Citizens' Jury: exploring public views on assisted dying in England

Briefing – an initial qualitative analysis of the Citizens' Jury findings

November 2024







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Executive Summary

In 2023, the <u>Nuffield Council on Bioethics</u> (NCOB) commissioned a project to explore how people living in England think and feel about assisted dying, including the underlying ethical, social and practical complexities. <u>Hopkins Van Mil</u> (HVM), a specialist deliberative social research agency, along with its partners <u>M.E.L Research</u> and the <u>Sortition Foundation</u>, were appointed by the NCOB to deliver this public engagement project. Further information on the organisations involved in the project is shared at Appendix 1.

This project has included the delivery of two nationally representative surveys and a Citizens' Jury – the first Citizens' Jury in England on the topic of assisted dying. The definition of assisted dying used in the project is given at Appendix 2.

In September 2024 an Interim Report was published sharing the key recommendations and vote results from the Citizens' Jury deliberations.¹ A final report on the full *Exploring Public Views on Assisted Dying* project, including depth analysis of the Citizens' Jury and survey findings will be published in early 2025.

This briefing gives a summary of the key Jury considerations. It is intended to show why the Jury voted as they did and why they made the recommendations described in the Interim Report. This briefing is being published in November 2024, in advance of the final analysis report, to inform the UK Parliamentary debate on The Terminally III Adults (End of Life) Bill 2024-25, which receives its second reading on 29 November 2024.² The Jury's discussions and voting decisions were not based on a specific draft bill. Issues and criteria emerged organically during their discussions, informed by the evidence they heard during the witness sessions.

The findings from the two nationally representative surveys³ are being published at the same time as this briefing, along with a film of the Citizens' Jury⁴, created by <u>Postcode Films</u>.

The Jury process and questions

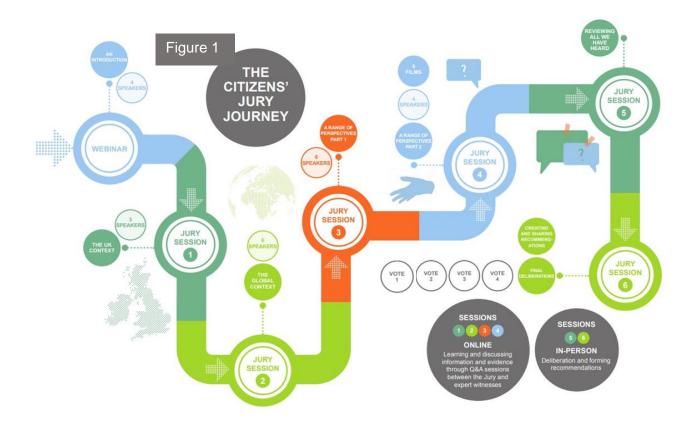
The Citizens Jury took part in the process for eight weeks from April to June 2024. The Citizens' Jury Journey is set out in Figure 1. More information on those who took part in the Citizens' Jury is available at <u>Appendix 3</u>.

¹ Nuffield Council on Bioethics/ Hopkins Van Mil (September 2024) *Citizens' Jury: exploring public views on assisted dying in England Interim report – key recommendations and vote results*, available at: www.nuffieldbioethics.org/publications/assisted-dying-project.

² UK Parliament (2024) Research briefing: The Terminally III Adults (End of Life) Bill 2024-25, available at: https://commonslibrary.parliament.uk/research-briefings/cbp-10123/.

³ Nuffield Council on Bioethics/ M·E·L Research (November 2024) *Survey 1 – February 2024 and Survey 2 – September 2024*, available at:www.nuffieldbioethics.org/publications/assisted-dying-project.

⁴ YouTube (11 November 2024) *NCOB Citizens Jury on Assisted Dying 2024,* available at: https://www.youtube.com/watch?v=cpXvJNy5KFw.



Jury members used the information and evidence they were given and their deliberative discussions over time to respond to the questions set out in Box 1.

Box 1: Jury questions

- 1. Should the law in England be changed to permit assisted dying?
 - What are the most important reasons in favour of permitting assisted dying?
 - What are the most important reasons against permitting assisted dying?
- 2. If the law is changed to permit assisted dying in England, what should it include? What should it exclude?
- 3. If the law is not changed to permit assisted dying in England, are there any recommendations or changes to assisted dying policy that should be made?

Key findings

In the final vote on question one, 20 Jury members either strongly or tend to agree that the law in England should be changed to permit assisted dying. Seven Jury members tend to or strongly disagree that the law should be changed. One Jury member was undecided (Box 2).



In-principle reasons for and against a change in the law

The three main reasons prioritised by Jury members for changing the law are **to stop pain**, **having the option to end your own life** and the **knowledge that you can die with dignity if the time comes**. These reasons are important to many Jury members because of personal experience either professionally or personally. They believe that extreme pain is distressing for those experiencing it, and those supporting them. As a result they also believe assisted dying is one way of giving people a peaceful and painfree death.

Choice, autonomy and freedom are three key concepts for the in-principle reasons to consider in relation to the legislation on assisted dying because many Jury members believe:

- Individuals should be protected in the law, whilst giving choice to those who wish
 to have an assisted death.
- The choices we have in life are numerous this should be extended to how our lives end.
- Legislation should provide effective safeguards to make sure assisted dying is not imposed on anyone but remains a choice for those who want it.

Taking away some of the fear of being dependent on others and losing dignity at the end of life by giving people the "comfort of knowing an assisted death is an option" is an important principle for many on the Jury.

In-principle reasons against a change in the law include **concern that the safeguards will not be strong enough to protect the vulnerable** in society from **coercion or being otherwise pressurised** into having an assisted death. This includes people putting pressure on themselves to take this route because they perceive this is what society or their family want for them. Other key reasons include:

- Normalising assisted dying, so that life is devalued.
- An ever-extending set of criteria due to challenges to the law whittling away the originally tightly-framed criteria.
- The belief that setting up assisted dying services will be costly and that this funding would be found by decreasing already-limited funding available to end-of-life and palliative care.

Eligibility criteria

If the law in England is changed to permit assisted dying most Jury members believe eligibility should be restricted to those who have a terminal condition. This is because intolerable suffering is hard to define; a perception that there will be greater support for assisted dying if it is restricted in this way; and concern that if it is not limited to terminal conditions it will be too easy to access, leading to a 'slippery slope' effect. There is limited support for intolerable suffering without a terminal condition being included in the eligibility criteria and most Jury members believe that mental illness should not be included.

Having the mental capacity to make a decision on assisted dying is a priority eligibility criterion for Jury members. This is stated in the context of **the gravity of the decision**, with appropriate safeguards against coercion and ensuring decisions are made freely.

There are **mixed views on an age requirement**. For some, under-18s could be included if they have parental consent. For a few Jury members it should be a case-by-case judgement based on the young person's maturity and competence. Those who believe assisted dying should only be available to adults do so because they are concerned about the burden on the parents and the impact this could have on families.

There are mixed views on residency in England being a requirement. Some feel strongly this should be the case as they do not want to see assisted dying tourism in England. For others this is not an issue, they believe non-residents would pay for the service, generating income for the NHS.

