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

Interim report - key recommendations and vote results
September 2024





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## **Executive Summary**



In 2023, the Nuffield Council on Bioethics (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. Hopkins Van Mil (HVM), a specialist deliberative social research agency, along with its partners M.E.L Research and the Sortition Foundation, were appointed by NCOB to deliver this public engagement project. It included a Citizens' Jury Exploring Public Views on Assisted Dying – the first Citizens' Jury in England on the topic of assisted dying – as well as two nationally representative surveys.

This is the first report of the Citizens' Jury. It provides initial insights into the main votes and the key recommendations in the words of the Jury members. It does not analyse these findings. A second, main report will be published in early 2025. This will provide a rigorous qualitative analysis of the full Jury findings, delving into the rationale behind the Jury members' recommendations. It will also include the results of two nationally representative surveys of public views on assisted dying conducted as part of the project. A film that follows the Citizens' Jury process, produced by Postcode Films, will be published at the same time as this second report.

Figure 1: Jury voting results Question 1, part 1



#### Citizens' Jury recruitment

30 Citizens' Jury members were brought together using a stratified sampling method. This creates a 'mini-public' broadly representative of the English population. This way of recruiting Jury members is a civic lottery method called 'sortition'. The process was delivered by the Sortition Foundation.

#### Citizens' Jury process

The Citizens' Jury took place between April and June 2024. The Jury met for seven sessions, five of which took place online and two in person. In total, they spent 24 hours learning about, exploring and deliberating on the topic over an eight-week period. Additional time was also spent in between the Jury sessions reviewing materials, information and evidence provided.

#### Citizens' Jury deliberations and voting results

Throughout the process, Jury members used the information and evidence they were given and their deliberative discussions over time to respond to the following 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?

Jury members considered these questions during seven Jury sessions over the course of eight weeks. In the final in-person sessions, Jury members discussed each question in depth and continued to reflect on what is important to society. As part of the deliberation process, they voted on all three questions. This was an iterative process that allowed Jury members' thinking to evolve in the light of their discussions.

Figure 1 shows the results of the final vote on Question 1. Two people were unable to attend the final Jury session due to illness. This means that 28 out of the 30 Jury members took part in the final vote.

Working in a deliberative and iterative way allowed Jury members the space 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 where agreement has been reached on a topic, but the basis of the final considerations and recommendations is the thoughtful depth of discussions over a period of time.

Having had these in-depth discussions, Jury members formed recommendations in response to each of the three questions. These are listed below in the words of the Jury members.

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#### **Responses to Question 1**

In answer to the sub-questions of Question 1, 'What are the most important reasons in favour of permitting assisted dying?' and 'What are the most important reasons against permitting assisted dying?', the most important reasons given by members of the Jury *in favour* of permitting assisted dying that gained the greatest number of votes were:

- To stop pain.
- Having the option to end your own life.
- Knowledge that you can die with dignity if the time comes.

The most important reasons given by members of the Jury *against* permitting assisted dying that gained the greatest number of votes were:

- Could be used for the wrong reasons if safeguarding is not in place.
- Can be misinterpreted or misused causing challenges for society and the legal system.
- Could result in less funding for palliative care.

#### **Responses to Question 2**

From the long list of recommendations created by Jury members to Question 2, 'If the law is changed to permit assisted dying in England, what should it include? What should it exclude?', the following three received the most votes:

- People who are allowed to have an assisted death should have a terminal condition.
- People must have the capacity to make their own decision.

 Both 'physician-assisted suicide' (prescribing) and [voluntary] euthanasia (administering) should be permitted.

#### **Responses to Question 3**

From the long list of recommendations created by Jury members to Question 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?', the following three received the most votes:

- There should be continued public conversations a national conversation about death, dying and how we can provide the best possible care at the end of life. This should include continued public and deliberative discussions like these on assisted dying.
- More funding should be put towards improving the quality and availability of NHS palliative care.
- The act of helping a friend/family member to travel to Dignitas should be decriminalised.

#### Jury statement

A statement created by the Citizens' Jury (see section 5) also highlighted the following topics as important throughout their deliberations in addition to the points made through the voting process:

- **Mode:** Options should be available to the patient for how the assisted death will take place, and how it is done.
- Safeguarding: If there is a change in the law ensure that both medical and legal advice is procured to safeguard vulnerable people so that they are not abused and do not feel pressured into taking this option. This must happen whilst ensuring that the service is equal and accessible for those who want it.
- Regulation: In all cases a medical practitioner should be on site to control
  the medication, support the process (and the family), and ensure all the
  procedures for an assisted death have been followed.

### 1. Introduction



#### 1.1 About the project

The <u>Nuffield Council on Bioethics</u> (NCOB) is interested in exploring how people living in England think and feel about assisted dying, including the underlying ethical, social, and practical complexities. As part of this work, a Citizens' Jury was commissioned – the first Citizens' Jury in England on assisted dying. The Citizens' Jury brought together 30 people broadly representative of the English population and is one element of a <u>wider project</u> exploring public views on assisted dying in England. The project also includes two nationally representative surveys and a series of opinion pieces on a range of ethical views on assisted dying that will be published in early 2025.

