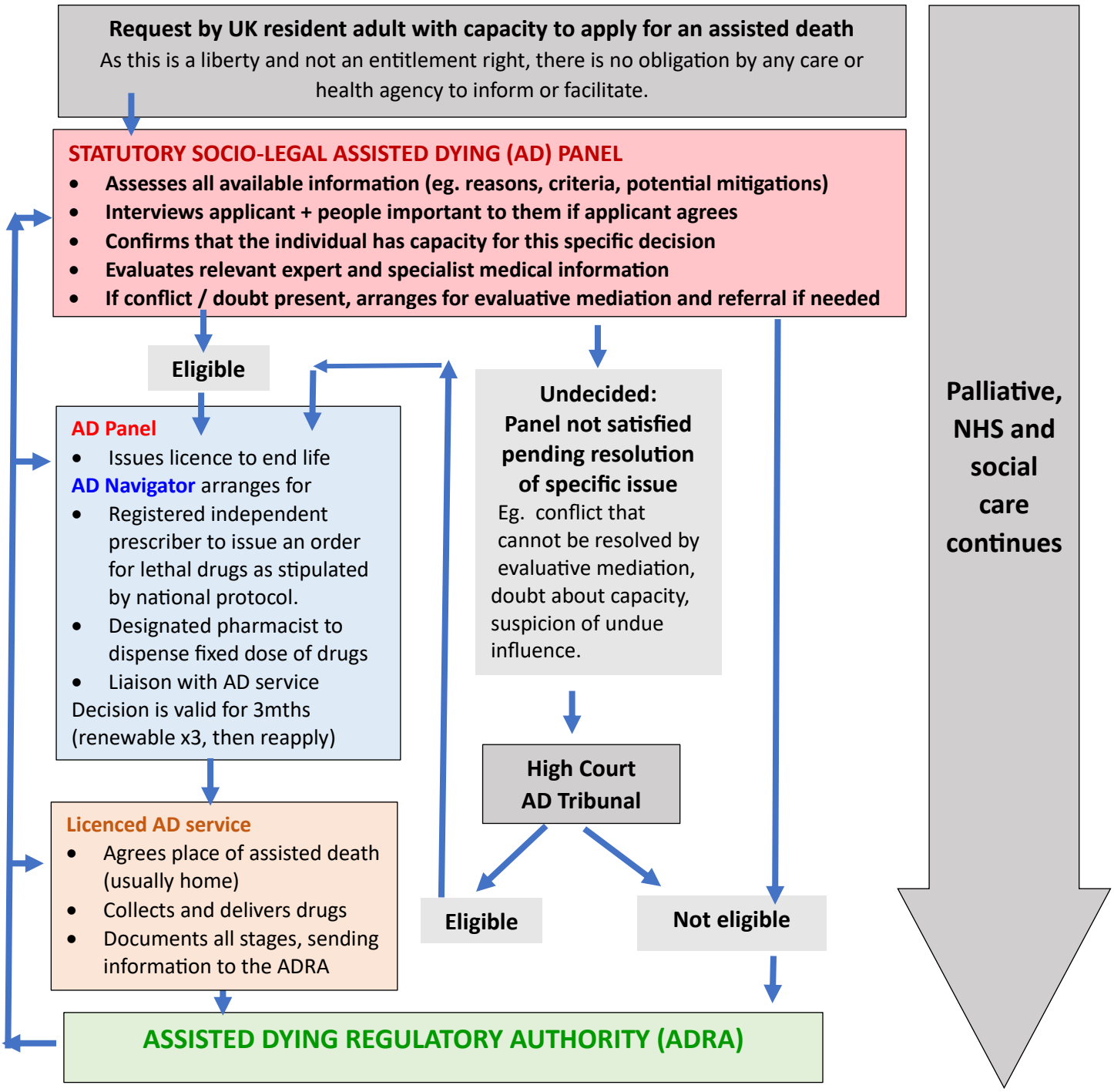
A safer model for assisted dying in the UK

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 similar to the UK Parole Board 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 body (established in any AD bill) that oversees the process of assisted dying by
- appointing socio-legal AD panels and AD navigators
- monitoring all decisions made by the AD panels
- licencing AD 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
- being responsible to parliament and relevant legal bodies (HM Courts and Tribunal Services in England & Wales. Procurator Fiscal in Scotland) or Public Prosecution Service in Northern Ireland

Socio-legal AD Panel

This 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.
   Their specialty may vary depending on the case
4. Administrator to document process

None 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.

A model is the Parole board. This is a legal body stemming from legislation but with a socio-legal perspective and whose purpose is public safety.

Statutory duties of panel
- requirement to compassionately verify the capacity and circumstances of the request
- issue license to end life and authorise release of lethal drug mixture for immediate use (within 1 week).
- ensure decision details are recorded

The social work guidance on working with families would be useful to ensure that panel hearings, despite their statutory responsibility, are conducted safely and constructively. For example, the panel could travel to a preferred care setting and hear cases urgently if required

AD Navigators

AD Navigators would be appointed by the ADRA outside of medical or nursing councils. They would
- ensure that the correct process is followed once an assisted death has been authorised.
- ensure all relevant data is collected, collated and returned to the ADRA.
- liaise with their local AD service ensuring that drugs are securely dispensed and collected by the AD 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.)

Licenced AD service

These would be licenced by the ADRA but run separately by non-profit assisted dying charities
- they may include some healthcare professionals who have volunteered for this role, but who have no links of any sort with the AD panels, AD navigators or their members.

Each service would liaise with the individual about the place of the assisted death and support the patient and family in taking or administering the AD drugs.
They would 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.

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 1% of all deaths being assisted (as in Oregon) this would mean 630/year in Scotland; 172/year in NI and 6100/yr. in England & Wales (5440 England; 660 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.

These estimates allow capacity for an increase in numbers in the first 5 years.

Cost

Canada have estimated that each assisted death costs Can$2,327 (£1300 as of Feb 2025)[11]

= £7.9 million for England and Wales (£7.1 million for Wales, £860,000 Wales)
= £223,600 for Northen Ireland
= £819,000 for Scotland

The Parole board's grant in 21/22 was £21.3 million.[12] This includes all secretariat, management, parole board members, training, HR, communication, medical reports etc.
In 2021/2 they conducted 8,085 oral hearings but reviewed a total of 15,103 cases in total.
The Parole board has 318 staff (including secretariat).

An estimate for the <u>total</u> number of statutory AD service staff needed would be

- 16 in Scotland (including 10 panel members)
- 8 in Northern Ireland (including 5 panel members)
- 160 in England & Wales (including 35 panel members)

This includes all secretariat, management, parole board members, training, HR, communication etc

AD panel costs: Training, supporting and funding socio-legal panel members is unlikely to be more that £2.5 million/year, which would be part of the above costs.

A reasonable estimate for assisted dying costs for all of the UK would be £10 million, but this could be reduced by charities funding the practice of providing the assisted deaths after the statutory decision has been made.

Savings

In 2021, Canada estimated savings of Can$86.9 million (£49.74 million) for 6,465 assisted deaths
= equivalent of £7,694 saved for each assisted death,
ie. UK saving of £53.1 million (at 1% level)
Socio-legal model is therefore cost-neutral

Drugs

The independent prescriber will be specifically certified to issue an order (prescription) for the lethal 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 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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