Mode of assisted dying

For most Jury members who wish to see a change in the law **both physician-assisted suicide** (where lethal drugs are prescribed to eligible patients to take themselves) **and voluntary euthanasia** (where lethal drugs are administered to eligible patients with the intention of ending that patient's life) **should be permitted**. This is because choice is such a strong principle for many. However, some participants see **more advantages in healthcare professionals administering lethal drugs** to patients than in enabling people to do this themselves, including concerns about the risk of lethal drugs being kept at home.

Process of assisted dying

Jury members discussed what requirements they would expect at different stages in the process of assisted dying if it was legalised. These are:

- Readily available and clearly signposted listening services, including counselling and chaplaincy to support decision making before a formal request for assisted dying is made.
- Involvement of medical practitioners is favoured by many (rather than a non-medical model) as they believe this will help trusted relationships to develop.
- Psychological assessments are made repeatedly to ensure that the person's decision is fixed; these assessments would also test for coercion by being done both with and without family members present.

There are mixed views on medical professionals **opting-in or out** of providing assisted dying. For some being able to opt-in or out is an issue in itself because they believe that assisted dying *should* involve the medical profession and *should not* be delivered by people who are outside of the profession. However, many also explain that if the medical profession is involved in assisted dying this may present a conflict for their normal ethos and values. Some also feel that being able to opt-in or out could create **geographic inequalities in the service**, if all the doctors in a particular area opt-out.

There is also concern for the medical practitioners – that they are **safeguarded** from action by those who do not wish the law to be implemented, and given **significant mental health support** to deliver the service.

Safeguarding was a key concern for all Jury members throughout the process, whether they agreed with a change in the law or not. Coercion and pressure on elderly, disabled people, or others in vulnerable situations, whether social, family, or political, to pursue assisted death is a key concern.

They call on the **involvement of a range of experts in the development of a safeguarding framework** before any legislation is introduced. If this happens, they feel that society will have greater confidence that due process has been followed and vulnerable people will be protected.

As such, an **independent regulatory body was a priority** for some to ensure transparency in all the workings of assisted dying and to ensure mandatory reporting and recording keeping.

A range of opinions were expressed about the **drugs used in assisted dying**, **focusing on the importance of standards**, **regulation and research** to ensure their efficacy and safety.

In the event that assisted dying is legalised in England, Jury members want to be sure that the drugs used are "100% effective", to ensure the final moments are painless, and do not have distressing side effects. Some Jury members want to see more research so that improvements can continue to be made on the efficacy of the drugs, including learning from jurisdictions where it has been legalised.

Jury members highlight the importance of the control and monitoring of drugs used in assisted dying, from drug deposition, to storage and safe disposal.

Jury considerations on the end of life

Whether the law changes or not Jury members are keen for **public conversations about death and assisted dying to continue.** This is for three main reasons - to:

- Ensure a wider public understanding of the complexities of assisted dying; it is
 not a simple or binary issue and the Jury hope that people across society will
 appreciate this.
- Provide ongoing support to policy and decision makers as they draft legislation and implement policy.
- Lessen the taboo that exists about death, dying and end of life care, supporting discussions to improve the options for people at the end of life and their families.

Through their deliberations the Jury also reflected on key considerations that are important to them about the end of life. Jury members want to make sure that:

- Palliative and end of life care is better funded and more evenly distributed across the country.
- There are improvements to health and social care for those with a terminal diagnosis.

Jury members also want to make sure the **act of helping a loved one to access assisted dying abroad is decriminalised** – because the law is currently 'woolly' leaving families uncertain as to what will happen if they support a family member to have an assisted death in another country.

Jury members are proud to have taken part in this Citizens' Jury. They hope their values and opinions will be helpful in informing the live deliberations on the issue.

About this briefing

This briefing is a summary analysis created by reviewing the main points made and considerations shared. We have written up, using qualitative techniques, those that are the highest priority from the Jury's perspective. Jury member quotations are taken from the transcripts of each of the Jury sessions. They are used to illustrate the issues being discussed.

We have included the main voting results from the Citizens Jury (as previously shared in the Interim Report⁵) to highlight these priorities. Voting is used in Citizens' Juries to understand where agreement has been reached on a topic, and where there remains a range of views and less agreement. In each of the vote boxes shared in this report the numbers relate to how many votes the statement received, not a number of individuals. However, the basis of the final Jury considerations is the thoughtful depth of discussions

⁵ Nuffield Council on Bioethics/ Hopkins Van Mil (September 2024) *Citizens' Jury: exploring public views on assisted dying in England Interim report – key recommendations and vote results*, available at: www.nuffieldbioethics.org/publications/assisted-dying-project.

over time. Two of the 30 Jury members did not take part in the votes on the final day due to illness.				

1. Key programme findings

Working in a deliberative and iterative way gave Jury members the time to consider the information and evidence, form their recommendations, and respond to the votes based on meaningful and considered discussions. Voting is the method used in Citizens' Juries to understand the extent to which agreement has been reached on a topic. The basis of the considerations and recommendations and why people voted as they did (the focus of this briefing) is the thoughtful depth of discussions over a period of time.

1.1 Key findings

In the final vote on question one, twenty people either strongly agreed (16) or tended to agree (4) that the law in England should be changed to permit assisted dying. Seven Jury members either tended to disagree (5) or strongly disagreed (2) that the law should be changed. One Jury member was undecided at the end of the process (Box 2).



Many Jury members said that 'public benefit' was an important principle to consider as they discussed the issues raised. They felt that a topic as significant for society as assisted dying should be considered at a societal level, beyond individual views, interests and preferences, and through a public benefit lens. This means considering if a change in the law would bring benefits to wider society.

"I think the bigger question is about society and is this a good thing for society? I don't know, I mean personally I believe it's a good thing, it's a value isn't it or a principle that you have to weigh up." Session 5

Jury members took their responsibilities very seriously including weighing up different perspectives and reflecting on the issues in great depth. They described their understanding of assisted dying as a complex and nuanced issue. They were pleased that the votes allowed for a range of views to surface and that the topic was not presented or discussed in simple binary terms. Many Jury members struggled with holding several, often contradictory ideas at once. For example, the dilemma of whether death should ever be a matter of choice, and the sense that being able to choose would provide some benefits.

"I find the whole subject terribly upsetting. As an individual, should we have the right to choose? It's also personal and subjective. I still think we should have that freedom of choice and hope that it will be used in a sensible way. We don't have to do it, but then if there's a choice there, we can do it if we want." Session 4

1.2 In-principle reasons for a change in the law

In thinking through question one, Jury members prioritised three main reasons, described below (Table 1⁶), for changing the law in England to permit assisted dying.

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The voting results for question one - reasons for permitting assisted dying

The most important reasons in favour of permitting assisted dying	Total Jury member votes
To stop pain	12
Having the option to end your own life	12
Knowledge that you can die with dignity if the time comes	11

1. To stop pain

For many Jury members people coming to the end of their lives in great pain is a serious concern. The reasons described for this are their own personal experiences of:

Having a professional caring role e.g., in social or health care.

