

Final report: full analysis of Citizens' Jury and survey findings
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Foreword

Assisted dying raises a host of ethical and social challenges for contemporary society. A growing list of countries have introduced legislation to permit assisted dying and the UK is currently in the process of legislating for assisted dying as the Terminally III (End of Life) Bill makes its way through Parliament. Politicians and policy makers are responding to public opinion in favour of assisted dying in bringing forward this legislation. Assisted dying has been receiving a lot of media attention, including from high-profile individuals with terminal conditions who have argued for their right to choose the time and manner of their own death, to avoid undue suffering. However, others have raised significant concerns about an assisted dying service, including the risks of coercion.

The Nuffield Council on Bioethics is an independent expert body which seeks to offer insights into ethically complex areas of biomedicine, including through engaging with public views and concerns. We have over 30 years' experience in advising practitioners and policymakers grappling with complex and difficult questions within medical research and care. Assisted dying is one such area where we can make an important contribution, drawing from a range of experts and engaging with publics to inform policy in this important but ethically sensitive area.

It is therefore my great pleasure to introduce our final report on the Citizens' Jury and survey findings. Working with Hopkins Van Mil (HVM), and their partners M.E.L Research and the Sortition Foundation, we have conducted a detailed and ground-breaking public engagement programme, researching what the public want to happen with respect to assisted dying in England. This work goes further than before to explore public attitudes on this matter in depth, bringing together two surveys of a nationally representative sample of the English population with England's first Citizens' Jury on assisted dying.

The Citizens' Jury brought together 30 people from all walks of life and broadly mirrored the English population in terms of attitudes towards assisted dying and demographics. The Jury members generously gave us their time and energy to deliberate on this important matter. Over a period of eight weeks, they heard from a range of speakers, considered a multitude of evidence and opinion, to inform themselves on the complex topic and worked together to produce detailed recommendations and conclusions.

In our surveys and in the Jury, the majority of people were in favour of giving people the option of assisted dying. There was most support for assisted dying being available to adults who have a terminal diagnosis with an estimated six-months to live. There was strong support for safeguards to protect vulnerable people from coercion and there was clearly an appetite for greater public engagement with this important topic as part of the policymaking process.

This report presents a rich and thorough analysis of what people think about assisted dying and why, which will be a vital resource for experts, support groups and policymakers in this area. I was particularly struck by how much consensus there was around the need for strong oversight and protection of palliative care services. I also think it is important to pay attention to differences in the surveys and Jury findings. Like the majority of survey respondents, Jurors also recommended that the service was only available to adults with a terminal condition. But the Jury did not say that should be restricted to people with 6 months to live. The Jury also could not find agreement about whether the service should be available to non-residents, or on the question of whether to provide a service for children. This lack of consensus arises from important tensions around how to define illness, capacity and entitlement that law makers must put centre-stage in their deliberations on safeguards and funding.

This report also shows the power of deliberative approaches to policy making in ethically complex areas. With the right tools, information and support for deliberation, members of the public can come together to provide thoughtful, detailed and useful advice to policymakers. Together with my colleagues at Nuffield Council on Bioethics and our partners in this project I share the Juror's strong sense of pride in their efforts to make this important contribution. What is particularly notable about this Jury process is not just the headline vote in favour of a change in the law to permit assisted dying. It is the thought that Jurors gave to the challenges of making recommendations in this contested space. They sought to find common ground and to respect differences of opinion. They accommodated others' views to inform their own positions. This is a vital lesson in how to live together in polarising times.

The findings from this project have much to offer to policymakers around the world, particularly our own MPs involved in the current legislative process in Westminster. Understanding and engaging with public attitudes and their careful deliberations and advice is key to good lawmaking in this and many other areas.

Professor Anne Kerr

Chair of the Advisory Board for the Exploring Public Views on Assisted Dying Project

Executive Summary

In 2023, the Nuffield Council on Bioethics (NCOB) commissioned the first ever Citizens' Jury into public opinion on assisted dying in England. This process found that a clear majority of citizens are in favour of a change in the law to permit assisted dying. After an extensive programme of deliberation, based on evidence from experts, advocates on both sides, and those with lived experience of the issues, the Citizens' Jury concluded that the law should be changed to allow assisted dying for those with terminal conditions. They did not feel that assisted dying should be permitted in any other circumstances, for example in cases of intolerable suffering. They were unanimous in concluding that, regardless of whether the law is changed to permit assisted dying, there must be a significant programme of investment and reform into palliative care.

Why explore public views in England on assisted dying?

When the NCOB engaged with experts across government and the health policy sector, it heard that robust and nuanced evidence on public views would be a welcome contribution to informing the conversation on assisted dying.

The purpose of this project, therefore, was to deliver credible and well-informed evidence of public views about assisted dying in England. This was done with the objective of generating an informed public conversation on the issue and embedding the findings from this with key decision-makers to inform future assisted dying policy and practice.

What methods were used?

A mixed methods programme was used to explore public views on assisted dying in England. A Citizens' Jury was at the centre, with two nationally representative surveys before and after the Jury.

What is a Citizens' Jury?

Citizens Juries are a valuable method for understanding public views when:

 The decision or policy area involves complex issues, uncertainty, or conflicting beliefs and values.

- 2. The decision requires an evaluation of the trade-offs between differing policy options.
- The decision makers cannot make or implement policy without an understanding of the values, principles and beliefs of a broad public.

People are recruited to Citizens' Juries broadly reflecting the demographics and prior attitudes of the general public. They are asked to hear and weigh the available evidence, deliberate together, and use their values to assess tradeoffs and make judgements to reach reasoned answers to the questions they are set. The evidence comes from expert witnesses who are briefed to make presentations that provide the Jury with a fair balance of relevant evidence.

Key questions and Jury process overview

The key questions put to the Jury were:

- 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?

The Citizens' Jury took place over eight weeks from April to June 2024. Over the course of a webinar and six sessions (four online and two in-person), Jury members explored the topic of assisted dying in-depth. Jury members went through a three-stage process of learning, deliberation and decision-making, prioritising their recommendations and creating a statement of their principles and key findings.

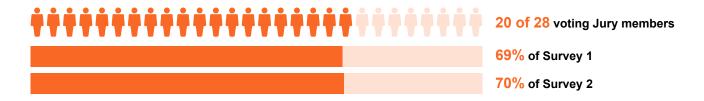


This report

This final project report provides a qualitative analysis of the Citizens' Jury findings, exploring their deliberations fully. It sets out the Jury findings alongside those from the two nationally representative surveys, when these add important context. Overall, this provides a clear overview of what a broadly representative sample of the English population think and feel about the topic of assisted dying.

What were the findings?

Most Jury members (20 of 28 voting Jury members) and the majority of survey respondents (69% of Survey 1 and 70% of Survey 2 respondents) agreed that the law in England should be changed to permit assisted dying.



The three main reasons prioritised by Jury members for changing the law were:

- To stop pain
- Having the option to end your own life.
- The knowledge that you can die with dignity.

These points were echoed by Survey 2 respondents who support a change in the law whose dominant explanations for wanting a change in the law were that:

- Someone terminally ill/ or without quality of life should be allowed to end their life.
- People should not have to suffer.
- People should have the right to choose an assisted death.

