this article and AP, RC and LH contributed to the article development. JD wrote the first draft, which was revised by CR, and subsequently circulated to AP, RC and LH for final revisions. JD is the guarantor.

#### Patient involvement

No patients were involved

#### **Ethics**

No ethics approval.

#### **Conflicts of Interest**

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## Reframing assisted dying through the civil law: possibilities and challenges for the UK

#### **Abstract**

If assisted dying is legalised in the British Isles, the authors propose that a socio-legal, civil law model is the most pragmatic, socially nuanced and ethical mode of regulation. It offers choice to end life, while ensuring social safeguarding of vulnerable persons. It also enables healthcare professionals and organisations to focus on healing and care, while protecting them from legal changes to which they may object.

#### Introduction

The tide of assisted dying legal change is turning. A swathe of global northern countries have implemented some form of legal change to permit either assisted suicide or euthanasia (AS/E) and parts of the UK have followed. Since Jersey's 2024 approval of assisted dying, Kim Leadbeater's Private Member's Bill proposes to legalise assisted dying in England and Wales for terminally ill adults with less than 6 months to live. the current Scottish Bill, and the recent debate by British MPs suggests that some form of legal change is immanent. Given this current context, Tthis article focuses not on the question of 'if' or 'when' assisted dying may become legalised in Britain, but 'how' such legal change may come into being.

In this Feature piece we argue that that a significant hurdle for prospective legal change will be how to involve doctors and healthcare in the process. Although UK medical organisations have changed their policy positions on assisted dying to 'neutral', this does not indicate universal medical acceptance of assisted suicide or euthanasia, and wide differences of opinion and ongoing concerns surrounding its possible legalisation remain.

There is a spectrum across legalised jurisdictions to the extent to which AS/E is medicalised and embedded in healthcare. At one end is Canada where some view AS/E in the same way as any other care option, and healthcare individuals and organisations are expected to be involved. At the other end of the spectrum is Switzerland where nearly all assisted deaths take place outside of healthcare, although healthcare professionals remain involved in the process. Other jurisdictions such as Oregon and Australia lie along that spectrum.

Some jurisdictions have or are proposing both assisted suicide (AS) and euthanasia (E) (such as Jersey and the Isle of Man), while others have or are proposing assisted suicide only (England, Wales and Scotland). This article does not address which form of assisted dying possible legislative change in Britain should take, though we acknowledge this to be an important, albeit different, question.

Alternatives to the medical model have been proposed for over 20 years, usually involving the courts as the primary decision-makers. The increasing pressures on the courts and concerns over how the law might be incorporated pragmatically into AS/E regulation have prevented any serious consideration of an alternative. This article begins by presenting the evidence concerning the challenges of medical AS/E models before detailing an alternative civil, socio-legal model.

#### The challenges with medical models of assisted dying

The implementation and regulation of any AS/E regime requires a group of people willing to enact it. Most jurisdictions that have legalised AS/E rely on doctors (and sometimes nurse practitioners) to take a lead role in its delivery. Although some healthcare professionals openly support AS/E, global data reveals that finding doctors willing to enact legislation is challenging.<sup>14</sup> While the 2020 BMA survey revealed a significant proportion of British doctors supportive of assisted suicide (48%), this sits alongside significant opposition (41%) or neutrality (10%). Fewer doctors support euthanasia (only 35%), and fewer still are willing to prescribe assisted dying drugs (24%).<sup>22</sup> Specialisms of palliative care, oncology, respiratory medicine, and geriatric medicine along with general practice, are least supportive; yet, when legalised, these groups are typically tasked with AS/E assessment and provision.

Although conscientious objection (CO) clauses could be built into a medical model to permit doctors to opt out of AS/E delivery, this would not overcome the barrier of finding sufficient numbers of willing doctors to provide it in the first instance. For example, only around 2% of doctors in Oregon prescribe AS/E drugs. CO clauses also present other challenges. First, they only apply to those directly involved in AS/E and not to doctors assessing a patient, nurses caring for an individual, pharmacists preparing lethal drugs, or to organisations. Most medical models require objecting practitioners to make a referral to another doctor. Second, reliance on CO fails to address institutional hierarchies and peer pressure.<sup>33</sup> Hierarchical pressure may be particularly concerning for junior doctors who rely on senior doctors for career progression.<sup>3</sup> CO clauses can also be legally challenged: some have even argued that healthcare provision is incompatible with CO because the latter may prevent doctors from fulfilling their legal as well as professional obligations. These issues may explain why the BMA ethics committee recently suggested that any AS/E process should be an opt-in approach for doctors through a separate service.<sup>44</sup>