#### 1.2 The organisations involved

#### THE NUFFIELD COUNCIL ON BIOETHICS (NCOB)

The NCOB 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 an independent <u>Advisory Board</u> for the project, 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.

#### 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 is responsible for the two nationally representative surveys for the project.

#### POSTCODE FILMS

The Citizens' Jury film is being 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 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.

#### 1.3 About this report

This is the first of two reports to be produced as part of this wider project. It is an interim report focused on how the Jury members voted on the Jury questions. It does not seek to analyse these findings. Instead, this report presents initial insights into the main votes and the key recommendations in **the words of the Jury members**, with some contextual information to explain the deliberative process.

The main report of the project will be published in early 2025. This will provide a rigorous qualitative analysis of the full Jury findings, delving into the rationale behind the Jury members' recommendations. It will also contain the in-depth methodology and recruitment process of the Citizens' Jury and an analysis of the results of the two nationally representative surveys.

A film explaining the Citizens' Jury will also be published at the same time as the main report. It follows the journey of some of the Jury members and records the in-person workshops, which were the culmination of two months of deliberation.

## 2. About Citizens' Juries



#### 2.1 What is a Citizens' Jury?

Citizens' Juries are a methodology for exploring issues that matter to society, finding common ground, and understanding different attitudes. The methodology was developed by the Jefferson Center (now known as The Center for New Democratic Processes) in the US in the 1970s and has been used widely as a form of democratic public involvement. Citizens' Juries are particularly effective in exploring value-laden and controversial questions, where knowledge is contested and there are important ethical and social repercussions. Citizens' Juries have a number of important features:

- The Jury members: The membership is designed to be broadly representative of a community or area; for this Jury, it is the population of England;
- The deliberative process: Jury members go through a three-stage process of learning, discussion, and decision-making;
- Evidence and information: Jury members are presented with balanced, accurate and comprehensive evidence during the learning phase; and
- **Independent facilitation:** To support the Jurors and ensure the deliberations are independent from the commissioning body.

<sup>1.</sup> The Center for New Democratic Processes (2024) How we work | Citizens Juries, available at: www.cndp.us/about-us/how-we-work/.

#### 2.2 Why have a Citizens' Jury on this topic?

Assisted dying is a highly complex, sensitive, and ethically-charged topic. Many jurisdictions worldwide do not permit assisted dying but there has been an increasing number considering or passing legislation to permit it in recent years.

Some form of assisted dying is legal in at least 27 jurisdictions, including New Zealand, the Netherlands, Canada, Switzerland, Belgium, all six states in Australia and ten states in the USA.<sup>2</sup> The law in jurisdictions that permit some form of assisted dying varies on eligibility and governance.<sup>3</sup>

Assisted dying is not permitted in England, and despite the longstanding ethical debate on the topic, there is a lack of robust qualitative evidence on public views towards assisted dying and the underpinning social, ethical, and practical issues. Most available data exploring public perspectives on assisted dying in England are based on opinion polls, which often do not capture the relevant complexities involved.<sup>4</sup> This lack of in-depth evidence is frequently referenced in political discussions as a reason for not revisiting the topic and when the NCOB engaged with experts across government and the health policy sector, it heard that quality evidence on public opinion would be a welcome contribution to informing the conversation on assisted dying. This provided the rationale for the Citizens' Jury Exploring Public Views on Assisted Dying.

The Citizens' Jury was an opportunity for a diverse group of residents in England, from different walks of life, to learn about and discuss the complexities relevant to assisted dying. The recommendations formed by the Jury are intended to deepen our understanding of public views and support policy makers, decision makers and wider civil society to better understand public perspectives on the topic.

<sup>2.</sup> UK Parliament POST (2022) Assisted dying, available at: <a href="https://researchbriefings.files.parliament.uk/documents/POST-PB-0047/POST-PB-0047.pdf">https://researchbriefings.files.parliament.uk/documents/POST-PB-0047/POST-PB-0047.pdf</a>.

<sup>3.</sup> UK Parliament POST (2022) Assisted dying, available at: <a href="https://researchbriefings.files.parliament.uk/">https://researchbriefings.files.parliament.uk/</a> documents/POST-PB-0047/POST-PB-0047.pdf; and House of Commons Health and Social Care Committee (2024) Assisted dying/assisted suicide. Second report of session 2023-24, available at: <a href="https://committees.parliament.uk/publications/43582/documents/216484/default/">https://committees.parliament.uk/publications/43582/documents/216484/default/</a>.

Sleeman, K. et al. (2021) Assisted dying: we must prioritise research *The British Medical Journal*; and Select Committee on the Assisted Dying for the Terminally III Bill (2005). Assisted Dying for the Terminally III Bill [HL]. House of Lords, in UK Parliament POST (2022) Assisted dying, available at: <a href="https://researchbriefings.files.parliament.uk/documents/POST-PB-0047/POST-PB-0047.pdf">https://researchbriefings.files.parliament.uk/documents/POST-PB-0047/POST-PB-0047.pdf</a>.