Choice, autonomy and freedom were three key concepts that underlie the main reasons Jury members shared for changing the law in England on assisted dying.

Qualitative analysis of the Citizens' Jury deliberations showed that the most important reasons against a change in the law identified by the Jury were:

- Concern that safeguards will not be strong enough to protect the vulnerable in society from coercion or being otherwise pressurised into assisted dying.
- Devaluing life as assisted dying becomes normalised.
- An ever-extending set of criteria when challenges to the law whittle away the originally tightly framed criteria.
- That the funds required for setting up assisted dying services will be drawn from the already limited funding available to end-of-life palliative care.

Safeguarding was a key concern for all Jury members throughout the process, whether they agreed with a change in the law or not. Both Jury members and Survey 2 respondents said that a consideration for any change

in the law was the potential for unintended consequences. For example, Jury members stated that they do not want to see the establishment of an assisted dying service in England taking away existing funds away from social and palliative care.

Jury members called for the involvement of a range of experts including lawyers, social care specialists and psychologists in the development of a safeguarding framework before any legislation is introduced. If this happens, they felt that society would have greater confidence that due process had been followed, and vulnerable people would be effectively protected.

Assisted dying criteria

Both the Citizens' Jury and Survey findings show support for:

- People only being eligible to have an assisted death if they have the mental capacity to make their own decision.
- Restricting assisted dying to terminal conditions.
 - Jury members did not agree on a specific timeline for prognosis, whereas 70% of Survey 2 respondents restricted this to a six-month prognosis.
- Excluding mental illness from being included as an eligibility criterion for assisted dying.

For the mode of assisted dying, there is also consistent support from both the Jury and Survey respondents in:

- Both modes of assisted dying being allowed within the law with healthcare professionals being able to prescribe or administer lethal drugs intended to end a patient's life at their voluntary request.
- The involvement of medical practitioners in the process of accessing an assisted death.
- People having a choice of where an assisted death can take place enabling them to choose somewhere they feel comfortable and safe and can be with loved ones.

Whether or not the law on assisted dying in England is changed Jury members and Survey respondents agree that there needs to be more funding, prioritisation and focus on providing high quality palliative care, guidance and emotional assistance to everyone nearing the end of their life or caring for someone with a terminal diagnosis:

- There was strong support from Jury members for more funding allocated to improving the quality and availability of NHS palliative care.
- 97% of Survey 2 respondents wanted to see increased funding to improve
 the quality and availability of NHS palliative care; 81% called for guaranteed
 continuity of care with their GP and 80% a government commitment to
 support home carers.

Support was also shared in the Jury and amongst survey respondents for:

 Increased open public discourse about death and dying - Jury members and a majority of Survey 2 respondents said there should be a continued national conversation to support the development of any new legislation and its implementation.

- The Jury said that supporting a friend or family member to travel to end their life in an assisted dying clinic in another country should be decriminalised.
 The majority of Survey 2 respondents also supported this.
- Jury members also wanted health professionals to be able to give advice to people seeking an assisted death at an assisted dying clinic in another country, a sentiment that 66% of Survey 2 respondents agreed with.

There are mixed views on some eligibility criteria:

Age:

- Some Jury members said under-18s should be eligible for an assisted death if they have a terminal illness and parental support for the decision.
- Other Jury members voted against under-18s being considered eligible for an assisted death, citing concerns about their capacity and maturity to make such an important decision.
- In Survey 2, 57% supported assisted dying being possible for someone under the age of 18 with a terminal condition, but this falls to 47% if the child does not have a terminal condition.

Residency status:

- Some Jury members felt strongly that only residents of England should be eligible for assisted dying in England.
- For other Jury members this was not an issue, they said non-residents would pay for the service, generating income for the NHS.
- In Survey 2, 51% of respondents were supportive of non-residents of England with a terminal condition being permitted to travel to the country for an assisted death – if they paid for this service. 39% were opposed to nonresidents being eligible for an assisted death.

Jury members discussed what requirements they would expect at different stages of the process of accessing an assisted death if it were legalised. These included:

- Readily available and clearly signposted listening services, including counselling and chaplaincy to support decision making before a formal request for assisted dying is made.
- Psychological assessments made repeatedly to ensure that the person's decision is fixed, and they are not being coerced.
- A cooling off period: views differ on whether this should be a standard period, or if flexibility should be allowed when a patient's life expectancy is short.

It was essential to Jury members and Survey respondents that any new legislation has:

- Firm guardrails to protect vulnerable citizens and ensure strong safeguarding measures are core to the legislation.
- Embedded guidelines for implementation.
- Transparency on what is and is not allowed in law.

The Jury 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 meant that policy makers should consider carefully if a change in the law will bring benefits to wider society.

Citizens' Jury statement

Over the course of the in-person workshops, Citizens' Jury members worked in small groups initially, and then all together, to create a collective statement of their principles and values, and to summarise key elements from their deliberations. The agreement statement in the Jury's own words is set out in Box 1.

Box 1:The Jury Statement created by Jury members in the final in-person sessions in June 2024



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 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 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 happened whist 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.

1. Introduction



Assisted dying is a highly complex, sensitive, and ethically-charged topic. Public opinion on the legalisation of assisted dying is known to be heavily influenced by people's understanding of the ethical and practical complexities. Most available data exploring public perspectives on assisted dying in England takes the form of opinion polls and surveys. It has been noted that while opinion polls and survey data are helpful in gauging the level of agreement or disagreement with a particular idea, they cannot delve deeply into the underlying factors that influence how people view complex and sensitive topics. When the NCOB engaged with experts across government and the health policy sector, it heard that robust and nuanced evidence on public views would be a welcome contribution to informing the conversation on assisted dying.

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.³ The law in jurisdictions that permit some

Mangino, D. R. et al. (2021) Assessing public's attitudes towards euthanasia and assisted suicide of persons with dementia based on their advance request: an experimental survey of US public The American Journal of Geriatric Psychiatry 29(4): 384–394.

² 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) [HL]. Assisted Dying for the Terminally III Bill [HL]. House of Lords, in UK Parliament POST (2022) Assisted dying, available at: https://doi.org/10.58248/

³ UK Parliament POST (2022) Assisted dying, available at: https://doi.org/10.58248/PB47.

form of assisted dying varies on eligibility and governance.4

Whilst many jurisdictions worldwide do not permit assisted dying, there has been an increasing number considering or passing legislation to change this in recent years.

Currently the law in England does not permit assisted dying, but both political and public conversations around the subject are intensifying.

In 2015, the parliament in Westminster debated this topic, with 118 MPs voting for and 330 against a change in the law to allow terminally ill adults to end their own lives with medical supervision.⁵ In November 2024, the UK Parliamentary debate on The Terminally Ill Adults (End of Life) Bill 2024-25 passed the Second Reading stage with a majority of 55.⁶ At the time of writing this report, the Bill is in the Committee Stage.

1.1 About the project

The complexity of the topic, and the need for robust evidence on public views in England to inform the current discourse, is why the <u>Nuffield Council on Bioethics</u> (NCOB) began a project to explore the topic in depth with people in England.

<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 in 2023 by the NCOB to deliver this public engagement project.