"From my experience as a carer I think a lot of people are going through a lot of pain, especially during the end-of-life care and palliative care they receive at the

⁶ Jury members reviewed two long lists of all the reasons for and against assisted dying that they had identified. (for long list see: Nuffield Council on Bioethics/ Hopkins Van Mil (September 2024) *Citizens' Jury: exploring public views on assisted dying in England Interim report – key recommendations and vote results*, available at: www.nuffieldbioethics.org/publications/assisted-dying-project). Each Jury member had 10 votes that they could allocate to each long list (20 votes in total). This meant if they felt strongly about a specific point they could put several votes against it. They could also spread their votes out across 10 different points.

care homes. I think people would rather have those sufferings shortened rather than continue to be in pain." Session 1

Caring for and being with a family member at the end of their life.

"I share... opinion on the fact that we have to look at my sister dying as caring instead of killing. We are not killing them, but we are caring for them. Why we want to care for them, because they are suffering or they have suffered for a period of time which could have been prevented or alleviated if such a law was enacted." Session 3

 Being in great pain themselves, a pain so dreadful that they wanted to end their own life – which makes them think that if they did have a terminal condition with limited time to live and in great pain they might wish to take the assisted dying route.

"I go on about people saying, "They're in agony, in pain," but nobody knows until you've been in that situation. I've been in that situation twice where life wasn't worth living. You just want to end your life, especially at the height of the pain." Session 3

Some argue that you might in principle be against assisted dying, but when it comes to enormous pain you might well choose the assisted dying route.

"It's easy to talk in theory, but when you are in a real situation, would you go for that decision finally? Or would you stick to your theory?" Session 4

2. Having the option to end your own life

Many Jury members raised the concepts of autonomy, freedom and choice in decision making about the end of life. Jury members said these concepts are important to them because:

 Legislation should always have public good at its heart which, in this case, many Jury members define as making sure individuals are protected within the law whilst giving choice to those who wish to have an assisted death.

"It's the same thing all along. It's protecting individuals, but then giving people the right to choose. It's that spectrum. It's always been about that spectrum, really." Session 4

 There is already so much choice for how we live our lives, and this should be extended to how our lives end.

"I can choose whether or not to have children, I can choose how to bring them up, I can choose where I work and where I live. Why shouldn't I also choose how I die if I am I am terminally ill." Session 4

If the law in England is changed to allow assisted dying, the legislation, in their view, should provide safeguards to make sure it is not imposed on anyone, it would remain a choice. "Looking on a broad spectrum, any law, you could go, 'Okay, some people might choose it, some people wouldn't.' It's a complete individual choice. There are always going to be people that would prefer to be in palliative care, and there's always going to be people that would prefer an assisted death. It's just finding whether we should open that up to those people that would want that." Session 4

Jury members raised their views about being people of faith and no faith. Some shared that although their faith means they would not choose assisted dying if it was legal, they nevertheless felt that the choice should be there for others who would like to take this route.

"From the religious aspects, my view hasn't changed from early on. Do I have the right to stop someone else from making a choice? My view is very similar to my view on abortion, which is I would never have an abortion personally, but I'm not in any position to tell or dictate over someone else what they should or shouldn't do with their body or their life. I may believe in God or the sanctity of life, for example, but they may not." Session 4

This explains why choice is important to many: because people are different, and have different views, faiths and values. They also have varying capacity to withstand pain and suffering.

"People are wired very differently. Their sensory needs are different. Speaking as an autistic person, the sensory needs that I have are very different from other people. I can withstand a lot more than other people can. So, it's very difficult to place just one sort of standard. Because it's case by case, which is why it should always be a choice." Session 5

3. Knowledge that you can die with dignity if the time comes

Taking away some of the fear of being dependent on others and losing dignity at the end of life by giving them "the comfort of knowing an assisted death is an option" is an important principle for many Jury members. Some had experienced the end of life of family members which had been difficult and distressing. They said this influenced their view that it is important to them to have knowledge that there is a route to take if people feel they have lost, or risk losing, their dignity. Others do not have this direct experience but, reflecting on the evidence shared and their discussions, believe that having the possibility of an assisted death is important. This reinforces the point made by many Jury members that assisted dying is an issue that should be considered in a broader societal perspective, not only from an individual perspective.

"It really seems to me that there's two sides here. One is in a controlled manner with dignity, and the other is especially listening to the consultant that there's an element of pain, prejudice, discrimination, and overall lack of dignity by letting nature take its course. That's really got me thinking in a funny way, the first way with dignity in a controlled manner seems a much cleaner and better way to end your life. It's not a question, but it just really got me contemplating." Session 4

Another reason cited for this knowledge that assisted dying could be an option is tha would, in their view, avoid what they perceive as being the "indignity of feeling compelled to die by suicide". Session 6					

1.3 In-principle reasons against a change in the law

Jury members prioritised three main reasons against a change in the law as set out in Table 2.⁷ A key theme running through these reasons is safeguarding the vulnerable in society, particularly disabled and older people. For many, ensuring those most at risk from coercion and being pressurised into having an assisted death is difficult, and for some a near impossible task.

"Like I said before, the safeguarding that we have now isn't good enough, so what makes us think that the safeguarding that we would implement would be good enough? It wouldn't be, because if we go off the models that we have now, it's not going to work. I have no, like, no way to resolve that because it is almost impossible to safeguard vulnerable people." Session 2

The voting results for question one – reasons against permitting assisted dying

The most important reasons against permitting assisted dying	Total Jury member votes
Could be used for the wrong reasons if safeguarding is not in place	12
Can be misinterpreted or misused causing challenges for the legal system	10
Less funding for palliative care	10

1. Could be used for the wrong reasons if safeguarding is not in place Identifying what the 'wrong' reasons for assisted dying are led Jury members to think about a range of issues. These included:

- Pressure for older people to take an assisted death in order to protect assets e.g. housing or money to pass on to their children, such pressure might be self-imposed, or due to coercion from family members.
- People choosing assisted dying because they believe that it is what society wants for them, or that it would be better for society if they did.

⁷ Jury members reviewed two long lists of all the reasons for and against assisted dying that they had identified (for long list see: Nuffield Council on Bioethics/ Hopkins Van Mil (September 2024) *Citizens' Jury: exploring public views on assisted dying in England Interim report – key recommendations and vote results*, available at: www.nuffieldbioethics.org/publications/assisted-dying-project). Each Jury member had 10 votes that they could allocate to each long list (20 votes in total). This meant if they felt strongly about a specific point they could put several votes against it. They could also spread their votes out across 10 different points.

"There is a concern that people who had due reasons for thinking of choosing assisted dying would start to feel that they were being selfless and helping society by taking the assisted dying route." Session 4

"How would it be possible to safeguard the elderly and vulnerable from feeling pressured for example by their families, by society as a whole?" Session 5

2. Can be misinterpreted or misused causing challenges for the legal system

Assisted dying being misinterpreted or misused ties into the argument made by some Jury members that once legalised, even if the legislation has very tight guardrails, it will become 'normalised' in society. This causes concern to these Jury members who fear it this will lead to 'misuse' of assisted dying in the following ways:

Used too frequently resulting in the devaluing of human life.

"I'm worried that if euthanasia was implemented and it was made so easy for a person to be able to end their life, maybe the meaning of life would be subverted. I'd just be worried about people throwing their lives away so easily, and when things go a little bit wrong for them, you know, the option is there to just kill themselves so easily." Session 5

 Used for an ever-extending set of criteria, with constant challenges in the High Court whittling away the originally tightly-framed criteria.