Alongside pragmatic critiques of medical models sit theoretical and empirical critiques of medicalisation. Medicalisation refers to the process of defining and treating non-medical issues as medical problems. <sup>5</sup> Applicants for AS/E typically experience terminal illness, severe and debilitating disabilities, or are elderly and infirm, groups who are often marginalised or stigmatised. It is important

to separate requests for AS/E from persons who are medically suffering, and requests from persons who are suffering due to social marginalisation;\_sometimes medicalisation blurs this boundary by treating social suffering as a medical problem to be resolved through medical solutions. Sociologists of disability, for example, argue that disability is medicalised, treating disability almost exclusively as an illness, rather than because of structural barriers and systemic ableism.<sup>56</sup> Medical models may not only permit structural vulnerabilities (SVs), but can sometimes unwittingly reinforce them. Systemic ableism cannot be separated from appeals to AS/E that may come from disabled people who are marginalised by socio-structural barriers and whose disabilities are medicalised as personal problems that can be 'treated' through AS/E.<sup>67</sup> Huxley et al, who were asked to give an ethics review of Jersey's assisted dying proposals, scrutinised the inclusion of a route for those with "unbearable suffering", "which will almost always be regarded as a disability," citing "ableism" as a significant ethical issue.<sup>78</sup> Canada has also witnessed increasing reports of disabled people being offered unsolicited Medical Assistance in Dying (MAiD), and their Human Rights Commissioner has identified this as a priority review area.<sup>8,9</sup> AS/E medicalisation may thus risk institutionalising unconscious discrimination.

Because of the increasing tendency to medicalise non-medical issues, medical models cannot sufficiently protect against the expansion of AS/E criteria to areas that may be better supported outside of healthcare, such as disability, 'tiredness of life' and mental illness, evident in Benelux nations and Canada. Although some argue that expansion of eligibility criteria is not inevitable this is not supported by the evidence. Oregon has not expanded from assisted suicide to euthanasia because Federal Law prohibits this, but they have expanded several eligibility criteria through broadening of practice patterns to include non-terminal illness such as those who refuse treatmenta and anorexia such as moving to non-terminal illness, allowing non-residents to access assisted suicide and removing the reflection period in a quarter of patients.<sup>940</sup>

Because disability, suffering, tiredness of life and mental illness can also be driven by SVs such as poverty, inadequate access to housing, care, finance, education, employment, reasons for requesting AS/E must be scrutinised. Some might argue that SVs are not an issue in AS/E requests or, if they are, that medical doctors are sufficiently trained to consider these. Evidence can respond to both challenges. First, claims that there are no SVs with AS/E recipients in Canada have been strongly challenged as misrepresenting reality. 1044 It is true that conflicting evidence relating socio-economic drivers to AS/E exists: some Swiss<sup>1142</sup> and American<sup>1243</sup> data links higher socio-economic status (SES) groups to AS/E applications and Canadian data correlates patients with low SES with restricted MAID access. 1344 Conversely, -the recent Canadian MAID Death Review Committee Report, 14 which has collated data from coroner reviews of every reported MAID death in Ontario, corroborates earlier academic research revealing correlations between illness, disability and marginalisation. Report data specifically reveals correlations between material resources (poverty) and MAID recipients, including social and housing vulnerability, while other Canadian data identifies that low SES groups comprise a disproportionate number of Canadian MAiD applicants, although they receive a similar proportion of assistance to other SES groups. 15 Qualitative Canadian data also reveals poverty can be a driver for MAiD, and that AS/E requests come from vulnerable persons with limited social care networks and

economic pressures. 1546—Contextualising and interpreting data is key. Data identifying that typical AS/E recipients are over the age of 70 elder, white, middle-class males diagnosed with cancer is sometimes used to undermine SV claims. 12, 13, 43 In Oregon, longitudinal data reveals that these categories shift over time; cancer diagnosis is a declining category, from 80% in the first 5 years to 64% in 2022; changes in health funding from private to predominantly government; an increase in the percentage of patients feeling a financial burden and a reduction in the physician-patient relationship by two thirds. 12, 42 Second, although some doctors may aspire to integrate SVs in AS/E requests, integrating SV fully into the medical curricula and into practice has proven challenging, 1647 and attention to SVs may be undermined by possible unconscious discrimination.