The specific aims of the project were to:

- Explore the public attitudes towards assisted dying in England and the circumstances and conditions where assisted dying should and should not be permissible.
- Understand the associated social, ethical, and practical considerations that the public considers important in forming their views and deliberations.
- Identify the most up-to-date evidence and analysis of the diverse range of ethical views on assisted dying in order to inform the public engagement process.
- Inform future conversations in this area and embed the findings of the public engagement with key decision-makers to inform any future policy and practice related to assisted dying.

The project consisted of three stages and a mixed methods approach, including the first Citizens' Jury in England on the topic of assisted dying and two nationally representative surveys.

⁴ UK Parliament POST (2022) Assisted dying, available at: https://doi.org/10.58248/PB47; and House of Commons Health and Social Care Committee (2024) Assisted dying/assisted suicide. Second report of session 2023-24, available at: https://committees.parliament.uk/publications/43582/documents/216484/default/

⁵ UK Parliament (2015) Assisted Dying (No.2) Bill, available at: https://hansard.parliament.uk/commons/2015-09-11/debates/15091126000003/AssistedDying(No2)Bill.

⁶ 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/.

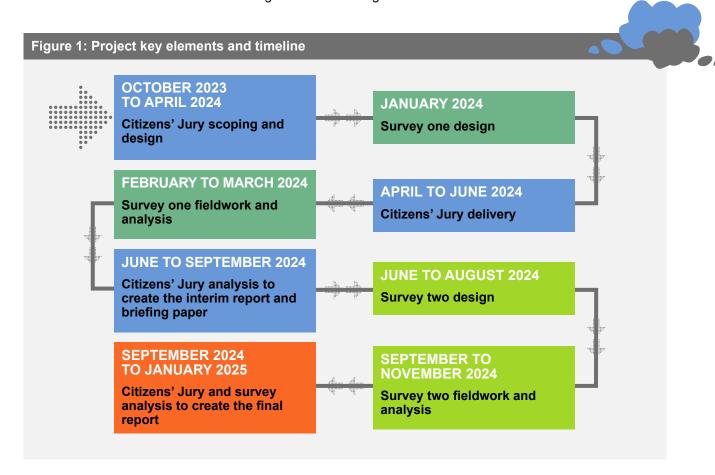
The stages were:

Stage 1: An initial nationally representative survey of the English population which informed the recruitment stratification criteria for the Citizens' Jury

Stage 2: A Citizens' Jury exploring public views on assisted dying in England

Stage 3: A second nationally representative survey which gathered views of the wider English population on the Jury's considerations and recommendations.

The timeline for these stages is set out in Figure 1:



An Interim Report sharing the key recommendations and voting from the Citizens' Jury deliberations was published in September 2024.⁷ An Information and Evidence Pack, containing all the information that informed the Jury deliberations, was published at the same time.⁸

A Briefing setting out an initial qualitative analysis of the Citizens' Jury findings was published in November 2024 to show why the Jury voted as they did and why they made the recommendations described in the Interim Report.⁹ This

⁷ 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.

⁸ Nuffield Council on Bioethics/ Hopkins Van Mil (September 2024) Information and evidence pack, available at: https://cdn.nuffieldbioethics.org/wp-content/uploads/Infomation-and-Evidence-pack-FINAL.pdf.

⁹ Nuffield Council on Bioethics/ Hopkins Van Mil (November 2024) Citizens' Jury: exploring public views on assisted dying in England Briefing – an initial qualitative analysis of the Citizens' Jury findings, available at: www.nuffieldbioethics.org/publications/assisted-dying-project.

was an additional output published to inform the UK Parliamentary debate on The Terminally III Adults (End of Life) Bill 2024-25¹⁰ which was given parliamentary time on a short timescale. The findings from the two nationally representative surveys¹¹ were published at the same time, along with a film of the Citizens' Jury¹², created by <u>Postcode Films</u>.

This final report provides a greater depth of qualitative analysis of the Citizens' Jury findings than was possible for the Briefing. In addition, in this report, we present the two nationally representative survey findings with the Jury findings. The result is a clear overview of what a broadly representative sample of the English population think and feel about the topic of assisted dying.

1.2 Who delivered the programme

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 two nationally representative surveys and a Citizens' Jury to explore public views on assisted dying in England.

The aim of this project has been 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 appointed 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 process was conducted by The Sortition
Foundation, 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.

¹⁰ 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/.

¹¹ 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.

¹² YouTube (11 November 2024) NCOB Citizens Jury on Assisted Dying 2024, available at: https://www.youtube.com/watch?v=cpXvJNy5KFw.



M·E·L Research

 $\underline{\mathsf{M}}\cdot\underline{\mathsf{E}}\cdot\underline{\mathsf{L}}$ 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 was responsible for delivering 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 project was funded by a charitable grant from the <u>AB Charitable Trust</u>. The Trust did not have a say in how the Citizens' Jury, or any other part of the project, was designed and delivered or it's outputs.

1.3 Programme governance

An independent Advisory Board was recruited to represent a range of backgrounds, including technical expertise and knowledge in public engagement and diversity, equity, and inclusion. The Board comprised both NCOB Council members and external experts. External members were chosen through an open recruitment process based on their prior contributions to the subject, their ability to be impartial, and their ability to offer objective advice on the planned engagement activities.

The project team was supported by a Content Group to ensure overall that the evidence, content and stimulus materials for the Citizens' Jury were balanced, accurate and accessible. The Content Group also advised on the range of speakers for the Citizens' Jury. All Content Group members were selected on the basis of their professional backgrounds and/ or published work on the subject, and the group represented a broad range of views on assisted dying.

A full list of Advisory Board and Content Group members is provided at Appendix 1.

The project was independently evaluated by Dr Leah Holmes.

1.4 Informing the design of the project

As well as working with the independent Advisory Board and the Content Group, HVM conducted 13 stakeholder interviews to inform the scope of the Citizens' Jury, and the questions asked in the nationally representative surveys. These interviews also helped to identify potential expert witnesses and speakers and understand what those in academia, stakeholder and policy organisations expected from the project. A full list of interviewees can be found at Appendix 2.

1.5 Analysis and reporting

The online and in-person Citizens' Jury sessions generated over 80 hours of audio recordings. These were transcribed and analysed by the HVM team using NVivo software to group key themes and understand where there was a diversity of views on key topics.

HVM applies grounded theory to its analysis of deliberative processes. Theories are built from what facilitators heard rather than having a preconceived hypothesis to test. Sciencewise Guidelines¹³ and the evaluation of previous Citizens' Juries and deliberative processes were used inform the design of the programme of deliberation. Throughout the process the HVM coding, analysis and writing team maintained a rigorous approach, holding frequent sense-checking sessions as a team to mitigate against researcher bias.

M·E·L Research collected, analysed and weighted the survey responses. Both surveys contained questions to which survey participants could respond with text, using their own words. These responses were reviewed and grouped into themes by the M·E·L Research team.

No AI based text analytics were used in either the qualitative or quantitative analysis.

¹³ Sciencewise (2020) Our guiding principles, available at: https://sciencewise.org.uk/about-sciencewise/our-quiding-principles/

1.6 About this report

This report contains summaries of Citizens' Jury reflections combined with survey findings resulting in a comprehensive review of all the data.