# 3. About the Citizens' Jury exploring public views on assisted dying



#### 3.1 Who took part?

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 broadly representative of the English population.

Stage 3: This information was then used as input into a 'sortition algorithm' which randomly selected 34 participants by computer, over-recruiting by four to ensure a final 30 members of the Jury. This is done in such a way as to create a broadly 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 <u>here</u>.

HVM then took over communication with the selected Jury members, including conducting onboarding 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, so the voting on the final day was completed by 28 Jury members.

#### 3.2 The Jury questions

The Jurors were tasked with examining and responding to the following questions:

#### **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?

It is typical for a Citizens' Jury process to involve both in-depth discussions and an iterative process of voting to understand where there is a coming together of views on the issues, and where there is less agreement.

#### 3.3 Overview of the Citizens' Jury process

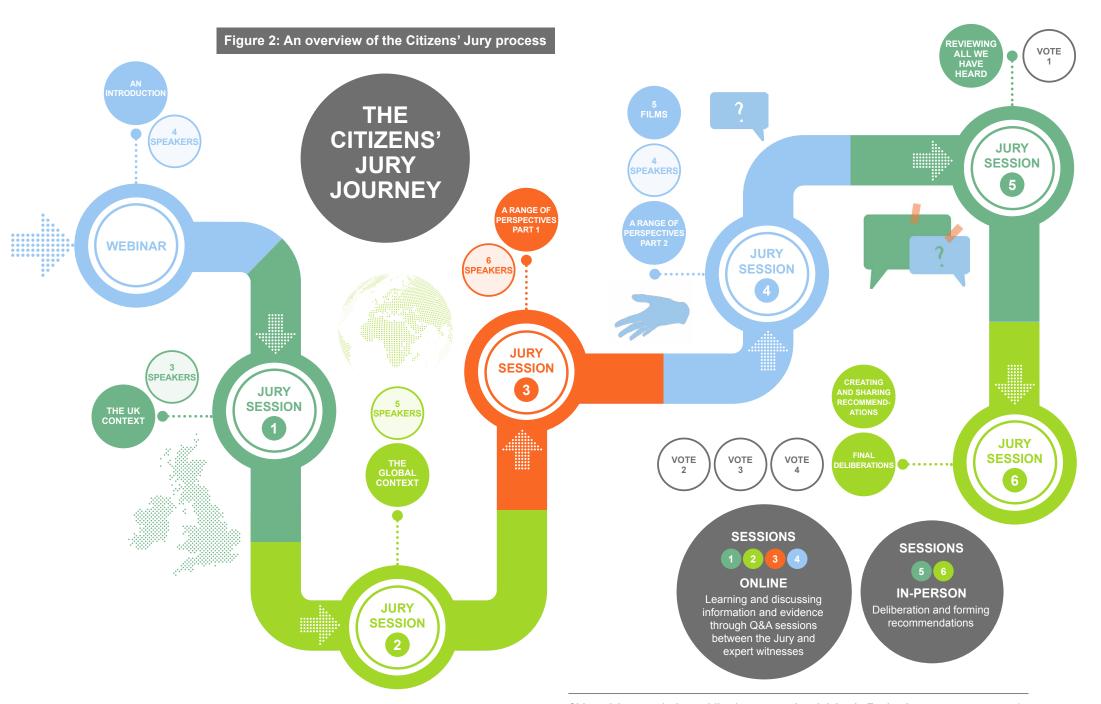
The Citizens' Jury took place between April and June 2024. The Jury met for seven sessions over a total of 24 hours. Figure 2 visualises the Citizens' Jury process. In addition, Jurors were also given a series of stimulus materials in preparation for attending the Jury sessions. The presentations they had seen at the workshops were also made available to Jury members on a dedicated webpage.

#### The Jury sessions:

#### A webinar

An introduction to the Jury's purpose and topic 17th April 2024 (6pm to 8pm with breaks)





#### Session 1 (online)

The UK context and overview of assisted dying 24th April 2024 (6pm to 9pm with breaks)

#### Session 2 (online)

The international context and case studies 8th May 2024 (6pm to 9pm with breaks)

#### Session 3 (online)

A range of perspectives (campaigning organisations and religious perspectives)

15th May 2024 (6pm to 9pm with breaks)

#### Session 4 (online)

A range of perspectives (lived experience, disability, palliative care and clinicians) 22nd May 2024 (6pm to 9pm with breaks)

#### Session 5 (in person)

Reviewing the evidence and information, deliberation and developing recommendations

14th June 2024 (6pm to 9pm with dinner)

#### Session 6 (in person)

Deliberation and developing recommendations
15th June 2024 (10am to 4pm with breaks including lunch)

Throughout the process, Jury members were supported by the independent facilitation team from HVM and by two 'Jury Friends' who helped Jury members to review and question the evidence.

In the webinar, and the first four online sessions, Jury members received a series of comprehensive, balanced, and accessible information, including presentations from experts and witnesses. As part of this stage of the Jury they also took part in:

- small group sessions to identify key questions of interest to the Jury;
- Q&A sessions as a whole group with the speakers;
- sessions hearing from the Jury Friends who summarised and reflected on the evidence that had been shared; and
- small group reflections on the expert witness presentations and the Jury questions.