#### Alternative models for assisted dying

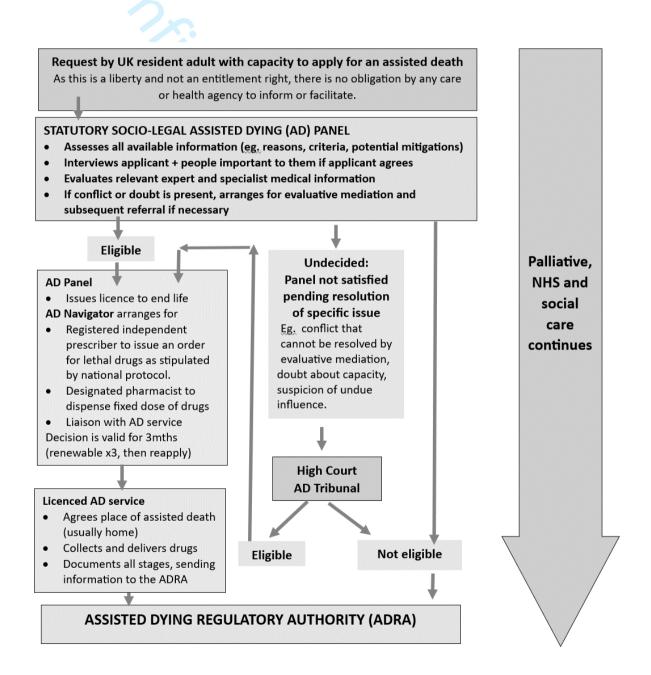
Given the pragmatic and theoretical issues with medical models of AS/E, some academics and practitioners have proposed a 'demedicalised model'.5, 48\_Preston et al cite the Swiss model as the only (partially) de-medicalised model of AS/E.1748 Indeed, qualitative data from Switzerland suggests that doctors do not wish to see a change in the law or a move towards a medical model. 18 However, the Swiss model remains complexly bound with medicine and cannot easily overcome the problems identified in this paper. Swiss AS, for instance, is decentralised, overseen by non-profit organisations, and regulated through a combination of laws, professional codes of conduct and social mores. Moreover, the Swiss model does not address the empirical and conceptual issue of medicalisation which requires a more robust social support filter to account for SVs. In addition, its outsourced AS/E services are not monitored and produce no detailed reports or research. In the qualitative study cited above, some Swiss doctors suggested they would prefer to see a modified lay model, which would introduce better safeguards including counselling, expertise and capacity assessment. The UK is not considering a devolved regulatory infrastructure and has thus far expressed most interest in considering a medical model, arguably because this is the most well established elsewhere; any prospective de-medicalised model like we are suggesting would require more central and statutory oversight.

In attending to concerns regarding medical models, Preston et al<sup>178</sup> proposed that AS/E requests are regulated instead through the civil law. They propose a statutory multidisciplinary oversight board, comprising a healthcare professional, a lawyer and an ethicist, that would review AS/E requests (and thereby grant or deny them). There is good reason to expand this board to include a social care worker, welfare officer and psychologist to widen the net of the duty of care towards applicants, and to give social and legal legitimacy to an individual's decision that is more meaningful and safeguarded than a decision behind closed doors by one or two healthcare professionals of variable experience. The Irish Joint Committee on Assisted Dying have recommended that AS/E should be entirely separate from palliative care.

A key feature of the proposed civil law model is that it is prospective. Some legal scholars have already written on the merits of such a prospective or 'ex ante' model of regulation. 1949 Prospective models license activities before they take place. Because prospective models provide better

safeguards through transparency and accountability, they tend to involve higher costs, so they must be justified as necessarily measures to protect against undesirable outcomes. The first part of this paper has addressed why medical models do not provide sufficient safeguarding. What follows is an overview of a possible prospective socio-legal civil law model of AS/E.