It is important to note that there are limitations to any engagement process. Analysis of Jury findings does not track how Jury members reacted to specific pieces of evidence, nor when they might have changed their mind on the topic of a specific aspect of it. Given that Jury members did not enter the process with fixed views, and might change their minds a number of times in the course of one workshop, and over the whole project, this would be impossible to achieve. The amount of evidence and expert witness and speaker presentations that the Jury could consider was limited to what was reasonable in the eight-week Jury process, as well as what was possible within the allocated budget.

Citizens' Juries are a qualitative methodology. By asking open questions and following lines of enquiry suggested by Jury members we gain an understanding of the subtleties and nuances of views, concerns, hopes and aspirations of a broadly representative sample of the population of England.

The main voting results from the Citizens' Jury (as previously shared in the Interim Report¹⁴ and Briefing¹⁵) have been included where appropriate to highlight Jury member priorities. Voting is used in Citizens' Juries to understand where agreement has been reached on a topic, and where there



¹⁴ 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.

¹⁵ Nuffield Council on Bioethics/ Hopkins Van Mil (November 2024) Citizens' Jury: exploring public views on assisted dying in England Briefing – an initial qualitative analysis, available at: www.nuffieldbioethics.org/publications/assisted-dying-project.

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

Throughout this report quotations from those who took part in the Jury, drawn from the transcripts, are used to illustrate the analytical points being made and to emphasise main points. Some quotes have been edited to remove repeat or filler words. There have been no other edits which might distort the meaning intended by participants.

In this report, when speaking of the Jury findings, terms such as 'a few', 'many', 'several' or 'some' are used to reflect areas of agreement and difference.

As a sample of the population was included in the surveys, the results are subject to a margin of error around various estimates. This means that, given the nature of the sampling process, we can be confident that the actual result lies somewhere within the margin of error. For the sample size of 2000+, we can be 95% confident that the actual value will fall within 2.2% either side of the results reported.

This report is presented by method, with common themes across methods highlighted. The analysis of the Citizens' Jury highlights key findings of relevance to current national conversations. This is followed by a summary of both the nationally representative surveys, with references to the Citizens' Jury where common themes arise. The concluding chapter highlights key themes identified across both the surveys and the Citizens' Jury. Additional survey analyses are available for both Survey 1 and Survey 2 including survey data tables.¹⁶

¹⁶ Nuffield Council on Bioethics/ M·E·L Research/ Hopkins Van Mil Survey one (February 2024) and Survey two (September 2024), both available at: https://www.nuffieldbioethics.org/publication/surveys-exploring-public-views-on-assisted-dying/

2. Methodology



This section explains the methods used in this public engagement programme.

Defining assisted dying

Many different terms are used when discussing assisted dying and people do not always agree on the terminology. To ensure meaningful responses and discussions in both the surveys and the Citizens' Jury it was important that survey respondents and the Jury worked using an agreed definition of 'assisted dying'. For the purposes of this project, the definition set out in Box 2 was used:

Box 2: The definition of assisted dying used throughout the project

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 currently legal in England.

Survey 1 respondents were only shown this definition once they had answered initial questions about their unprompted understanding of the topic.

2.1 Survey method

Survey design process

Both nationally representative surveys were developed collaboratively by M·E·L Research, HVM and NCOB, with the Advisory Board providing feedback.

Survey fieldwork was conducted online with members of a panel.¹⁷ During data collection, the composition of the survey sample was controlled using quotas. These quotas were set based on the following characteristics, with targets set using Office for National Statistics (ONS) 2021 Census data for England:

- Age (5x age bands)
- Gender
- Ethnicity
- Socio-economic group (SEG)
- Geographic region

The number of respondents to Survey 1 was 2,031 and to Survey 2 was 2,011. After the completion of fieldwork, the profile of the cleaned data set was reviewed by these variables. To correct some minor under- and over-representation, weights were applied by age, gender, ethnicity, and region. This weighting process ensures that the resulting data set was broadly representative of the population of England. Disability was also monitored for the sample.

During fieldwork the responses from participants were checked and removed if they did not meet any of the following criteria:

- Took under 3 minutes to complete the survey, which was designed to take between 10 and 15 minutes to complete if done thoroughly
- Didn't give full postcode or their full postcode didn't match the region they selected to make sure respondents were from England

¹⁷ Invitations were sent to members of the <u>Dynata</u> online panel. Dynata is the preferred panel partner of M·E·L Research which conducted the surveys.

 The respondent input random characters/numbers into open-ended questions. The quality of the responses to text-based (open) questions, in MEL's experience, is a key indicator of response quality.

The design of Survey 2 was built on the findings from the Citizens' Jury from which assisted dying scenarios were developed. Survey respondents could consider these scenarios to inform their responses. Survey 2 questions were worded in such a way to avoid any sense that the survey was seeking to test or validate the conclusions reached by Jury members. Indeed, no explicit mention of the Jury process was made within the design of Survey 2.

2.2 The Citizens' Jury method

What is a Citizens' Jury?

Citizens' Juries were developed by Ned Crosby, the founder of the Jefferson Center (now known as The Center for New Democratic Processes) in the US in the 1970s and have been used widely as a form of democratic public involvement.¹⁸

Citizens' Juries help to address the gap between public opinion (captured through polling and surveys) and public judgment (a carefully considered view that citizens come to after engaging with a subject and hearing an overall balance of expert evidence). Citizens' Juries can be a helpful tool to explore and consolidate public judgment and this means that the recommendations they propose can help inform decision-makers. Citizens' Juries are a particularly valuable methodology when, as in this case:

- The decision or policy area involves complex issues, uncertainty, or conflicting beliefs and values
- The decision requires an evaluation of the trade-offs between differing policy options
- The decision makers cannot make or implement policy without an understanding of the values, principles and beliefs of a broad public.

In common with many such processes, the Citizens' Jury exploring public views on assisted dying in England had a number of key features:

- A representative sample: a broadly representative sample of the
 public from England was recruited to take part. This Citizens' Jury provided
 an opportunity for a diverse group of people in England, from different
 backgrounds to come together over eight weeks, learn about and discuss
 the complexities of assisted dying.
- The deliberative process: Jury members went through a three-stage process of learning, discussion, and decision-making.
- Independent facilitation: Jury members were supported by experienced facilitators, ensuring they had a clear process for sharing their views and that the deliberations were independent from the commissioning body.
- Evidence and information: Jury members were presented with relevant and accurate evidence during the learning phase.

¹⁸ The Center for New Democratic Processes (2024) *How we work* | *Citizens Juries*, available at: <u>www.cndp.</u> us/about-us/how-we-work/.

- **Support:** Jury Friends¹⁹ were present for each session, supporting the Jury to question and challenge the evidence they were presented with.
- Transparency: the two sets of Survey Findings, a Citizens' Jury Interim report, briefing paper, full report, and process film have all been published, as have the expert witness and speaker presentations, and the supporting Evidence and Information pack. Observers were able to watch the Citizens' Jury process and NCOB has updated its website with key information and FAQs throughout the process.

Jury recruitment

34 Jury members were recruited using a stratified sampling method, which creates a group of people broadly representative of the national population of England. This is a civic lottery method called 'sortition'. The process was delivered by <a href="https://doi.org/10.1007/jhp.2007

The recruitment process had three stages:

Stage 1: The Sortition Foundation randomly selected 7000 addresses across England. Each received a letter inviting anyone over 18 and resident at that address to register their interest in participating in the Citizens' Jury Exploring Public Views on Assisted Dying. 147 people responded to this invitation to express an interest in taking part in the Citizens' Jury.

