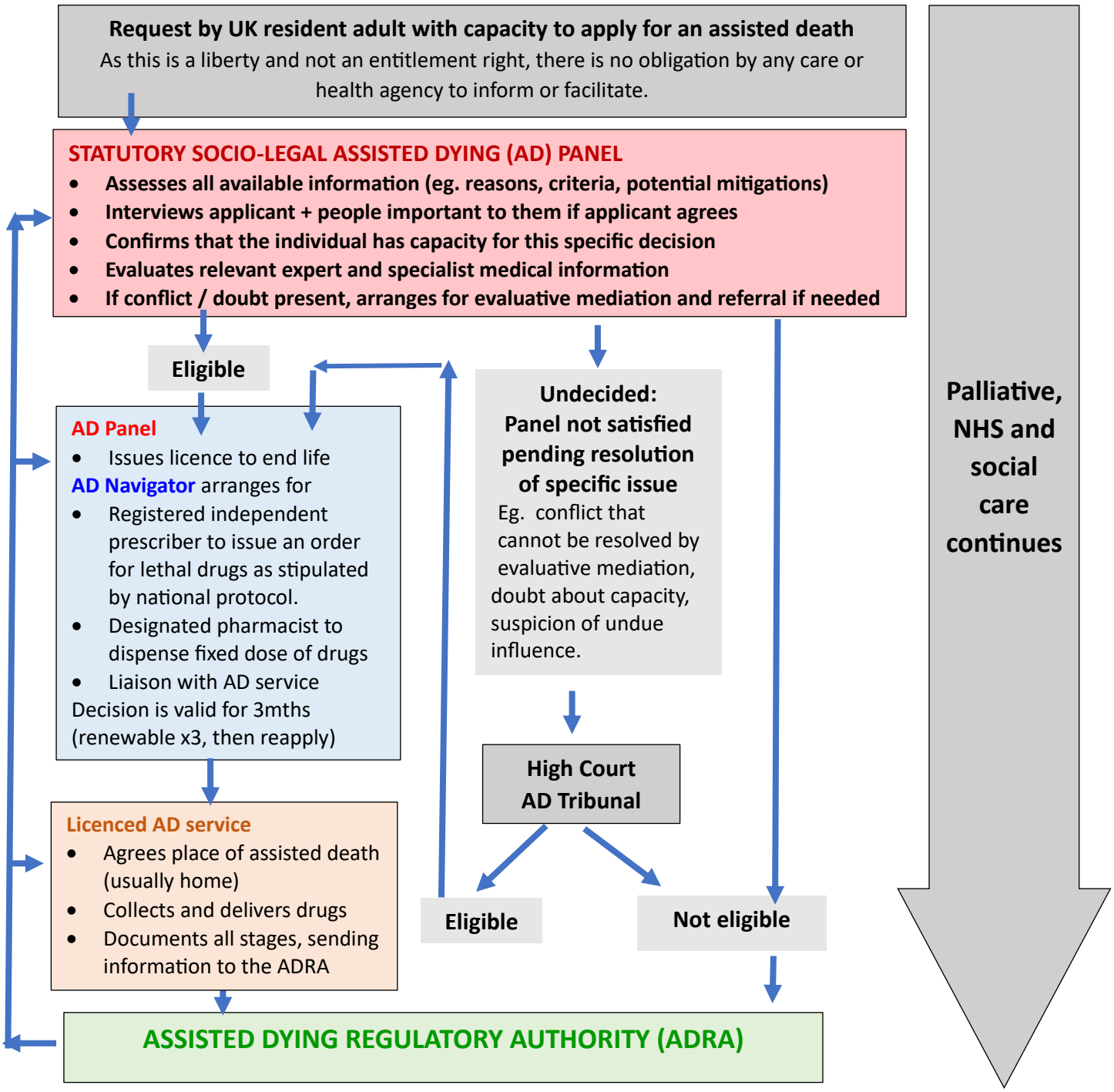
A safer model for assisted dying in the UK