The two concluding Jury sessions were held in person in London - one of three hours and one of six hours. During these in-person sessions, Jury members reviewed all the evidence and information they had heard and read across:

- 20 presentations from speakers;
- 9 fact-giving information sheets;
- 5 briefing papers from campaigning and advocacy groups;

<sup>5.</sup> The role of the 'Jury Friend' was to act in a neutral and objective capacity to support Jury members to think about and challenge the information and evidence they received and answer questions from the Jury members. The two Jury Friends for this Citizens' Jury were Suzanne Ost, Professor of Law at Lancaster University and Alexandra Mullock, Senior Lecturer in Medical Law at the University of Manchester.

- 1 panel discussion;
- 5 lived experience films; and
- 4 reflections from the Jury friends.

In small and whole group facilitated discussions they thought hard about:

- the important things that the Citizens' Jury should consider;
- the most important reasons for and against permitting assisted dying;
- the values and principles underpinning the thinking of the Citizens' Jury;
- inclusions/exclusions to consider should the law change;
- recommendations or changes to current policy around assisted dying in England;
- developing recommendations; and
- prioritising recommendations.

All the evidence and information provided to the Jury, the Jury schedule of activities, and a full list of expert witnesses, including their presentation slides, are published <u>here</u>.

## 4. Key recommendations and votes



This section describes how the Citizens' Jury deliberated and voted, by secret ballot, on each of the Jury questions. The Jury was reminded of the questions at each of their Jury sessions and reflected on all of them throughout the process. It is important to note that voting is the method 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. However, the basis of the final Jury considerations and recommendations is the thoughtful depth of discussions over time taking into account the evidence received. It was in the final in-person Jury sessions that the votes were held and the Jury recommendations decided upon.

It should be noted that 28 of the 30 Jury members took part in the voting in the final session due to illness of two Jury members. The reasons why Jury members voted as they did, and a full qualitative analysis of the findings will be set out in the second project report, due for publication in early 2025.

#### 4.1. FRIDAY - Question 1, initial deliberations

The first in-person session for this Citizens' Jury took place on Friday 14th June, 6-9pm. The Jury was reminded in a presentation by the facilitation team of everything they had heard from expert witnesses, the written stimulus material, and the briefing papers they had received. This material was also printed and available to the Jury as they worked over the two in-person sessions.

During this session, Jury members were asked to vote for the first time on Jury Question 1. They were told that this vote was an opportunity to understand what the voting process feels like for them and, in responding to the question, consider whether they had come to a settled view at this point.

Box 2: Voting paper wording for Question 1		7
Should the law in England be changed to permit assisted dying?	7	
The law in England should be changed to permit assisted dying:  (Please select one of the following options)  Strongly agree Tend to agree Undecided  Tend not to agree Strongly disagree		
What are the most important reasons in favour of permitting assisted dying? [3 main reasons in a free text box]		
What are the most important reasons against permitting assisted dying? [3 main reasons in a free text box]		

The results of this first vote will be shared in the second report as part of the analysis of how the Jury's views evolved.

Bearing all of the evidence and information they had received over the eight weeks of the deliberative process in mind, the Jury worked in facilitated small groups to develop a long list of points that the Citizens' Jury believed it was important to either remember or to include as they developed their recommendations about Jury questions 2 and 3 (which the Jury was aware they would be doing on Saturday). The Jury took the points made in this exercise and mapped them on to the headings in Box 3 covering the points that they had heard and discussed throughout the Jury process.

#### **Box 3: Main theme areas for Jury deliberations**

#### **Eligibility**

- Age
- Health Status
- Resident status

#### Mode

- Physician assisted suicide (prescribing)
- Euthanasia (administering)
- Either or both of these modes

#### Safeguards and regulations

- Who decides?
- Who can assist?
- Whether or not there is a cooling off period
- Assessing mental capacity

- Are advanced decisions permissible?
- Should there be an opt-in/opt-out for the medical profession?
- Should there be protections for the medical profession?
- How should a request for assisted dying be made?
- How can people withdraw a request?
- How should assisted deaths be monitored and reported?

#### Other

What other points need to be taken into account when developing the Citizens' Jury recommendations which may not fall into these categories?

#### Box 4: Voting paper wording question 1



#### What are the most important reasons in favour of permitting assisted dying?

Select up to ten most important reasons **in favour** of assisted dying from the list collated yesterday (put an X in the relevant boxes).

What are the most important reasons against permitting assisted dying?

Select up to ten most important reasons **against** assisted dying from the list collated by the Jury yesterday (put an X in the relevant boxes).

In both cases you can put your vote in the 'abstain' box.

#### 4.2 SATURDAY - Question 1, deliberations and voting

On Saturday morning, Jury members reflected and voted on the most important reasons for and against changing the law in England to permit assisted dying by selecting from the long list of reasons collated on the Friday night by the HVM team. The words on the voting paper are set out in Box 4.