Stage 2: As part of the sign-up procedure, all potential participants were required to share responses to 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 from the 147 applicants, over-recruiting by four to ensure a final 30 members of the Jury. This was 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).

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 15th June was completed by 28 Jury members.

Citizens' Jury make-up

Target numbers were set for key demographics (age, gender, ethnicity, education level, disability, region of England, and location rating on the scale of multiple deprivation), all based on Office for National Statistics Census Data (ONS 2021). The NCOB's nationally representative survey of 2,000 people from the English population, conducted in February 2024 (Q: To what extent, if at all,

¹⁹ Jury members were supported by two 'Jury Friends', Professor Suzanne Ost, Professor of Law, Lancaster University and Dr Alexandra Mullock, Senior Lecturer in Medical Law, University of Manchester. The Jury Friends were briefed to act in a neutral and objective capacity, answering questions on the topic and supporting the Jury to think about and challenge the evidence about the topic that they received. This differs from the role of the facilitator. Experienced HVM facilitators worked with the Jury to provide a framework for their deliberations, to give them an open and supportive space in which to discuss the issues, and to record their deliberations.

do you agree or disagree that assisted dying should be legal in England?)²⁰, was the data used to set target numbers for attitudes towards assisted dying.

Since the number of participants in a Jury is relatively small, target numbers for recruitment criteria were set instead of strict quotas. A minimum target was set for ethnic minorities, people with disabilities and attitudes towards assisted dying to ensure no under-representation of minority views.

The following Table 1 shows how the 34 Jury members compares to the English population. Of the 34, four withdrew before the Jury process began, so that 30 Jury members took part in all sessions until the final workshop. Two Jury members were unwell for the final in-person session, resulting in 28 Jury members being present for the final voting.

Criteria Population of England % Target % Citizen Jury % a number 34 participants Citizens' Jury numbers (final workshop) number 28 participants Demographics: source - Office for National Statistics (ONS) Census (2021) data GENDER Female 51.0 51.0 50 (17) 15 Male 49.0 49.0 47.1 (16) 12 Non-binary or other 0.2 0.2 2.9 (1) 1 AGE 18-24 10.5 10.5 11.8 (4) 2 25-34 17.1 17.1 14.7 (5) 3 35-44 16.5 16.5 14.7 (5) 3 45-54 16.7 16.7 17.6 (6) 6 65-74 13.8 13.8 14.7 (5) 5 75+ 9.8 8.8 (3) 3 ETHNICITY Asian or Asian British 9.6 8.8 (3) 3 Black or African or Caribbean or Black British 4.2 4.2 8.8 (3) 3 Mixed or Mu	TABLE 1: Demographic breakdown of the Citizens' Jury exploring public views on assisted dying compared to the English population				
GENDER Female 51.0 51.0 50 (17) 15 Male 49.0 49.0 47.1 (16) 12 Non-binary or other 0.2 0.2 2.9 (1) 1 AGE 18-24 10.5 10.5 11.8 (4) 2 25-34 17.1 17.1 14.7 (5) 3 35-44 16.5 16.5 14.7 (5) 3 45-54 16.7 16.7 17.6 (6) 6 55-64 15.9 15.9 17.6 (6) 6 65-74 13.8 13.8 14.7 (5) 5 75+ 9.8 9.8 8.8 (3) 3 ETHNICITY Asian or Asian British 9.6 8.8 (3) 3 Black or African or Caribbean or Black British 4.2 8.8 (3) 3 Mixed or Multiple ethnic groups 3.0 5.9 (2) 0	Criteria		Target %	& number	numbers (final workshop) number 28
Female 51.0 51.0 50 (17) 15 Male 49.0 49.0 47.1 (16) 12 Non-binary or other 0.2 0.2 2.9 (1) 1 AGE 18-24 10.5 10.5 11.8 (4) 2 25-34 17.1 17.1 14.7 (5) 3 35-44 16.5 16.5 14.7 (5) 3 45-54 16.7 16.7 17.6 (6) 6 55-64 15.9 15.9 17.6 (6) 6 65-74 13.8 13.8 14.7 (5) 5 75+ 9.8 9.8 8.8 (3) 3 ETHNICITY Asian or Asian British 9.6 9.6 8.8 (3) 3 Black or African or Caribbean or Black British 4.2 4.2 8.8 (3) 3 Mixed or Multiple ethnic groups 3.0 3.0 5.9 (2) 0	Demographics: source - Office t	or National Statistics	(ONS) Census (2021) data	
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18-24 10.5 10.5 11.8 (4) 2 25-34 17.1 17.1 14.7 (5) 3 35-44 16.5 16.5 14.7 (5) 3 45-54 16.7 16.7 17.6 (6) 6 55-64 15.9 15.9 17.6 (6) 6 65-74 13.8 13.8 14.7 (5) 5 75+ 9.8 9.8 8.8 (3) 3 ETHNICITY Asian or Asian British 9.6 9.6 8.8 (3) 3 Black or African or Caribbean or Black British 4.2 4.2 8.8 (3) 3 Mixed or Multiple ethnic groups 3.0 5.9 (2) 0	Non-binary or other	0.2	0.2	2.9 (1)	1
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45-54 16.7 17.6 (6) 6 55-64 15.9 15.9 17.6 (6) 6 65-74 13.8 13.8 14.7 (5) 5 75+ 9.8 9.8 8.8 (3) 3 ETHNICITY Asian or Asian British 9.6 9.6 8.8 (3) 3 Black or African or Caribbean or Black British Mixed or Multiple ethnic groups 3.0 3.0 5.9 (2) 0	25-34	17.1	17.1	14.7 (5)	3
55-64 15.9 15.9 17.6 (6) 6 65-74 13.8 13.8 14.7 (5) 5 75+ 9.8 9.8 8.8 (3) 3 ETHNICITY Asian or Asian British 9.6 9.6 8.8 (3) 3 Black or African or Caribbean or Black British 4.2 8.8 (3) 3 Mixed or Multiple ethnic groups 3.0 3.0 5.9 (2) 0	35-44	16.5	16.5	14.7 (5)	3
65-74 13.8 13.8 14.7 (5) 5 75+ 9.8 9.8 8.8 (3) 3 ETHNICITY Asian or Asian British 9.6 9.6 8.8 (3) 3 Black or African or Caribbean or Black British Mixed or Multiple ethnic groups 3.0 3.0 5.9 (2) 0	45-54	16.7	16.7	17.6 (6)	6
75+ 9.8 9.8 8.8 (3) 3 ETHNICITY Asian or Asian British 9.6 9.6 8.8 (3) 3 Black or African or Caribbean or Black British Mixed or Multiple ethnic groups 3.0 3.0 5.9 (2) 0	55-64	15.9	15.9	17.6 (6)	6
Asian or Asian British 9.6 9.6 8.8 (3) 3 Black or African or Caribbean or Black British Mixed or Multiple ethnic groups 3.0 3.0 5.9 (2) 0	65-74	13.8	13.8	14.7 (5)	5
Asian or Asian British 9.6 9.6 8.8 (3) 3 Black or African or Caribbean or Black British Mixed or Multiple ethnic groups 3.0 3.0 5.9 (2) 0	75+	9.8	9.8	8.8 (3)	3
Black or African or Caribbean or Black British Mixed or Multiple ethnic groups 4.2 4.2 8.8 (3) 3 5.9 (2)	ETHNICITY				
or Black British Mixed or Multiple ethnic 3.0 3.0 5.9 (2) 0 groups	Asian or Asian British	9.6	9.6	8.8 (3)	3
groups		4.2	4.2	8.8 (3)	3
White British 73.5 73.5 64.7 (22) 20	·	3.0	3.0	5.9 (2)	0
	White British	73.5	73.5	64.7 (22)	20