"That's how laws get changed over time. People feel that they're not being included or considered, and they campaign, and the momentum builds, and then it gets revisited and the law changes. We need to be careful of legislative creep." Session 3

- Used inappropriately, for example if someone wants to avoid a life sentence for murder.
- In a way that puts more pressure on the vulnerable to conform with the 'norm' and have an assisted death.

"If it was legalised, it would take a long time, maybe 10, 15, 20 years, but it would then become the norm. Then, even though you might not have people, friends and family saying to you, 'Look, I think this is what you ought to do', you still have in the back of your head, 'Well, I've got to 75, 80 or whatever, perhaps it's time I should press the button and be on my way.' I think that's the tragedy that we have to have to be aware of as a society." Session 3

Some Jury members felt that the term 'dignity' could be misinterpreted in drafting a law permitting assisted dying. A dignified death was one of the three key reasons for being

in favour of assisted dying, but these Jury members expressed the view that there is dignity in *not* choosing assisted dying.

"I think the dignity has been thrown around as a word in favour of allowing assisted dying, and I think there's dignity in not going down that route. It relates to sanctity as well. That should be a big influence on the law." Session 5

3. Less funding for palliative⁸ care

Many Jury members, whether for or against a change in the law, are concerned that setting up an assisted dying service would inevitably drain funds from a palliative care system already under pressure.

"Let's face it, we have to spend money to set [assisted dying services] up. If you want to set up all the safeguards and all of the medicines and the drugs and provide it free of charge, that's going to cost money. That would take away from further investment into palliative care because you now have this option, end of life care is the obvious candidate." Session 6

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⁸ Note: Jury members were told that the topic of palliative care is beyond the scope of a deliberation on the law in England on assisted dying. However, Jury members understood that they should include whichever topics they considered relevant in their recommendations.

2. If the law is changed what should it look like?

In this section, we summarise Jury members' views from initial analysis of their deliberations on what the law should look like if it is changed to allow assisted dying in England.

2.1 Eligibility criteria

In this section, we explore what eligibility criteria Jury members think would be important to include in a new law permitting assisted dying.

Many propose restricting assisted dying to terminal (physical) conditions only

_	nly Table 3:			
	f the law is changed to permit assisted dying in England not not an extended the control of the	d, what sho	uld it	
		Include	Exclude	
	People who are allowed to have an assisted death should have a terminal condition	22	0	

If the law in England is changed to permit assisted dying, most Jury members feel it should include people who have a terminal condition (Table 3⁹). The reasons given for restricting the law to terminal conditions include:

- Challenges in defining and measuring intolerable suffering, given it is a subjective experience.
- A perception that there will be greater support for assisted dying if it is limited to terminal conditions.
- Concern that if it is not restricted to terminal conditions, there will be widespread access to assisted dying and it could lead to a slippery slope.

"I'll be open about it, I'm against euthanasia. If it was to happen hypothetically, I'd want to try and keep it locked in place so there's not going to be any backsliding going on. And I think when you go into the realm of unbearable suffering, that's where the backsliding comes, isn't it? It's a slippery slope, isn't it, whereas the (focus) on terminal (illness), that keeps it in place." Session 6

⁹ In deciding on what should be included/ excluded if the law should be changed Jury members reviewed the long list of inclusions and exclusions they had generated (for long list see: Nuffield Council on Bioethics/ Hopkins Van Mil (September 2024) *Citizens' Jury: exploring public views on assisted dying in England Interim report – key recommendations and vote results*, available at: www.nuffieldbioethics.org/publications/assisted-dying-project). Each Jury member had 5 votes that they could allocate throughout the long list. This meant that if they felt strongly about a specific point they could put several votes against it. They could also spread their votes out across 5 different points.

Jury members' opinions diverge on whether there should be a specified timeframe for eligibility for assisted dying in cases of terminal illness. Some argue against a timeframe due to the unpredictability of a terminal illness progression. Others prefer a 6-month time limit from terminal prognosis, while some advocate for a 12-month prognosis to allow more time for preparation, decision-making, and spending time with family.

Some Jury members think intolerable (physical) suffering should be considered

However, some Jury members think conditions that are not terminal, but which do cause intolerable (physical) suffering should also be considered as an eligibility criterion because in their view:

- Autonomy and choice to end your life should be available when there is intolerable suffering that can't be reversed.
- People living with progressive diseases that cause suffering over an extended period should be able to choose an assisted death before receiving a terminal diagnosis.

"Surely it should be also for those who aren't terminally ill but have Parkinson's disease or multiple sclerosis or something which is unbearable suffering but it's not terminal really. It can go on for years and you're paralysed. I mean you don't have to be terminally ill to be at the end of your tether." Session 6

Most Jury members think mental illness should not be included

Most Jury members who discussed mental illness do not think it should be included as an eligibility criterion. The reasons given include that people with mental illnesses have the potential to improve, and that the person suffering may not have capacity to decide.

Having the mental capacity is a priority eligibility criterion

Table 4:

If the law is changed to permit assisted dying in England, what should it include? What should it exclude?

	Include	Exclude
People must have the capacity to make their own decision	22	0

Jury members believe that having the mental capacity to make your own decisions is one of the most important eligibility criteria (Table 4). They comment on the importance of capacity in the context of the gravity of the decision to have an assisted death. They also highlight the challenge of capacity assessments and the extent to which it can be guaranteed that mental capacity is genuinely in place. They worry about people who are vulnerable and emphasise the importance of ensuring that any decision made is voluntarily without pressure or coercion.

Mixed views on an age requirement

Jury members' views diverged on whether an assisted death should only be available to adults or whether under-18s should be considered eligible if they have a terminal illness (Table 5).

Table 5:

If the law is changed to permit assisted dying in England, what should it include? What should it exclude?

	Include	Exclude
Under 18s can be considered eligible if they have a terminal illness and have parental support for their decision	10	6

Some Jury members feel under-18s should be considered eligible if they have a terminal illness and have parental support for their decision. This is to prevent suffering at the end of life. Some Jury members feel there should be a lower age limit, such as 14 or 16, for when a child is eligible for an assisted death. Others reflect on the importance of assessing whether a child has the maturity and competence to understand the situation and make their own decision, given children develop at different rates.

Some Jury members voted against under-18s being considered eligible for assisted dying, citing concerns about their capacity and maturity to make such an important decision. Some worry about the emotional burden on parents, who would be supporting their child's decision or making the decision on their behalf, and the impact this could have on families. Another described including under-18s as a "legal minefield".

Mixed views on residency status

Views diverge on whether there should be a residency criterion to be eligible for assisted dying in England. Some feel strongly that it should be for **residents of England only**. They do not want to see assisted dying tourism in England and they are concerned about the additional pressure this could potentially place on the health service, if assisted dying falls within the NHS. A few Jury members think that **people from other countries should be permitted** to come to England for an assisted death, on condition that they pay, and it does not put more pressure on the NHS.

2.1 Mode of assisted dying

Table 6:

If the law is changed to permit assisted dying in England, what should it include? What should it exclude?