Jury members reviewed the long list of all the reasons for and against assisted dying that they had identified which were set out on the voting paper using Jury members' words. These are provided in full below to demonstrate the full range of factors being considered by the Jury. Each Jury member had 10 votes that they could allocate throughout the long list. 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.

The reasons given by members of the Jury *in favour* of permitting dying that gained the greatest number of votes were:

- To stop pain (12 votes)
- Having the option to end your own life (12 votes)
- Knowledge that you can die with dignity if the time comes (11 votes)

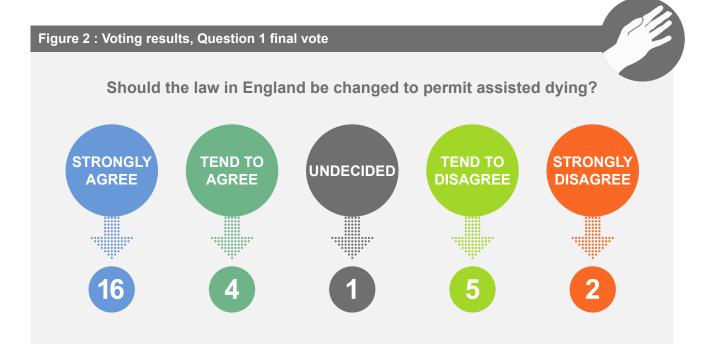
Table one (see Appendix, page 25) lists how many votes were allocated by Jury members to each point. They could also abstain from voting by using the 'abstain' box.

The most important reasons given by members of the Jury *against* permitting assisted dying that gained the greatest number of votes were:

- Could be used for the wrong reasons if safeguarding is not in place (12 votes)
- Can be misinterpreted or misused causing challenges for society and the legal system (10 votes)
- Could result in less funding for palliative care (10 votes)

A final main vote on the first part of Question 1, **Should the law in England be changed to permit assisted dying?** was cast by Jury members on the Saturday. The results are set out in Figure 2, showing 20 Jury members strongly

or tend to agree with a change in the law to permit assisted dying, while 7 Jury members tend to disagree or strongly disagree with this question.



#### 4.3 SATURDAY - Question 2, deliberations and voting

Jury members worked in small groups to develop lists of their recommendations in response to Question 2, **IF the law IS changed to permit assisted dying in England, what should it include? What should it exclude?** 

Each small group created one list of recommendations for what the law should *include* if it was changed to permit assisted dying, and one list of recommendations for what the law should *exclude* if it was changed to permit assisted dying.

The HVM team then collated all of these small group lists to produce the voting sheet for Question 2.

Jury members voted on Question 2 in a final vote on Saturday afternoon. The wording on the voting paper is set out in Box 5.

In a deliberative process conducted as a whole group, Jury members reviewed and amended the long list that they had created on what should be included and/or excluded if the law in England is changed. The final list was set out on the voting paper using Jury members' words. These are provided in full below to demonstrate the range of factors being considered by the Jury. 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.

The table lists how many votes were allocated by Jury members to each point. They could also abstain from voting by using the 'abstain' box. This was the final vote on Question 2.

#### **Box 5: Voting paper wording Question 2**



#### **VOTE 3: SATURDAY mid-afternoon – part one**

## IF the law IS changed to permit assisted dying in England, what should it include? What should it exclude?

Choose up to 5 things from the list collated today that the law should include

Choose up to 5 things from the list collated today that the law should exclude.

In both cases you can put your vote in the 'abstain' box.

From the long list of recommendations created by Jury members in relation to Question 2, the following three received the most votes:

- People who are allowed to have an assisted death should have a terminal condition (22 votes include, 0 votes exclude)
- People must have the capacity to make their own decision (22 votes include, 0 votes exclude)
- Both physician-assisted suicide (prescribing) and [voluntary] euthanasia (administering) should be permitted (16 votes include, 1 vote exclude).

Throughout the eight weeks of deliberations, Jury members held mixed views on a number of areas, as shown by the range of points on which the votes for Question 2 were allocated. Two topics were consistently raised as points throughout the Jury process where the Jury noted that they were not able to gain any sort of agreement. These points are:

- Whether the person requesting an assisted death should be a resident of England
  - For some being a resident of England is important and they did not want to see people travelling to England in order to have an assisted death.
  - Others felt non-residents accessing an assisted dying service would be appropriate. They felt there would be financial benefits for the NHS if people could travel to England for this purpose, and were required to pay for the service - they felt these funds could make a contribution to funding the NHS.
- If a child could be eligible for an assisted death
  - For some, only adults should be eligible, with no circumstances in which it would be acceptable for anyone under 18 to choose an assisted death.
  - Some others in the discussions shared their view that under 18s should be eligible if they had a terminal diagnosis with less than six months to live, or were experiencing intolerable suffering if parental support is in place.

These are not the only two areas on which the Jury found it hard to agree, but they are the two points that were raised consistently as points of contention throughout the eight-week process.