Figure 1: A socio-legal, civil law model for AS/E



#### A socio-legal, civil law model for AS/E (see Figure 1)

There are two key elements of the AS/E process: the decision and the assisted death itself. We propose that neither need to be within healthcare. The decision would be moved to a statutory, multidisciplinary socio-legal panel, and the assisted death moved from healthcare to certified providers.

Assisted Dying Regulatory Authority (ADRA): This would be a statutory body that oversees the process of AS/E. It would appoint the socio-legal panels and AS/E navigators (see Figure 1 above). It would also monitor all decisions made by the panels, license the AS/E services, designate secure, regional pharmacies, certify licensed prescribers and ensure drug use and disposal is recorded. In addition, the ADRA would ensure the AS/E services record and analyse the death process, collate and analyse all data, reporting at least annually. Finally, the ADRA would have a review process in case of disagreement with a panel's decision. The body would be responsible to the parliament and legal authority in the relevant jurisdiction. In the UK, a well stress-tested model exists for such a body, the Parole Board.

Statutory socio-legal panel: As a minimum this would consist of an individual with at least 10 years' experience in law and who would be legally accountable to their jurisdiction's legal authority; a social worker or psychologist with 10 years' experience; a healthcare professional with at least 10 years' experience in end-of-life care decisions. Finally, an administrator would to document the process. None of the panel could be employed by, have any financial / commercial relationships with, or act in a voluntary capacity for, any agency providing the assisted death. Such statutory separation of the decision from the assisted death is a key safeguard that is not present in current medical models (see Table 1 below).

The panel would evaluate the need and understanding of the individual and order specialist reports.- If the patient is considered eligible the panel would issue a license to end life, authorise the release of the AS/E drugs, and ensure that the details of the decision are recorded. The latter is a key difference with medical models where the decision is rarely monitored or recorded. Despite their statutory requirements, panels would ensure that their hearings are as informal as possible. They would also travel to a patient's setting if required and hear applications urgently.

The AS/E process: this would be managed in two ways:

AS/E navigators would be appointed by the ADRA to ensure the correct process is followed once an assisted death has been authorised. They would liaise with the local AS/E service to ensure that drugs are dispensed, collected and that any unused drugs are recorded and disposed of. They would ensure that all relevant data is collected, collated and returned to the ADRA.

AS/E services would be licenced by the ADRA but run separately by existing AS/E charities. They may include healthcare professionals who have volunteered for this role, but who have no links of any sort with the AS/E panels, AS/E navigators or the ADRA. Each service would liaise with the individual about the pace of the assisted death and support the patient and family in taking or administering the drugs. The service would be responsible for documenting the assisted death and sending the information to the ADRA.

Health, social and palliative care: these services would continue unchanged. Anyone with a wish to die would be given all help to resolve those issues continue to be treated, with the option of also pursuing a request for an assisted death through the socio-legal model proposed.

Numbers and costs: Assuming a rate of 1% of assisted death would result in 6900 assisted deaths each year in the UK, including 630 in Scotland and 170 in Northern Ireland. Estimates are that 11 AS/E panels would be needed and approximately 50 panel members. Based on Parole Board numbers, an additional 120 staff would be needed. Based on costs seen in Canada, this would cost around £10 million for the UK. Against this would be savings in care. Each assisted death in Canada is estimated to save the equivalent of £7,700, which would result in savings for the UK of £53 million. Cost analysis discussions can be deeply uncomfortable but are an unfortunate pragmatic reality. A civil law model would distance doctors from any possible speculations over utilitarian calculations made about end-of-life care, allowing physicians to continue to uphold their professional responsibility to ensure that patient safety and alleviation of suffering are prioritised through the comprehensive utilisation of all available health and social resources.

*Drugs*: an independent prescriber would be certified by the ADRA to issue a prescription for the lethal drugs; they must be independent of any AS/E panel and the ADRA. The prescription would be according to a nationally agreed and approved protocol. The ADRA would designate secure pharmacies staffed by pharmacists who have individually agreed to dispense AS/E drugs. These arrangements assume that relevant drug regulatory authorities have approved both the drugs and doses to be used.