	Include	Exclude
Both physician-assisted suicide (prescribing) and euthanasia (administering) should be permitted.	16	1

The importance of choice

When voting, many Jury members felt that both physician-assisted suicide (prescribing) and euthanasia (administering) should be permitted if assisted dying is legalised in England. The primary reasons they give are to provide choice and autonomy in decision-making, and to ensure no-one is excluded from having an assisted death who wants one. In their deliberations, participants discussed why they preferred one mode over another, even if on balance they voted for a law that includes both modes.

Reasons for preferring / including (voluntary) euthanasia

Many participants see advantages to healthcare professionals administering lethal injections to patients, rather than patients taking lethal drugs themselves. Several reasons were given including:

- Some patients may not be physically able to self-administer due to their condition, and should not be discriminated against.
- Some Jury members feel there will be people who find it hard to administer a lethal drug themselves and would prefer a medical practitioner to do it for them.
- Many are concerned about the risk of lethal drugs being kept at home, with a
 potential risk of ingestion by other family members, or of drugs being stolen or sold.

"Some jurisdictions allow you to take the prescription home and take it at our time, whilst good idea, but can be abused if drugs are then sold online, stolen or taken by other family member." Session 6

Reasons for preferring / including permitting physician-assisted suicide (prescribing)

The reasons given by Jury members for preferring physician-assisted suicide, whereby a healthcare professional prescribes lethal drugs to patients to take themselves, include:

- It makes it easier for someone to have the option of dying at home, with their family.
- If a person wants an assisted death, and they are physically able, they should be "brave enough" to self-administer the lethal dose.

"When you have got the capacity and the ability to do it yourself, I just feel if I make that decision, I should be brave enough to take it, to see it through, unless if you are disabled and you can't administer it yourself, then someone can do the injection. But I just feel people...otherwise people opt for injection because it's easier." Session 6

Drugs used in assisted dying: regulation, research and reporting

A range of opinions were expressed about the drugs used in assisted dying, focusing on the importance of standards, regulation and research to ensure their efficacy and safety.

In the event assisted dying is legalised in England, Jury members want to be sure that the drugs used are "100% effective", to ensure the final moments are painless, and do not have distressing side effects – one of the main reasons to have an assisted death in the first place.

Some Jury members are concerned there is a lack of research into the efficacy of drugs used in assisted dying. They want to see more research so that improvements can continue to be made, including learning from jurisdictions where it has been legalised.

Jury members highlight the importance of the control of drugs used in assisted dying, from drug deposition to storage and safe disposal. If assisted dying is legalised in England, they argue that there needs to be a "robust system and high confidence that deadly drugs are handled safely" Session 6.

Some Jury members call for mandatory reporting of all assisted deaths including all complications, in the event it is legalised. They believe this is the only way there can be confidence that data gathered reflects a "true picture" of assisted dying in practice. They note that the level of reporting in jurisdictions where assisted dying is currently legal varies and they worry about under-reporting of complications.

2.3 Process of assisted dying

Jury members discussed what requirements they would expect at different stages in the process of assisted dying, if it was legalised.

Listening services, information and other support

Jury members discussed the importance of support when considering an assisted death. Recommendations include providing professional counselling to support decision making and/or chaplaincy care, before a formal request for assisted dying is made. At the same time people who are considering assisted dying should be provided with detailed information about process. Such support also includes advice if they decide not to have assisted dying, such as options for end-of-life and palliative care and wellbeing support. One person argues that the process should be centred on the whole person, rather than feeling too clinical.

"It all sounds very clinical, "You do this, this, and this, and there we are, that's it, done." We're not like that. It's not deciding whether to switch off a

computer. We're people, and we have bodies, souls, minds, and everything else, and that needs to be taken care of. It needs to be fully understood that the patient is really aware of what they're actually choosing as a decision in their life." Session 1

Involvement of medical practitioners

Some Jury members feel strongly that a medical practitioner who knows the person should be involved when someone is considering an assisted death. They worry that people often see different GPs each time they go to the doctor, and that consultations are frequently over the phone. They are concerned that a person considering an assisted death will have to repeat their stories each time they see a different doctor and will not get the support they need.

"If I (was considering) assisted dying, every time I went, I would have to go back to the start to explain to a different doctor why I wanted to go for assisted dying. But how would he ever then get to know me? Because I wouldn't see him for five weeks, would I? I'd only see him for that day." Session 4

Eligibility (and psychological) assessments

Table 7:

If the law is changed to permit assisted dying in England, what should it include? What should it exclude?

	Include	Exclude
A patient must have multiple psychological assessments to be considered eligible and must be repeatedly asked if their mind is made up	10	3

Jury members made several recommendations relating to the eligibility assessment including that:

- It is imperative that there are multiple psychological assessments as part of the eligibility assessment. This is to ensure a person's decision remains constant.
- Eligibility assessments should be conducted in different settings, for example both at home and in a hospital, and with and without family present.
- Two physicians and a psychiatrist should be present as a clear and visible safeguard.

Involvement by the medical profession

Jury members were interested in how assisted dying might work in relation to the medical profession. They said key considerations around the extent to which the medical profession should be involved in assisted dying need to be resolved.

1. Medical practitioners opting-in or out

For many this includes whether they should be able to opt-in or out of delivering assisted dying. This was an area on which there was no clear agreement by the Jury, as can we see in their vote on this issue in their response to question two (Table 8).

Table 8:

If the law is changed to permit assisted dying in England, what should it include? What should it exclude?

	Include	Exclude
Clinicians/ medical practitioners should be able to opt out	5	5
Clinicians/ medical practitioners should have to opt in and prove they have had appropriate training	5	2

For some being able to opt-in or out is an issue in itself. These Jury members believe that assisted dying *should* involve the medical profession and *should not* be delivered by people who are outside of the profession, but have been trained to deliver assisted dying services. However, many also explain that if the medical profession is involved in assisted dying this may present a conflict for their normal ethos and values.

"The doctor's whole faith is to preserve life, to expect them to actually kill somebody, I think that's asking too much." Session 1

Those that are concerned about doctors opting-out fear that this will perpetuate inequalities in the health and care system with some people being unable to have an assisted death because all the doctors in their area have opted out.

"We have a postcode lottery with our health care as it is, so would this be another thing that would turn into a postcode lottery because of doctors opting out?" Session 2

2. Protections for medical practitioners

Jury members also discussed the importance of providing protection and support for the medical professionals who do provide assisted dying to their patients. They see this in terms of protecting them from those who might protest about what they are doing, and also in psychological terms. This would include risk assessment for those involved so that they could clearly understand the complexities of providing assisted dying services.

"I feel quite strongly about the protection of healthcare administrators involved in any of these situations. From being a target for groups campaigning against what they do, but also for their state of mental health doing this over time." Session 2

3. Training

Some Jury members are more in favour of opting-in because they believe part of the opting-in process would be to receive specialist training.

"I think the advantage for me for opt-in is the fact that you can either show some one-to-one training to understand some of the psychological and some of the other issues, it's not your normal GP type of stuff." Session 6

They feel training is important to ensure that there is a standardised system of assisted dying across England, with appropriate standards in place.

A few Jury members feel that training is necessary, but that it should be offered to non-medical staff so that they can safely deliver assisted dying. This would create a specific technical role for people to administer assisted dying separately from health care.