²⁰ Nuffield Council on Bioethics/ M·E·L Research/ Hopkins Van Mil Survey one (February 2024), available at: https://www.nuffieldbioethics.org/publication/surveys-exploring-public-views-on-assisted-dying/

ETHNICITY				
White Other	7.5	7.5	8.8 (3)	1
Other ethnic group	2.2	2.2	2.9 (1)	1
DISABILITY				
Yes – limited a lot	7.3	7.3	5.9 (2)	0
Yes – limited a little	16.8	16.8	17.6 (6)	4
No	75.9	75.9	76.5 (26)	24
EDUCATION				
No qualification / none yet	18.1	18.1	11.8 (4)	4
Level 1	9.7	9.7	8.8 (3)	2
Level 2	13.3	13.3	11.8 (4)	3
Level 3, Apprenticeship, Other	25.0	25.0	26.5 (9)	8
Level 4 and above	33.9	33.9	41.2 (14)	11
REGIONS				
North East	4.7	4.7	8.8 (3)	2
North West	13.1	13.1	11.8 (4)	4
Yorkshire and The Humber	9.7	9.7	8.8 (3)	2
East Midlands	8.6	8.6	14.7 (5)	5
West Midlands	10.5	10.5	8.8 (3)	1
East of England	11.2	11.2	8.8 (3)	2
London	15.6	15.6	14.7 (5)	4
South East	16.4	16.4	11.8 (4)	4
South West	10.1	10.1	11.8 (4)	4
INDICES OF MULTIPLE DEPRIVATION				
1-2	20	20	17.6 (6)	5
3-4	20	20	23.5 (8)	4
5-6	20	20	17.6 (6)	5
7-8	20	20	23.5 (8)	8
9-10	20	20	17.6 (6)	6

Criteria	Population of England %	Target %	Citizen Jury % & number 34 participants	Citizens' Jury numbers (final workshop) number 28 participants ²¹
Attitudes towards assisted dying (Source: NCOB survey Feb 2024. Q: To what extent, if at all, do you agree or disagree that assisted dying should be legal in England?) ²²				
Strongly disagree	7.1 (rounded to 7%)	7.1	8.8 (3)	2
Somewhat disagree	7.5 (rounded to 8%)	7.5	8.8 (3)	3
Neither agree nor disagree	11.8 (rounded to 12%)	11.8	11.8 (4)	4
Somewhat agree	34.6 (rounded to 35%)	34.6	35.3 (11)	7
Strongly agree	34.4 (rounded to 34%	34.4	29.4 (11)	10
Don't know	4.6 (rounded to 5%)	4.6	5.9 (2)	2

The Jury questions

Citizens' Juries are given a set of specific questions to consider. The Citizens' Jury questions in this case are set out in Box 3.

Box 3: 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?

How the Jury was conducted

The Citizens' Jury exploring public views on assisted dying took place between April and June 2024. The Jury met for seven sessions over eight weeks, equating to a total of 24 hours of deliberative time. Figure 2 sets out the journey that the Citizens' Jury went on from the initial introductory webinar to the concluding in-person sessions. In addition, Jury members were given a series of written materials that they were encouraged to review outside of the Jury sessions (see the Information and Evidence pack). HVM team members

²¹ The figures in this column express how members responded to this question as they began the Jury process. They do not express the final outcome of the vote on this question which is set out in Chapter 3 (Box 4).

²² Survey respondents were given the same contextual information and definitions to respond to this question as used throughout the project (Box 1)

conducted one-to-one conversations with Jury members to ensure they could access this information and could read and understand it. All presentations delivered during the Jury sessions were also made available to Jury members on a private dedicated webpage.

The Jury sessions: April to June 2024:

ONLINE

Webinar, 17th April 6pm-8pm: An introduction to the Jury's purpose and topic. Session 1, 24th April 6pm-9pm: The UK context and an overview of assisted dying.

Session 2, 8th May, 6pm-9pm: The international context and case studies. **Session 3, 15th May, 6pm-9pm:** A range of perspectives - campaigning organisations and religious perspectives.

Session 4, 22nd May, 6pm-9pm: A range of perspectives - lived experience, disability, palliative care and clinicians.

IN-PERSON

Session 5, 14th June, 6pm-9pm: Reviewing the evidence and information, deliberation and developing recommendations.

Session 6, 15th June, 10am-4pm: Concluding deliberations, creating recommendations

Jury members took part in:

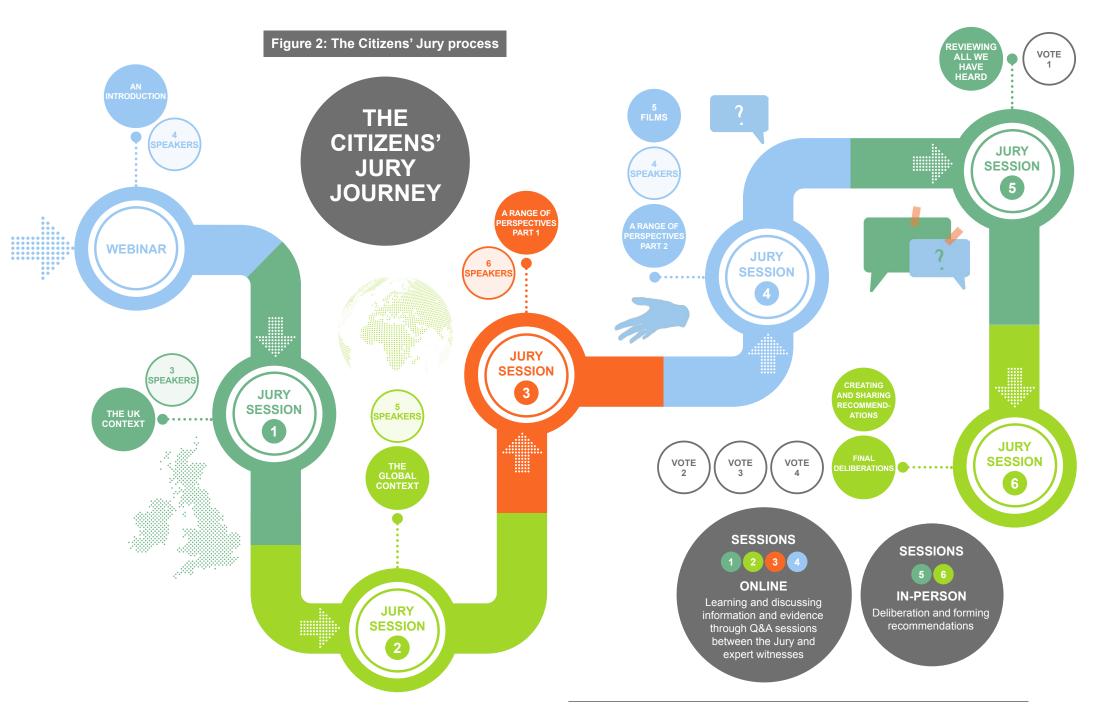
- Small group sessions to identify key questions of interest to the Jury.
- Q&A sessions as a whole group with the speakers.
- Sessions hearing from the Jury Friends who summarised and reflected with the Jury on the evidence that had been shared.
- Small group reflections on the expert witness and speaker presentations and the three Jury questions (Box 3).