Table 1: comparison of the socio-legal and medical models

Factor	Socio-legal model	Medical model
Decision-makers	Multi-disciplinary expert	Single doctor,
	panel	no expertise expected (or two
		doctors, as with the current
		model for abortion provision)
Assessing social vulnerability	Expertise within expert panel	No expertise expected

Decision process	Open, transparent, documented	Isolated, never monitored
Separation of decision + process	Statutory separation	No separation
Oversight	Statutory authority	Often absent
Assisted death process	Licensed AD service	Isolated professionals
Drugs	Statutory monitoring	Left to individuals
Reporting	Statutory, detailed reports	Dependent on individual doctors
Impact on healthcare	Minimal	Large impact

#### Discussion

The statutory separation between an AS/E decision and the assisted death is key to safeguarding patients, providing greater legitimacy. Healthcare professionals who want to participate in AD provision would be better protected with a prospective socio-legal model because the requests for death are regulated and approved before they take place. This is fundamentally different to most existing medical models where reviews take place after the patient has died. It would safeguard, as well as avoid the adversarial criminal law model in UK jurisdictions. Prosecution remains a possibility in other jurisdictions where, even when assisted death is decriminalised, doctors may be subject to criminal investigation after a death. 2020 The BMA has affirmed a solution like the socio-legal model, suggesting that "eligibility for assisted dying could be decided by a panel, committee or ombudsman....to protect doctors from litigation, [and] better protect patients from coercion".44 Accountability would have greater prominence if a practitioner fails to comply with the law causing a wrongful death. The criminal law would thus continue to operate as a backstop in such cases where a patient's life is ended in circumstances outside those approved by the statutory panel. In such a case, in the proposed model the criminal law would clearly still be involved. As the ADRA is a statutory body it would have the power and responsibility to refer individuals to the police.

Critics may argue that a socio-legal civil law model would be too protracted to deal effectively with AD requests. In reality, people resolved to seek an assisted death do so long before the last days of life, often many months or even years before the assumed death. -The socio-legal panels could consider and respond to cases deemed urgent. Hypothetical stress-testing of the civil-law shows that it is possible to cover all the UK with a small number of panels that could, if necessary, travel to the person's care setting. Despite their statutory responsibilities, such panels can ensure encounters make the person and those close to them feel safe and at ease.

The socio-legal model would also be mandated to balance SV assessments with autonomy claims. It would not be used to block applications for AD, an important concern in any legalised system premised on choice. A socio-legal model would foreground and mitigate against the possibility of structural coercion, something that Canada's MAiD model has not robustly built into its assessment process. It would also recognise autonomy as fundamental to healthcare decisions, ensuring that eligible-requests can be heard so long as social support filters remain strong.-\_The social support filter of an oversight board also enables a sound evidence base to exert pressure on governments and policy makers that will strengthen social care provision. It would collect and review demographic data on assisted deaths including applications that are denied or permitted. A statutory authority would also better protect against the prospect of economic calculations placed on the value and quality of an individual's life.

#### Conclusion

Using doctors and healthcare organisations to deliver AS/E gives the impression of respectability and safety. However, evidence reveals that a medical model presents challenging regulatory issues, both for patients, doctors, vulnerable citizens, and the broader healthcare sector: (1) it ignores professional objections to involvement, which has distorted clinician roles; (2) it fails to robustly address SVs to safeguard vulnerable persons, and; (3) having assisted dying as part of healthcare frames it as a treatment and thus subject to health economics. A prospective, socio-legal, civil law approach potentially has severaltwo key benefits that would mitigate these challenges: (1) it provides a better social support filter which gives greater legitimacy for the applicant's decision and considers alternate solutions, and (2) it reduces the problem of having doctors recommending death as a treatment to address gaps in access to health and social services or due to unconscious bias regarding perceived quality of life, and (3) it protects doctors from institutional pressures, possible personal moral conflicts, and potential prosecution for a criminal offence to overstretched clinical teams responsible for day-to-day care provision. If assisted dying is a question of 'when, not if' then it is also incumbent upon us to carefully, and pragmatically, consider the question of 'how'.

#### a. Contributor statement

JD is a sociologist specialising in bioethics and socio-legal studies. CR is a retired palliative care medicine physician and the main contributor to www.kadoh.org.uk, a website propounding that assisted dying should not be part of healthcare. AP is palliative medicine physician and past president for the Association for Palliative Medicine of GB and Ireland. LH is Professor of Palliative Medicine and former President of the Canadian Society of Palliative Care Physicians. RC is an independent family medicine physician in Canada. JD and CR were the primary authors of this article and AP, RC and LH contributed to the article development. JD wrote the first draft, which was revised by CR, and subsequently circulated to AP, RC and LH for final revisions. JD is the guarantor.