"I think if someone was technically trained in that specific thing, because they you are not relying on the doctors, it can be apart from health care." Session 6

2.4 Safeguarding vulnerable people

Safeguarding people in more vulnerable situations was a significant issue in Jury member considerations, whether in favour of the law being changed or not. Coercion and pressure on elderly, disabled people, or others in vulnerable situations, whether social, family, or political, to pursue assisted death is a key concern.

There is a concern that the cost of ongoing palliative care and care at home towards the end of life may mean that someone living in a vulnerable financial situation may choose assisted dying. Some also worry that individuals may choose this option because they feel a burden or lonely. They worry that some vulnerable people may feel less valued by society, or as "second class citizens", if the law is changed to permit assisted dying in England. Some also worry that assisted dying would become normalised. Jury members therefore call for robust legislation, regulation and safeguarding rules to protect people, particularly vulnerable people, in the event the law is changed to permit assisted dying in England.

Development of a safeguarding framework

Some Jury members recommend including medical and legal specialists in the development of safeguards to protect vulnerable people. They call on the involvement of a range of experts in the development of a safeguarding framework before any legislation is introduced. If this happens, they feel that society will have greater confidence that due process has been followed and vulnerable people will be protected.

"The safeguards need to be there, and they need to be very strong, and they need to consider everybody's viewpoint, coming from all the different directions people can come from so that they can make the right decisions, the best decisions, the kindest decisions for each individual's point of view." Session 6

A cooling off period

Many Jury members support the principle of a cooling off period that allows the person requesting an assisted death to reflect on their decision. Some feel there should be **flexibility** regarding a cooling off period, believing there may be situations where it wouldn't be practical, or it would need to be shortened, because the person requesting an assisted death is expected to die within a matter of a few days. In contrast, some Jury members are uncomfortable with an inconsistent approach and think there needs to be a **set timeframe** which is standardised to avoid ambiguity and to better safeguard individuals.

Specific safeguarding measures

Specific measures were discussed by participants to help safeguard vulnerable individuals at different stages in the assisted dying process, these have been referred to already in this section and are summarised below:

- Eligibility assessments with/ without family present, over time, in different locations.
- Three specialists involved in the eligibility assessment, two doctors and a psychiatrist.
- Listening services (e.g. counselling, chaplaincy) offered to all considering assisted dying.
- Ensure people are signposted to other support available, so they know assisted dying is not the only option (e.g., palliative care, organisations that support quality of life, support organisations for specific illnesses and conditions).
- Providing information about assisted dying, including side effects, to support informed choices.
- Having a set cooling off period.
- Mandatory monitoring and reporting of all assisted deaths, including any complications.

2.5 Governance, regulation and oversight

Jury members highlight the need for effective, robust legislation, governance and regulation of assisted dying to ensure high quality of care is provided to all involved.

Independent regulatory / governing body

Jury members highlight the importance of having an independent regulatory and/ or governing body in the event that assisted dying is legalised in the England. The purpose would be to:

- Ensure transparency in relation to standards and safeguarding to ensure open scrutiny of the process.
- Establish a clear record of assisted deaths, including drugs used and complications.
- Ensure that mistakes are recorded, and investigations undertaken, while also providing opportunities for learning.
- To build public trust and reassurance in assisted dying processes and procedures.
- To ensure that decisions are unbiased, and processes are followed, so patients have equal opportunities and can appeal or complain about a decision.

Mandatory reporting and record keeping

Jury members highlight the importance of mandatory record keeping and reporting throughout the process. If assisted dying is legalised, they argue that robust data will:

- Help to ensure due process is followed.
- Provide a record of drugs used, from acquisition to safe disposal.
- Provide data on all assisted deaths, including complications and side effects.
- Mean that when mistakes occur, they are recorded, so that investigations can be undertaken.
- Ensure learning occurs across the process.

3. Jury considerations on the end of life

The importance of improving end-of-life care, through more open public discourse about death and dying, better funding for and provision of palliative and social care, and clarifying the law around travelling abroad to access assisted dying was important to many Jury members. This remains important whether or not the law in England on assisted dying is changed.

3.1 Public conversations about death and assisted dying should continue

Jury members voted in favour of a recommendation to continue public conversations around assisted dying, and about death and dying more generally. This reflects a key theme throughout the deliberations relating to the need for more public discourse around death and dying, and the difficulties that arise from people being unaccustomed to talking about the end of life.

The aim of their recommendation is twofold:

- To make progress in providing the best possible end of life care by overcoming taboos around death and dying (including assisted dying).
- To raise awareness about assisted dying and the issues associated with it, so that informed public conversations can continue to evolve.

Jury members were also keen to recommend, whether the law in England is changed or not, more opportunities for public deliberation, like the Citizen's Jury. They are interested in this to ensure wider public understanding of this complex topic. They see these processes as a space for informing people through robust and balanced evidence, and then supporting a respectful dialogue on the issues that it raises.

If the law is changed this would include discussions on the detail of defining and implementing the law. If the law is not changed this would create the space for society to consider end-of-life care more broadly. In both cases this deliberation provides support for policy makers as they craft the legislation that is needed for assisted dying and for end-of-life care.

"For me this, this Jury is the start of a conversation. You'd expect people to have enough research, statistics, like we are. Shouldn't more people, from all parts of society be given the option to discuss this? Wouldn't that be valuable?" Session 6

"The outcome is that end-of-life care can improve and death and dying is less of a taboo subject." Session 6

3.2 Palliative care needs better government funding

Jury members called for better palliative care whether or not the law is changed to permit assisted dying. This includes better and more evenly distributed funding from government to ensure that NHS palliative care provision is equitable and of a high standard. Many were surprised to learn that only around a third of palliative care funding comes from government, and the remainder comes from charitable sources. They feel that this contributes to an uneven distribution of provision across the country and across different medical conditions.

"Hospices run on voluntary donations, cake sales etc., not government funding (...) Palliative care is a postcode lottery." Session 6

"Macmillan covers cancer, but even so, that's a stretch for them. But there are all the other diseases that need more palliative care." Session 6

In the context of underfunded services, Jury members are concerned about how palliative care and assisted dying provision could negatively impact each other. Some believe that future assisted dying systems could divert focus and funding away from already stretched end of life care. Jury members also raised concerns about inadequate end-of-life care contributing to a person's decision to consider assisted dying.

3.3 Improvements to health and social care for those with a terminal diagnosis

From their own lived experiences, and from specialist presentations and personal testimonies during the workshops, Jury members were very aware of the crisis in health and social care, and the implications for those with a terminal diagnosis. Jury members, whether they are in favour of a change in the law or not, call for support networks across multiple settings to provide consistent care, guidance and emotional support to everyone nearing the end of their life or caring for someone with a terminal diagnosis. This includes similar points to those made in Section 2:

- Continuity of care should be guaranteed through a social care plan and a named GP.
- Home carers should be provided with better guidance and support, including more information about how a condition is likely to progress.

"We weren't advised enough what happens at the end of dementia. Nobody told us that they stop eating at the end. She couldn't tell us because she had dementia. I just think illnesses need to be explained better." Session 6

 Improvements in pain management are needed, such as training for specialist nurses.

"I was sent home with only paracetamol (...) It took us three days to get stronger painkillers. Just for me, it's bad, never mind for people who are thinking about ending their lives, they're in more pain than I'm in." Session 1

 Care homes should be inspected and regulated more effectively to ensure consistent quality of end of life care, irrespective of whether the law on assisted dying is changed or not.