Problems in many assisted dying jurisdictions exist because assisted dying is embedded within a largely medical model. Contrary to claims that this provides greater legitimacy, this model results in secretive medical assessments that are never monitored, poorly reported, rarely reviewed and hide errors, unconscious bias and discrimination. It also increases the strain on exhausted services and effectively removes the right to conscientious objection for individuals and organisations. Although some jurisdictions have models that are largely outside healthcare, the decisions are still made by doctors. Alternative models have been proposed for over 20 years.[1-10] Key features are moving the decision-making from the solely medical to the socio-legal sphere, separating this from the assisted death process, and placing both outside healthcare. Healthcare would still be involved in providing evidence and reports, but the assisted dying decision would be made by a statutory panel with much wider legal, social and psychological skills than current proposals. A statutory process would make such a jurisdiction the first in the world to monitor assisted dying decisions prospectively and transparently, while avoiding many of the problems of the medical, healthcare model.



ADRA Assisted Dying Regulatory Authority

A statutory, executive non-departmental public body (NDPB) established in any AD bill
oversees the process of assisted dying by
- appointing Assisted Dying panels and Assisted Dying Navigators
- monitoring all decisions made by the Assisted Dying Panels
- licencing and monitoring Assisted Dying Services
- ensuring drug use and disposal is recorded
- ensuring the AD service records and analyses the death process, including complications
- recording, collating and analysing all data and reporting at least annually on this information
- supporting retrospective and prospective research
- being accountable to parliament through the secretary of state.

No member of the ADRA can be employed by, have financial / commercial relationships with, or act in a voluntary capacity for any agency providing an assisted death.

Assisted Dying Panel

All requests would be assessed by this panel, which consists of the following as a minimum requirement:
1. Legally trained individual with at least 10 years' experience.
   -accountable to HM Courts and Tribunal Service (England & Wales) or Procurator Fiscal (Scotland)
2. Social worker and/or psychologist with at least 10yrs experience that includes identifying coercion.
3. Healthcare professional with at least 10yrs experience in end-of-life decisions and who is a specialist in the person's disorder. Additional members can be co-opted if necessary.
4. Administrator to document process

No member of the panel can be employed by, have financial / commercial relationships with, or act in a voluntary capacity for any agency providing the assisted death.

Statutory duties of panel
- compassionately verify the capacity and circumstances of the request from a health, social and legal perspective.
- issue licence to end life and authorise release of lethal drug mixture for use within 1 month.
- ensure decision details are recorded; give an explanation why a request is refused or refer to the High Court if the request is outside their remit.

The practice of the panel is to conduct hearings safely and constructively including travelling to the person's preferred care setting and hearing cases urgently.

AD Navigators

AD Navigators are appointed by the ADRA as a healthcare professional of 10 or more years' experience with full registration (Health Professions Council, Nursing and Midwifery Council or the GMC). Duties are to
- ensure that the correct processes are followed once an assisted death has been authorised.
- ensure all relevant data is collected, collated and returned to the Assisted Dying Regulatory Authority.
- liaise with their local licenced Assisted Dying Service ensuring that drugs are securely dispensed and collected by the Assisted Dying Service, and that any unused drugs are recorded and disposed of.
- ensure that each assisted death is recorded as an *extraordinary death* (the death certificate would state 'assisted death', followed by the underlying diagnosis or contributory factors
- verifying that death has occurred and ensuring the next of kin is informed the death has occurred.
- notifying all clinical teams involved in the patient's care that the death has occurred.

No navigator can be employed by, have financial or commercial relationships with, or act in a voluntary capacity for, any agency providing the assisted death

Licenced AD service

These are licenced by the ADRA and run separately in a non-profit capacity. They may include some healthcare professionals who have volunteered for this role, but who have no links of any sort with the Assisted Dying Regulatory Authority, panels, or navigators. The duties of each service are to -
- liaise with the person about their wishes for the place of the assisted death and who they wish to be present during the dying process.
- support the patient and family in taking the approved drugs within 1 month of issue, and be responsible for documenting this process and sending the information to the ADRA.

Any service breaking codes of conduct or failing to return documentation would risk losing their licence, with a potential fine according to the criminal code.

Further information

Courts

These would only be used in situations when the panel believes an issue is unresolved. This would be administered by HM Courts and Tribunal Services in England & Wales, the Procurator Fiscal Service in Scotland, or Public Prosecution Service in Northern Ireland.
It could be badged as the AD Tribunal.