#### b. Competing interests

We have read and understood BMJ policy on declaration of interests and have the following interests to declare:

CR is the main contributor to www.kadoh.uk (this is an information website only with no membership or affiliations). CR does not belong to any campaign group for or against assisted dying. In March 2024 he was invited onto the content group for the Nuffield Bioethics project on assisted dying.

RC and LH are recognised and respected experts in their fields who have spoken and published widely on assisted dying. They have both been invited as expert witnesses to testify at several parliamentary committees studying MAiD legislation in Canada.

RC is a member of the MAiD Death Review Committee: In collaboration with the Office of the Chief Coroner, members offer multidisciplinary expertise in the review of MAiD deaths in Ontario to assist in evaluating public safety. RC is co-founding member, Physicians Together with Vulnerable Canadians: a national group of physicians concerned about the expansion of MAiD in Bill C7 to those with chronic illness disability whose death is not foreseeable. RC is an expert panel member of Expert Advisory Group (EAG) on Medical Assistance in Dying (MAiD) which consists of pre-eminent national and international experts and those with lived experience/expertise of mental illness and aims to ensure evolving MAiD policies are guided by best evidence and practice. RC Is on the advisory council of the Society of Canadian Psychiatry which is a group preserving psychiatry's evidence-based integrity, biopsychosocial scope, and scientific relevance.

LH is a Subject Matter Expert and Researcher with Pallium Canada and receives a stipend for her work in updating Pallium's Learning Essential Approaches to Palliative Care (LEAP) courses and for the development of the Canadian Atlas of Palliative Care. LH is also a Senior Fellow, Cardus Health. Receives an honorarium for work as a palliative medicine expert giving expert input into research and policy priorities for Cardus Health. Cardus is a non-partisan think tank dedicated to clarifying and strengthening, through research and dialogue, the ways in which society's institutions can work together for the common good. LH is co-founding member, Physicians Together with Vulnerable Canadians: a national group of physicians concerned about the expansion of MAiD in Bill C7 to those with chronic illness disability whose death is not foreseeable. LH is former President, Canadian Society of Palliative Care Physicians. Unpaid. Represented the national specialty society for Palliative Medicine in Canada at various parliamentary committees, testifying as an Expert Witness on the State of Palliative Care in Canada and on the expansion of MAID. LH is Co-Editor, Palliative Medicine - A Case Based Manual, Oxford University Press 2021. Receive royalties from the sale of the textbook.

AP speaks as a recognised expert in palliative medicine and is a past president of the Association for Palliative Medicine. She has never been a member of the *Our Duty of Care* group or other campaign groups for or against assisted dving.

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#### e. Ethics approval

No ethics approval.

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#### Figure Legend

Figure 1 outlines a proposed socio-legal, civil law model for assisted dying. A UK resident adult with capacity would apply for an assisted death to a statutory socio-legal assisted dying panel. The model describes the process if a person is deemed eligible, not eligible, or undecided.

Request by UK resident adult with capacity to apply for an assisted death

As this is a liberty and not an entitlement right, there is no obligation by any care or health agency to inform or facilitate.

### Statutory socio-legal assisted dying (AD) panel:

- Assesses all available information (e.g. reasons, criteria, potential mitigations)
- Interviews application and people important to them if applicant agrees
- Confirms the individual has capacity for this specific decision
- Evaluates relevant expert and specialist medical information
- If conflict/doubt present, arranges for evaluative mediation and referral if needed

#### Eligible:

#### **AD** Panel

- Issues licence to end life

#### **AD Navigator**

- Registered independent prescriber to issue an order for lethal drugs as stipulated by national protocol
- Designated pharmacist to dispense fixed dose of drugs
- Liaison with AD service

Decision is valid for 3 months (renewable x 3, then reapply)

#### Licenced AD service:

- Agrees place of assisted death (usually home)
- Collects and delivers drugs
- Documents all stages, sending information to the Assisted Dying Regulatory Authority (ADRA)

#### **Undecided**:

Panel not satisfied pending resolution of specific issue

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Tribunal decides if L.

AS and social care continu. e.g. conflict that cannot be resolved by evaluative mediation, doubt about capacity, suspicion of