Table three: The voting results for Question two		
QUESTION 2: FINAL VOTE	VOTE	VOTE
If the law is changed to permit assisted dying in England, what should include? What should it exclude?	INCLUDE	EXCLUDE
People who are allowed to have an assisted death should have a terminal condition.	22	0
People must have the capacity to make their own decision.	22	0
Both physician-assisted suicide (prescribing) and [voluntary] euthanasia (administering) should be permitted.	16	1
A patient must have multiple psychological assessments to be considered eligible and must be repeatedly asked if their mind is made up.	10	3
Under 18s can be considered eligible if they have a terminal illness and have parental support for their decision.	10	6
Intolerable suffering (physical) should be considered within the eligibility criteria.	9	0
Equality of access to assisted dying services – there should be no postcode lottery.	9	2
Those with a terminal (physical) illness should be eligible, with no time limit from their diagnosis.	8	4
Those with a terminal (physical) illness should be eligible, with a six-month time limit from their diagnosis.	8	5
There should be safeguards in place for vulnerable people.	6	0
There must be a clear record of all assisted deaths and monitoring of the use and safe disposal of drugs.	6	2
Clinicians/medical practitioners should have to opt-in and prove they have had appropriate training.	5	2
There should be standardised medication (backed-up by research into the appropriate methods to use) for all assisted deaths.	5	3
The length of the cooling off period should be decided on a case-by-case basis.	5	3
Only adults should be eligible.	4	1
Only English residents should be eligible.	4	3
Patients must have a longer-term relationship with the physician.	4	4

## 4.4 SATURDAY – Question 3, deliberations and voting

As the iterative process of deliberating on recommendations developed during the course of Saturday, Jury members worked in small groups to develop lists of their recommendations in response to Question 3. Each small group created a list of recommendations or changes that should be made to assisted dying policy if the law **is not changed** to permit it in England. These lists were combined by the HVM team to create the long list on which Jury members voted.

Jury members voted on Question 3 during the final vote on Saturday afternoon. The wording on the voting paper is set out in Box 6.

#### Box 6: Voting paper wording Question 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?

Tick the relevant column in relation to each of the recommendations the Jury has created: Like it, Can live with it, Dislike it.

The final list was set out on the voting paper using Jury members' words. These are provided in full below to demonstrate the range of factors being considered by the Jury. Each Jury member could put a tick against the recommendation to say whether they, 'Like it', 'Can live with it' or 'Dislike it'.

From the long list of recommendations created by Jury members to Question 3, the following three received the most responses.

- There should be continued public conversations a national conversation about death, dying and how we can provide the best possible care at the end of life. This should include continued public and deliberative discussions like these on assisted dying (25 like it, 0 can live with it, 0 dislike it).
- More funding should be put towards improving the quality and availability of NHS palliative care (25 like it, 3 can live with it, 0 dislike it).
- The act of helping a friend/ family member to travel to Dignitas should be decriminalised (23 like it, 0 can live with it, 1 dislike it).

The voting results show that, if the law in England is not changed, Jury members want clarity on the law in relation to accessing the Dignitas service. They feel that the current law is not providing such clarity at the moment. They also want to see a greater focus on improved provision for end-of-life and palliative care. It should be noted that Jury members were reminded in the presentations on the Friday evening that the questions the Jury have been asked relate specifically to assisted dying and that the consideration of the provision of palliative care in England is beyond the scope of the Jury. However, the Jury could include whichever topics they considered relevant in their recommendations.

The table lists the responses to the final vote on Question 3.

Table four: The voting results for Question three			
QUESTION 3: FINAL VOTE	VOTE	VOTE	VOTE
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?	LIKE IT	CAN LIVE WITH IT	DISLIKE
There should be continued public conversations – a national conversation about death, dying and how we can provide the best possible care at the end of life. This should include continued public and deliberative discussions like these on assisted dying.	25	0	0
More funding should be put towards improving the quality and availability of NHS palliative care.	25	3	0
The act of helping a friend/ family member to travel to Dignitas should be decriminalised.	23	0	1
People at the end of their life should have a guaranteed continuity of care with their GP and social care plan.	20	3	0
There should be a commitment from the government for more support and guidance for home carers.	19	3	0
Health professionals should be able to give advice to people on how to seek an assisted death at Dignitas without the fear of being prosecuted.	19	3	1
There should be more transparency about the implementation of the law on supporting a friend/ family member to travel to Dignitas.	18	4	0
Allow people to talk openly about a loved one wanting to go to Dignitas and access the right support at every stage of the process.	18	4	0
Ensure that care homes are regularly inspected to minimise the difference in care home quality across England.	18	2	2
There should be increased transparency and education about what palliative care and end of life involves, helping to remove fear around death.	18	6	1
Train more pain management nurses.	17	4	1
There should be a commitment to review the English law on assisted dying every 5-10 years.	16	4	1
There should be a universal offer of chaplaincy care to patients who are close to death.	16	5	2
The number of people who travel from England to have an assisted death abroad should be closely recorded and monitored.	14	7	0
There should be somewhere for people to go if they are caring for someone who is repeatedly asking for death, but as the law has not changed, they cannot help.	14	6	2

## The Citizens' Jury Statement



Over the course of the in-person workshops Citizens' Jury members worked in small groups initially, and then together to create a collective statement of their principles and to summarise key elements from their deliberations. The following sets out their statement *in their own words* as agreed on as a group.