"A lot of people get worried about the care that is provided (in care homes), so if the law's not changed, maybe regulate the care that is provided." Session 6 • Emotional support and counselling should be provided to patients and their families, including for friends and family of people requesting help for assisted dying.

"More social work to help people go through this situation, emotional help, mental health help." Session 3

3.4 The act of helping a loved one to access assisted dying abroad should be decriminalised

Jury members feel that the current law in relation to accessing assisted dying services abroad is unclear and inconsistently applied. They raised concerns about a system where bereaved families or friends are being subjected to criminal investigations for helping loved ones travel abroad to access assisted dying, yet very few prosecutions are made.

"187 people were taken in, but none of them were prosecuted, so why are we wasting the police's time?" Session 2

The current law is seen by many Jury members as unfair and lacking in compassion. It punishes families or friends for assisting with another person's decision and means that those who choose to access assisted dying abroad, are obliged to both travel alone despite their ill health, and die without loved ones present.

"If my husband helped facilitate and booked the flights, I don't think it's fair that he could be 14 years in prison when it's my wishes." Session 5

Jury members feel that the lack of clarity and potential heavy penalties involved, contribute to a culture of secrecy around death and assisted dying, which causes distress and prevents people from seeking the support they may need from family or health professionals. They point out that terminally ill people will continue to travel abroad to access assisted dying while that possibility exists, and that whether or not the law is changed support needs to be given for people in this situation.

For these reasons, Jury members call for the act of helping a loved one travel abroad to access assisted dying to be decriminalised, even if the overall law on assisted dying is not changed, and for a more compassionate safeguarding procedure to be established. Jury members suggest that this procedure should take place before the person travels. Including the terminally ill person in their safeguarding is a more effective way of ensuring there is no wrongdoing, and the person concerned and their families can openly make their decision and their arrangements with the reassurance that a criminal investigation will not follow.

4. Public policy

As part of their discussions Jury members raised wider points about the legislative process around assisted dying, and reflected on comparisons with other countries. They also considered what it had been like to take part in this Citizens' Jury. The key points made are summarised in this section.

4.1 The legislative process

Jury members valued the evidence presented to them on the legislative process: parliamentary debates, Green and White papers and Royal Assent. They appreciated the 'Assisted dying policy timeline' and the presentations on current policy in the UK, which informed their deliberations. ¹⁰ Key points raised in relation to the legislative process on assisted dying are that:

- Decision and policy making on this issue is complex and can take time from passing the Bill to the implementation of the law.
- Current legislation appears 'wishy-washy' with a lack of clarity on whether the law will be imposed if someone chooses to travel abroad for an assisted death (see 3.4).
- The law in England should not be driven by the fact that other UK nations and crown dependencies have taken legislation forward, it should be driven by what is appropriate within the context of the needs of the population of England.
- Drafting legislation tightly, including on terminology and definitions, so that safeguards are robust, monitored and regularly reviewed.
- How the law is designed and implemented needs to be clearly communicated to the population affected – including through the national conversation proposed in Jury member recommendations (see <u>3.1</u>).

"The (Government) must create clear policy and procedures which benefit the citizens of the country. These should have standard protocols which can be measured, scrutinised and improved." Session 6

4.2 International comparisons

Jury members appreciated the evidence they received in presentations and in briefing papers on the situation in different jurisdictions around the world.¹¹ They raised the following points in relation to these examples:

 Drafting legislation which is informed by what has gone well and not gone well in other countries seems a valuable exercise; learning from their experience is vital.

¹⁰ Nuffield Council on Bioethics/ Hopkins Van Mil (September 2024) *Citizens' Jury evidence and information pack: an assisted dying policy timeline,* available at: www.nuffieldbioethics.org/publications/assisted-dying-project.

¹¹ Nuffield Council on Bioethics/ Hopkins Van Mil (September 2024) *Citizens' Jury evidence and information pack: international examples*, available at: www.nuffieldbioethics.org/publications/assisted-dying-project.

 Caution was expressed about any direct translation of the legislation designed by other jurisdictions to England because our own context, culture and legislative processes need to be considered in depth.

4.3 Reflections on being part of a Citizens' Jury

Jury members reflected on being part of the Citizens' Jury and taking eight weeks to reflect on this complex topic meaningfully. They shared that receiving a range of evidence and information was an essential part of the process. They appreciated that this included expert witnesses providing factual evidence of a specific situation as well as a range of advocates both for and against changing the law in England.

Many said that having the introductory sessions which explored ways of thinking¹² about the evidence presented was very helpful in their deliberations. They also said that having a full range of support from Jury Friends, facilitators and the counsellor was valued.

"The fact that we spent quite a long time going over things like how to think critically and ethically, it shows the depth or the intensity of the challenge. I suppose this links to the fact that there's counselling available. Not everything in life comes with counselling attached so the fact that that's on offer reflects the emotional intensity of the topic. I'm glad all these things were in place to help us." Session 6

As we see from the film of the project¹³, Jury members are proud to have taken part in the project and to have had the opportunity of sharing their views to inform public policy.

"Hearing the values, the ideas, the ideologies that people as individuals have, and hearing their thoughts and opinions, merging those together to come to some kind of conclusion has been very, very special." Session 6

¹² Nuffield Council on Bioethics/ Hopkins Van Mil (2024) *Citizens' Jury evidence and information pack*: Webinar presentations on thinking and listening critically (Renfrew, A) and ethical thinking (Chan, S), available at: www.nuffieldbioethics.org/publications/assisted-dying-project.

¹³ YouTube (11 November 2024) *NCOB Citizens Jury on Assisted Dying 2024*, available at: https://www.youtube.com/watch?v=cpXvJNy5KFw.

Acknowledgements

The Nuffield Council on Bioethics and Hopkins Van Mil would like to thank all the members of the Citizens' Jury who from April to June 2024 explored the topic of assisted dying with such care, thought and kindness. Their commitment to the responsibility of hearing the evidence, reviewing the information and forming their recommendations was impressive and profound.

Thank you to members of the project's <u>Advisory Board</u>, chaired by Professor Anne Kerr, who have given impartial, informed advice on the project process and planning. We are also grateful to the <u>Content Group</u>, which supported the project team to ensure overall the evidence, content, and stimulus materials presented to the Citizens' Jury were balanced, accurate, and accessible. They also advised on the range of speakers for the Citizens' Jury.

Thanks too to Suzanne Ost (Professor of Law, Lancaster University) and Alexandra Mullock (Senior Lecturer in Medical Law, University of Manchester) who as the Jury Friends helped Jury members to review and question the evidence. Thanks also to the Jury counsellor Sandeep Ganatra who was available throughout the process to provide emotional support to Jury members.

During four online and two in-person sessions, and in their own time, Jury members heard and read across:

- 20 presentations from speakers;
- 9 fact-giving information sheets;
- 5 briefing papers from campaigning and advocacy groups;
- 1 panel discussion:
- 5 lived experience films.

We are very grateful to all our expert witnesses, panel discussion members, and those who provided filmed lived experience interviews. They generously gave their time to ensure that Jury members heard evidence and heard a balanced range of views on this complex topic.