The two concluding Jury sessions were held in person in London – one of 3 hours and one of 6 hours. During these in-person sessions, Jury members reviewed all of 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.
- 1 panel discussion.
- 5 lived experience films.
- 4 reflections from the Jury Friends.

In small and whole group facilitated discussions, Jury members responded to the Jury questions ($\underline{Box\ 3}$) by initially creating a long list of things that they felt were important for the Jury to consider. They then deliberated on:

- The most important reasons for and against permitting assisted dying.
- The values and principles underpinning their thinking.
- Inclusions/ exclusions to consider should the law change.
- Recommendations or changes to current policy around assisted dying in England.
- What they wanted to recommend and how the recommendations should be prioritised.





During the process, Jury members heard from expert witnesses and speakers who presented different themes and a balanced range of perspectives on the topic.²³ The full list of expert witnesses and speakers and their affiliations is included at Appendix 3. Links to all presentations are also provided here. An example of an expert witness and speaker brief is included at Appendix 4. Jury members were told in advance whether a witness was speaking as an 'Informant' or an 'Advocate', or from both perspectives. Informants were asked to describe the policy landscape, describing the range of views, options and opinions that exist on the topic. Advocates presented personal opinions or, where relevant, the opinion of the organisation they were there to represent. To ensure balance, all advocates presented to the Jury in pairs, one advocating for a change in the law in England, and one advocating against a change in the law.

Jury members were also supported by two 'Jury Friends', Professor Suzanne Ost, Professor of Law, Lancaster University and Dr Alexandra Mullock, Senior Lecturer in Medical Law, University of Manchester. The Jury Friends were briefed to act in a neutral and objective capacity, answering questions on the topic and supporting the Jury to think about and challenge the evidence about the topic that they received. This differs from the role of the facilitator. Experienced HVM facilitators worked with the Jury to provide a framework for their deliberations, to give them an open and supportive space in which to discuss the issues, and to record their deliberations.

²³ Nuffield Council on Bioethics/ Hopkins Van Mil Speakers and Jury sessions (September 2024), available at: https://www.nuffieldbioethics.org/project/exploring-public-views-on-assisted-dying/citizens-Jury/speakers-and-Jury-sessions/

2.3 An inclusive and supportive process

Due to the sensitive nature of the topic, HVM's counselling service, provided by counsellor Sandeep Ganatra, was made available to all Citizens' Jury members throughout the process. The counsellor was present at every Jury session and could be contacted by Jury members and facilitators for additional confidential support if required.

Signposting to three support organisations – The Samaritans, The Silver Line and Mind – was included at the start and end of both surveys. This information contained both telephone numbers and website links. This information was also shared with Citizens' Jury members, in advance of their participation, in their Jury member handbook. When answering the survey questions, respondents could select 'prefer not to say' if they felt uncomfortable answering any questions.

The Citizens' Jury was designed to be as accessible as possible, including:

- Providing support for participation, including one-to-one phone calls and online introductory sessions.
- Paying all Jury members £440 in recognition of the time and commitment devoted to taking part.
- Lending those who did not have access to a suitable device an internetenabled digital device.
- Lending those who did not have access to a reliable Internet connection a portable Wi-Fi hotspot device.
- Lending additional equipment such as web cams and headsets with microphones as required.
- Holding in-person Jury sessions at a fully accessible venue.
- Access to a prayer room and quiet space during the in-person workshops.
- Providing any additional support for example translation or childcare where needed.

2.4 Evaluation

As part of NCOB's commissioning for the project Dr Leah Holmes was appointed as the independent evaluator of the process. The purpose of this evaluation was to provide an independent and transparent assessment on the quality and integrity of the Citizens' Jury and Surveys on assisted dying.

The evaluation approach was both formative and summative and included the following elements:

- **Scoping:** attending Project Team and Advisory Board meetings to feed constructive questions during the setup, scoping and design phases.
- **Fieldwork:** attending each Jury session as a silent observer, collecting survey data on the Jury experience, and conducting interviews with a selection of Jury members, expert witnesses and speakers, Advisory Board and Content Group members, plus NCOB and HVM team members.
- Analysis and reporting: sharing immediate reflections and survey results after Jury session 1 so that any relevant feedback (e.g. on design, tech support or content areas where Jury members need further information)

could be built into subsequent sessions. More detailed evaluation feedback was shared with the Project Team and Advisory Board at various points throughout the project. could be built into subsequent sessions. More detailed evaluation feedback was shared with the Project Team and Advisory Board at various points throughout the project.

The independent evaluation report will be made available in Spring 2025.



In this section we share the key findings from the Citizens' Jury, including the factors affecting public views as understood by the Citizens' Jury members. Many Jury members shared that they struggled with holding several, often contradictory, ideas at once. For example, the dilemma of whether death should ever be a matter of choice, balanced against the sense that being able to choose an assisted death might 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

Jury members took their responsibilities for weighing up different perspectives and reflecting on the issues very seriously. They welcomed the opportunity to explore the topic in great depth. Some spoke about the process as an intensive process, "almost like studying for a degree on assisted dying." Session 6.

They described their understanding of assisted dying as having developed over the course of the Jury deliberations, with agreement that assisted dying is a complex and nuanced issue. They were pleased that voting was one small part of the process used to understand where consensus and disagreement lay at various points and on various issues. They agreed that the votes allowed for a range of views to surface, and that the topic was not presented or discussed in simple binary terms.

3.1 Final vote on Jury question 1, part 1 "Should the law in England be changed to permit assisted dying?"

The main finding of the Jury is that most Jury members agreed that the law in England should be changed to permit assisted dying. We understand this through their deliberations and the results of votes on the main Jury questions. In the final vote on the first part of Jury question one, "Should the law in England be changed to permit assisted dying?" twenty people either strongly agreed or tended to agree that the law in England should be changed to permit assisted dying. Seven Jury members either tended to disagree or strongly disagreed that the law should be changed. One Jury member was undecided at the end of the process (Box 4). Two Jury members did not take part in the vote on this final day of the Jury deliberations due to illness. Subsequent votes and key findings are described in this Chapter.



It is important to note that prior to this final vote some Jury members said that they had changed their mind, some several times, during the process. Some said that they were 'on the fence' at various points but then changed their mind, but not necessarily in a way that remained fixed for the full process. They said changes of mind could occur in response to a range of different stimulus, including the evidence they heard from expert witness presentations in the learning phase. They also said that it was listening to the views of fellow Jury members and deliberating in-depth on the topic over time. Minds were not changed for the same reason and some people who came in to the process with one view said that they retained the same view throughout.