As members of the Citizens' Jury exploring public views on assisted dying we take our responsibilities very seriously. Over the last eight weeks we have worked together on the basis of respect and kindness. We have shared the values, ideas, ideologies that we as individuals have, and we have heard everyone's thoughts and opinions. Merging those together to come to a conclusion has been very special. We have not always agreed on the way forward, but we do all strongly agree on the need have an open conversation across society about assisted dying in the context of a wider discussion about the end of life, helping to remove fear around death. We set out the following principles and values as the foundation for our recommendations:

- Empathy, compassion and ethics
- Duty of care to protect those who are vulnerable
- Consider people's desire for self-governance and autonomy
- Conscience and faith
- Respect for people as adults and respect for the law
- Doing your best for the people you love

- Concern for the good of society which is prioritised over the needs of the individual
- Human rights.

During our discussions we have created a long list of reasons for and against changing the law on assisted dying in England and considered what the law on assisted dying in England should include and exclude if it is taken forward. The following is a summary of some of the key topics in our discussions.

- National conversation: There should be continued public conversations

   a national conversation about death, dying and how we can provide the best possible care at the end of life. This should include continued public and deliberative discussions like these on assisted dying.
- **Eligibility:** People should have capacity to make their own decision no one can do this on their behalf.
- **Mode:** Options should be available to the patient for how the assisted death will take place, and how it is done.
- Safeguarding: If there is a change in the law, ensure that both medical and legal advice is procured to safeguard vulnerable people so that they are not abused and do not feel pressured into taking this option. This must happen whilst still ensuring that the service is equal and accessible for those who want it.
- Regulation: In all cases a medical practitioner should be on site to control
  the medication, support the process (and the family), and ensure all the
  procedures for an assisted death have been followed.

## Summary and next steps



The NCOB commissioned this Citizens' Jury to explore public views on assisted dying in England and understand the associated social, ethical, and practical considerations that people consider important in forming their views and in their deliberations. This work aims to fill a gap in the existing qualitative evidence on public views on assisted dying. A Citizens' Jury, with accompanying quantitative surveys, provide robust approaches for understanding and exploring public views using qualitative, deliberative and quantitative methods.

The majority of Jury members voted in favour of a change in the law to permit assisted dying, with 20 out of 28 members either strongly agreeing (16) or tending to agree (4). Of those that disagreed that the law should be changed, five members tended to disagree and two strongly disagreed. One Jury member was undecided.

Jury members' deliberations over the whole process showed deep consideration of a range of issues, drawing on a diversity of views and a range of evidence on the reasons both for and against a change in the law. If the law is changed to permit assisted dying, the recommendations for policy makers and legislators that received the highest number of votes amongst Jury members were:

 people who are allowed to have an assisted death should have a terminal condition:

- people must have the capacity to make their own decision; and
- both 'physician-assisted suicide' (prescribing) and [voluntary] euthanasia (administering) should be permitted.

However, irrespective of a change in the law, their deliberations also highlighted the need for:

- Continued public conversations a national conversation about death, dying and how we can provide the best possible care at the end of life.
   This should include continued public and deliberative discussions like these on assisted dying.
- More funding to be put towards improving the quality and availability of NHS palliative care.
- The act of helping a friend/ family member to travel to Dignitas should be decriminalised.

This interim report is a high-level summary of how the Citizens' Jury ran and what the Jury said. We hope these findings will be helpful in informing ongoing public debates about assisted dying.

The main report for the project will be published in early 2025 and will set out not only what the Jury members said but also explore why they said it. It will analyse the depth and breadth of qualitative data HVM has collected as a result of conducting the Citizens' Jury Exploring Public Views on Assisted Dying Project. It will give the full reasoning behind the Jurors' views shared in this report. It will also present the analysis from two nationally representative quantitative surveys and will be accompanied by the Citizens' Jury film showcasing Jury process and Jury members' views on their participation.

## **Appendix**

#### Table one: The voting results for question one – reasons for permitting assisted dying

WHAT ARE THE MOST IMPORTANT REASONS IN FAVOUR OF PERMITTING ASSISTED DYING?	TOTAL JUROR VOTES
Stop pain	12
Having the option to end your own life	12
Knowledge that you can die with dignity if the time comes	11
To avoid prosecution, when helping a loved family member to die	9
Quality of life	8
Just because you do not need a service, doesn't mean someone else does not	8
Dying with dignity	8
People will make the most of living while they can, because they have the reassurance that they can have an assisted death.	8
It alleviates people from irreversible pain	7
To enable those who want to an assisted death in the presence of family and friends to do so without them being prosecuted	7
To end a person's life who is suffering from terminal illness	6
Intolerable suffering	6
Dying is hard and may result in loss of dignity time and control, this law will help	5
It offers the right for the suffering terminally ill	5
Prevents painful death	5
People who are suffering and want a way out should be allowed it	5
The value of autonomy	5
Autonomy, dignity and choice	5
Having that choice / right to decide	5
Giving the right to choose (with robust safeguards)	5
It should give choice to a small number of people and comfort for those who don't take it but know it is there	4
It should be fully funded across the country (not a postcode lottery)	4
A chance to say goodbye, family and friends have closure	4
Everyone should have a choice	4
Not forcing people to life	4
To limit the extent of end of life suffering	4
Autonomy	4
To allow people who are suffering to make their own choices	4
It should be the individual's choice	4
Right of autonomy/self determination	4
In theory, it is easy to disagree but when facing reality and when in agony, one should ask how far does human resistance go?	3
For patients to have that choice	3
Personal reason - I would want it for myself	3
It is a person's choice, we should have a choice	3