Thank you to our partners M·E·L Research, the Sortition Foundation and Postcode Films, who worked tirelessly to deliver key elements of the project.

Appendices

Appendix 1: The organisations involved

THE NUFFIELD COUNCIL ON BIOETHICS (NCOB)

<u>The NCOB</u> is a leading independent policy and research centre, and the foremost bioethics body in the UK. The NCOB aims to place ethics at the centre of decisions regarding biomedicine and health so that we all benefit.

It commissioned this Citizens' Jury to explore public views on assisted dying in England.

The NCOB set up the independent <u>Advisory Board</u> to give impartial, informed advice on the process and planning for the Citizens' Jury and associated activities. It also created a <u>Content Group</u> to ensure overall that the evidence, content and stimulus materials were balanced, accurate, and accessible. They also advised on the range of speakers for the Citizens' Jury.

The aim of this project was to support an informed public discussion on the topic of assisted dying by generating a range of evidence on public views on assisted dying. The NCOB will not publish its own recommendations or an organisational position on assisted dying as part of this project.

HOPKINS VAN MIL (HVM)

The NCOB chose the deliberative social research agency <u>HVM</u> to design and deliver the Citizens' Jury and work with their partners to recruit Citizens' Jury members, design and deliver the two quantitative surveys, and create a film to record the Jury process. HVM facilitates participatory, engagement and research projects. The team creates safe and trusted spaces for productive and engaging discussions on the important issues of our day, bringing people together to discuss the topics that matter to everyone in society.

Our award winning team specialises in deliberation. We have over 20 years' experience in independent facilitation. We do not bring personal perspectives to any of our work to ensure that Jury members are meaningfully supported to explore the topic.

THE SORTITION FOUNDATION

Citizens' Jury members were recruited to take part using a process called 'sortition' or 'civic lottery'. This was conducted by <u>The Sortition Foundation</u>, a not-for-profit organisation which frequently works in partnership with HVM. The process ensures that people are selected to take part in a way that is broadly representative of the wider population. Sortition is recognised internationally as the gold standard model for recruitment to deliberative processes such as Citizens' Juries.

M.E.L RESEARCH

M-E-L Research is an independent social research consultancy that has a track record of 35 years' experience of working for a wide range of public service and public sector agencies nationwide. Its vision is to make a positive difference to organisations, employees, customers and wider society. It has been responsible for the two nationally representative surveys for the project.

POSTCODE FILMS

The <u>Citizens' Jury film</u> was created by <u>Postcode Films</u> which make film and audio documentaries that explore the relationship between people, place and identity – with imagination and integrity at their heart.

AB CHARITABLE TRUST

The Exploring Public Views on Assisted Dying Project is funded by a charitable grant from the <u>AB Charitable Trust</u>. The charity did not have a say in how the Citizens' Jury, or any other part of the project, was run or what it covered.

Appendix 2: The definition of assisted dying used in the project

Many different terms are used when discussing assisted dying and people do not always agree on the terminology. For the purposes of this project, we define 'assisted dying' as:

The **involvement of healthcare professionals** in providing lethal drugs intended to end a patient's life at their voluntary request, subject to a set of conditions. This covers:

- Healthcare professionals prescribing lethal drugs to eligible patients to take themselves. This is sometimes referred to as 'physician-assisted dying' or 'physician-assisted suicide'
- Healthcare professionals administering lethal drugs to eligible patients with the intention of ending that patient's life. This is sometimes referred to as '(voluntary) euthanasia'.

Why are we using the term 'assisted dying'?

We have chosen to use the term 'assisted dying' to talk about all types of physician-assisted deaths, including healthcare professionals prescribing lethal drugs to patients to take themselves to end their own lives and healthcare professionals administering lethal drugs (sometimes referred to as (voluntary) euthanasia). The choice of terminology used throughout the exploring public views on assisted dying project, and in associated publications, are not intended to endorse or reflect any particular stance on the law on assisted dying.

The law: assisted dying is not legal in England.

Appendix 3: Who took part in the Citizens' Jury?

34 Jury members were recruited using a stratified sampling method which creates a mini-public broadly representative of the national population of England. This is a civic lottery method called 'sortition'. The process was delivered by The Sortition Foundation.

The recruitment process had three stages:

Stage 1: The Sortition Foundation randomly selected 7,000 addresses from across England, who each received a letter in the post. This invited those aged 18 years or older, living at an address that received a letter to register their interest in participating in the Citizens' Jury Exploring Public Views on Assisted Dying.

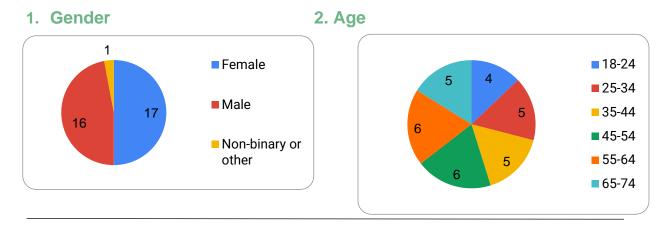
Stage 2: As part of the sign-up procedure, all potential participants were required to share a small number of demographic and attitudinal questions. This was needed to ensure that the Citizens' Jury final make-up was representative of the English population.

Stage 3: This information was then used as input into a 'sortition algorithm' which randomly selected 34 participants, over-recruiting by four to ensure a final 30 members of the Jury. This is done in such a way as to create a representative sample of the English population (e.g. the age profile of participants in the Citizens' Jury is broadly similar to the age profile of the population of England as a whole). Details of the specific algorithm used, including information about the fairness of the algorithm, can be found here.

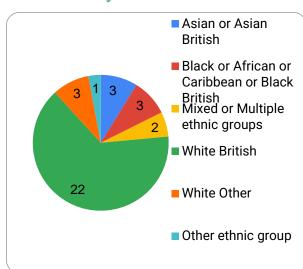
HVM then took over communication with the selected Jury members, including conducting welcome calls with each potential Jury member, to ensure all their participation needs were taken into account and to allow for people to change their mind about their participation if they wished. 30 people committed to participating in the Jury process. Two Jury members were unwell on the final day of deliberations, which meant the voting on the final day was completed by 28 Jury members.

Demographic data

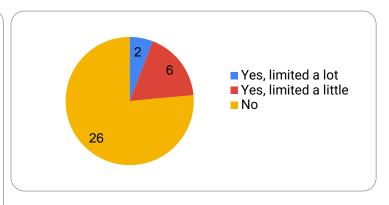
Jury members were recruited to be broadly representative of the English population. The following pie charts set out the final demographic data of Jury members.



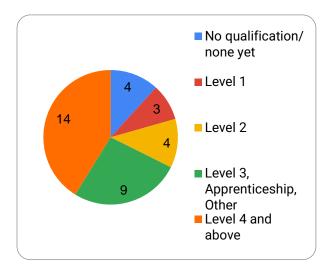
3. Ethnicity



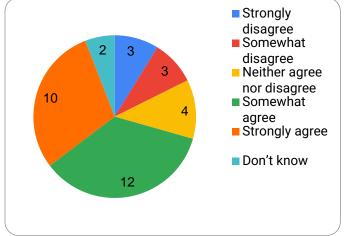
4. Disability



5. Education



6. Attitudes to assisted dying



7. Location



8. Indices of multiple deprivation