The HMCTS, Procurator Fiscal Service or PPS would have responsibility for recruiting the legal representative. The ADRA would appoint and select the remaining panel members, and provide training for all panel members.

Oversight and breaches of assisted death practice:

Unlike the voluntary oversight of funeral directors and crematoria which are not overseen by the government, assisted deaths would be monitored centrally by a compulsory code of practice.

Breaches may be minor indicating poor practice but no harm, or serious, indicating harm. The monitoring body would have the power to remove a licence and to refer for prosecution if necessary.

Numbers

Assuming a rate of 0.9% of all deaths being assisted (as in Oregon) this would mean 571/year in Scotland; 155/year in NI and 5107/yr. in England & Wales (4788 England; 319 Wales).

Experience in Oregon suggests that requests are one third higher than assisted deaths, so each total needs to be increased by one third to give the eventual number of applicants each year, ie **759/year in Scotland; 206/year in NI and 6792/yr. in England & Wales (6368 England; 424 Wales).**

Assuming 250 working days/year and each panel seeing 2-3 cases daily;

- Scotland would need 2 panels
- Northern Ireland would need 1 panel
- England & Wales would need 8 panels

Panels would meet in main population centres, but would be expected to travel to care settings based on clinical need or remote locations.

Assuming 4-5 members per panel, this would amount to around 50 panel members to recruit, train and support.

Initially the first year may see one tenth of the eventual numbers, but increasing by 25% each year.

Cost

Canada have estimated that the cost of each assisted death in 2020 was Can$2,327. Known inflation in Canada would make this Can$2809 in 2025.[14] This is equivalent to £1526.

On this basis, costs for England and Wales would be
Year 1 = £1.04 million, Year 5 = £3.16 million, Year 10 = £9.64 million

However, this is a model that embeds assisted dying in healthcare.

In a model that sits outside of healthcare, there are four separate costs: a) Administration of the ADRA; b) Staff in the Assisted Dying Panels; c) The Assisted Dying Navigators; and d) the licenced Assisted Dying Services

The first three can be considered together as they all come under the ADRA.. Since the ADRA is an executive, non-departmental public body (ExNDPB), the costs of other ExNDPB's are well known. One example is the Parole Board, which has a monitoring, administrative and training role, in addition to running multidisciplinary socio-legal panels. This has 220 staff and had a case load of 10,263 in 2023.

The estimated ADRA case load in Year 10 would be 40% lower.

For England & Wales, an estimate is that the ADRA would need 95 permanent staff (including 18 Navigators), plus 35 part-time panel members to cover 8 panels in different regions of England and Wales.

Based on the known costs of existing ExNDPBs **the full cost of the ADRA would be £5.54 million by year 10**.
Costs would be lower in Year 1.

Costs of Assisted Dying Services:

Many ExNDPB's work with charities as partners in their work. For example, the Environment Agency works closely with charities such as the Rivers Trust.

The ADRA would work in partnership with existing assisted dying charities to run the Assisted Dying Services.

Each service would be licenced and monitored by the ADRA.

Since this part of the service is charitable, it would not be part of state funding.

Savings

In 2021, Canada estimated savings of Can$86.9 million for 6,465 assisted deaths. Taking inflation into account this equates to Can$101.3 million in 2025.[14] This equals £55.06 million, or a saving in healthcare of £8517 for each assisted death.

This would equate to a **healthcare saving of £5.66 million in Year 1.**

This amount will change depending on the stage at which an individual opts for an assisted death and what care they would have needed.

However, it is likely that the socio-legal model of assisted dying would be cost neutral to the state.

Drugs

The independent prescriber will be specifically certified to issue an order (prescription) for the approved drugs, and must be independent of any AD panel or tribunal.
Prescription would be according to a nationally agreed and approved protocol.

Drugs would only be dispensed for immediate use (within 1 week). They would not be dispensed for future use since, by definition, criteria for an assisted death have not been met. However, the patient's request would be kept on file and could be rapidly accessed for approval if the criteria are met in the future.

The ADRA would designate secure, designated pharmacies staffed by pharmacists who have individually agreed to dispense the AD drugs according to a nationally agreed protocol.

These arrangements assume the approval of AD drug and doses by the Medicines and Healthcare products Regulatory Agency (MHRA) and not based on 'off-label' prescribing rules or approval by ministers.

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