#### Table one: The voting results for question one – reasons for permitting assisted dying cont...

WHAT ARE THE MOST IMPORTANT REASONS IN FAVOUR OF PERMITTING ASSISTED DYING?	TOTAL JUROR VOTES
Human dignity and the right to have a pain free life	3
Relief from suffering	3
No suffering if terminally ill	3
From having some evidence we have received does not show that having the law changed will negatively impact us	2
It should stop people having to go to Dignitas	2
Only the rich can currently afford to fly to Dignitas	2
To remove the need to travel to other jurisdictions	2
Gives somebody security it is there if they are told they are ill	2
Control of your own destiny	2
Palliative care is underfunded	2
Freedom of choice	2
Sense of control	2
To relieve suffering if that person wishes	2
Possibly more cost effective	2
AD is neat and suicide is messy	2
Cost savings for palliative care no longer required	1
It doesn't have to be a slippery slope	1
Merciful deaths	1
Less suffering	1
Giving us the right to say yes or no if we want to die	1
I cannot in good conscience as a Christan see any reasons in favour which do not threaten the dignity of a person	1
Free will to end life	0
Population control	0
You don't ban abortion, you only ban safe abortion	0
Family and friends	0
It is the human thing to do	0
Abstain	0

#### Table two: The voting results for question one – reasons against permitting assisted dying

WHAT ARE THE MOST IMPORTANT REASONS AGAINST PERMITTING ASSISTED DYING?	TOTAL JUROR VOTES
Could be used for the wrong reasons if safeguarding not in place	12
Can be misinterpreted or misused causing challenges for the legal system	10
Less funding for palliative care	10
Opens up suicide mentality	9
The prediction of death period can be wrong	9
The pressure of feeling like a burden	9
Safeguarding	8
People can change their mind	8
Concern that vulnerable people will feel coerced	8
Drugs used for AD are not always effective – taking the drug and it not working.	6
Unfair pressure on patients, family and medics to choose AD as the normal accepted route	6
The control of safeguarding for medical staff	6
Need very strong safeguards	6
Trust of future Governments	6
A cure for illness, can be found within life span	5
There will be slippery slope regardless of assurances	5
The capacity to consent	5
Can the vulnerable be protected?	5
Pressure on old people	5
Record keeping	4
Ending life for the wrong reasons	4
Slippery slope	4
Defending the higher meaning of suffering	4
Risk of abuse	4
Abstain	3
There will be 'horror stories'	3
AD is likely to affect overall suicide rates "What's ok for them is ok for me"	3
Administering the prescription drugs	3
Safeguarding for vulnerable people is almost impossible (actually completely impossible)	3
We are not able to assess people's suffering degree and their state of mind when they make such a decision	3
Rejecting population control	3
The concerns with the actual process/drugs/incidents and failures	3
The parameters might change and it could be abused	3
Palliative care will slide	3
The potion given is not always effective	3
Lack of safeguards	3

#### Table two: The voting results for question one – reasons against permitting assisted dying cont...

WHAT ARE THE MOST IMPORTANT REASONS AGAINST PERMITTING ASSISTED DYING?	TOTAL JUROR VOTES
Not convinced that appropriate safeguards are possible	3
Legislative creep to broaden eligibility criteria	3
Causing more pain and suffering / not having the choice to stop the pain	2
Control of substances	2
Human life is very precious, God permitted it via your parents	2
Unclear whether there is much research into the drugs used - it is dangerous making policies without evidence	2
Unknown and untested experience for patients taking AD drug	2
Current social problems with suicide in the young	2
NHS waiting lists; I can see the newspaper headline "Gov solves NHS waiting list problem by introducing AD law"	2
It may affect future medical research into some conditions	2
Improper safeguards	2
Social pressures	2
Upholding a culture of stoicism in the face of adversity	1
People will not fight over their lives	1
People with houses will volunteer rather than go into a home and there is no house for children	1
Legal creep making safeguards null and void	1
The sanctity of life as orated in the natural law and the catechism of the Catholic church	1
People feeling pressure from friends and family	1
Open to abuse	1
Safety for the future	1
Assisted dying is throwing away life and not living life to the end	1
Are humans just trying to control nature?	0
Fear of the slippery slope	0
Dignity of the person and protecting the value of their life	0
Christian faith	0