3.2 Most important reasons for a change in the law

Public benefit

Throughout Jury sessions, in particular the final in-person sessions, Jury members said that 'public benefit' was an important consideration 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 meant considering if a change in the law will bring benefits to wider society.

"I think the bigger question is about society and is this a good thing for society?" Session 5

In deliberating question one Jury members created a long list of reasons for permitting assisted dying. Through voting the Jury prioritised the three main reasons, presented below (Table 2²⁴), for changing the law in England to permit assisted dying.

TABLE 2: 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		

The following analysis explains the main reasons given by Jury members for why people across society may wish the law in England to change to permit assisted dying.

1. To stop pain

For many Jury members, people coming to the end of their lives in great pain was a serious concern. The reasons they 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 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 in pain 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

²⁴ Jury members reviewed two long lists, which they created, 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 each 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.

 Being in great pain themselves, a pain so dreadful that they wanted to end their own life – which made 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 argued 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 were 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 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, and 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 was 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 when 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" was 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 did not have this direct experience but, reflecting on the evidence shared and their discussions, believed that having the possibility of an assisted death is important.

"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, the first way, with dignity in a controlled manner, seems a much cleaner and better way to end your life.." Session 4

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

3.3 Most important reasons against a change in the law

Jury members prioritised similar key reasons against a change in the law. Three main reasons came to the fore as set out in Table 3.25 A key theme running through these reasons is safeguarding the vulnerable in society, particularly disabled people and those with diminished mental capacity. For many, ensuring those most at risk from coercion and being pressured 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

TABLE 3: 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.

²⁵ 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 each 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.

 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.

"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 would become 'normalised' in society. This caused concern to these Jury members who fear that this would 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 wanted to avoid a life sentence for murder.

"What if someone had been sentenced to life for murder. I wouldn't want it to be possible for them to have an assisted death to avoid years in prison." Session 2

• 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 palliative care

Many Jury members, whether for or against a change in the law, were 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

Some Jury members also shared they do not want to see a change in the law because of their religious beliefs. This includes the view that it is not for people to decide when they should die. It also includes the reflection that for some with a religious conviction suffering is important at a spiritual level.

"What about the spiritual value of suffering? Would euthanasia be depriving people of an experience that could actually help them evolve on a spiritual level? For many people who have Christian or



other religions, death is that moment of moving from this life to the next. By having a law that makes it normalised for people to end their life at their chosen moment, they're cutting off that opportunity to meet their creator here and be taken into a heavenly kingdom." Session 3

3.4 Public understanding and awareness of the issues

Some Jury members were concerned that the current discussions in broadcast and social media on assisted dying, as well as campaigns both for and against a change in the law, are presenting the topics in a binary manner: for or against the legalisation of assisted dying. They felt that as a result the complexity and nuances of the issue of assisted dying are not well understood across society. They were concerned that this could mean people are in favour of a change in the law when they have not fully thought through the ethical and societal implications of such a change.

"I thought it was interesting how a couple of (speakers) were talking about there was a general lack of understanding in the public about the terminology of what assisted dying actually meant or didn't realise until it was spelt out to them a bit more clearly what it actually is. When it's presented in the media, on the news, or whatever about assisted dying, people are obviously thinking it means something completely different." Session 3

3.5 If the law is changed - eligibility criteria

In this section, we explore the eligibility criteria that Jury members think would be important to include (and exclude) in a new law on assisted dying. The following topics are covered:

- Health status (e.g., terminal (physical) conditions, intolerable (physical) suffering, assisted dying for mental illness)
- Mental capacity to make a decision
- Age requirement
- Residency status

Restricting assisted dying to terminal (physical) conditions

If the law in England is changed to permit assisted dying, most Jury members thought it should include people who have a terminal condition. There was less support for non-terminal physical conditions which cause intolerable suffering being eligible (Table 4²⁶).

²⁶ 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 to each long list (meaning they had 10 votes in total). This meant that if they felt strongly about a specific point they could put several votes against it.

TABLE 4: If the law is changed to permit assisted dying in England, what should it include? What should it exclude?		
	Include	Exclude
People who are allowed to have an assisted death should have a terminal condition	22	0
Intolerable suffering (physical) should be considered within the eligibility criteria	9	0

The reasons Jury members gave 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 intolerable 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

Terminal illness prognosis: 6-months, 12-months, or no timeframe

Jury members' opinions diverged on what the specified timeframe for eligibility for assisted dying in cases of terminal illness should be. Some preferred a 6-month time limit from terminal prognosis, while others advocated for a 12-month prognosis to allow more time for preparation, decision-making and spending time with family. Additionally, some Jury members argued against a timeframe due to the unpredictability of a terminal illness progression.

"And I only disagree with the six months period actually because nobody can predict a death, you cannot say like... my mum they gave a year, and she passed away in seven days so that's part of the reason I'm here and also people I'm working with are also in the same situation." Session 6

Why some think intolerable (physical) suffering should be considered

Even though there was more support for restricting eligibility to terminal conditions, some Jury members felt that non-terminal (physical) conditions, where there is intolerable suffering, should also be considered as an eligibility criterion.

The following reasons were given:

- 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 intolerable 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 think assisted dying for mental illness should not be permitted

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

The few Jury members who thought severe mental illness should be considered as an eligibility criterion were concerned for individuals who have suffered over an extended period and for whom treatments have proven ineffective.

"...because like I said, you know, there's conditions like schizophrenia, bipolar, BPD, where people have got really long histories, you know, they've tried counselling, they've tried medications, and you know, they've got a long history of being hospitalised, and then that's when I think about their quality of life. But I think it would have to be really airtight. So just food for thought on that one, I guess." Session 6

Having the mental capacity is a priority eligibility criterion

When voting, Jury members indicated that having the mental capacity to make your own decisions would be one of the most important eligibility criteria (Table 5)²⁷.

TABLE 5: 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

Many commented on the importance of mental capacity in the context of the gravity of the decision to have an assisted death. They also highlighted

²⁷ 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 to each long list (meaning they had 10 votes in total). This meant that if they felt strongly about a specific point they could put several votes against it.

the challenge of capacity assessments and the extent to which it could be guaranteed that mental capacity is genuinely in place.

"We talk about capacity to make a decision, but I feel the gravitas of this decision far outweighs me making a decision about some other medical treatment, or even whether to take on surgery versus radiotherapy or chemotherapy. Those decisions are one thing, but this is such a final decision that, "What's my state of mind going to be? Do I really have the capacity?" Because this quite-- I'll only make this decision when I'm in such a bad way. Am I always going to be a--Am I genuinely going to have the capacity?" Session 1

Some Jury members worried about people who are in vulnerable situations and emphasised the importance of ensuring that any decision is made voluntarily, without pressure or coercion. They were concerned about people with severe learning disabilities or neurological conditions, who find it hard to express themselves. They also worried about people who, despite being articulate and informed, may still be vulnerable because they are more easily influenced by others. They questioned whether it is possible to assess mental capacity accurately in such circumstances.

"Also, autism in women. There's been a lot, myself included, (who have been) diagnosed at a late age, going through life not having that diagnosis, so it might not be readily available, on hand. If someone was going to put me through a capacity assessment, they would see that I can retain information and make judgments, but I can be very easily swayed. How would you police that?" Session 1

They also recommended that the mental capacity assessment process is well-regulated by an independent body.

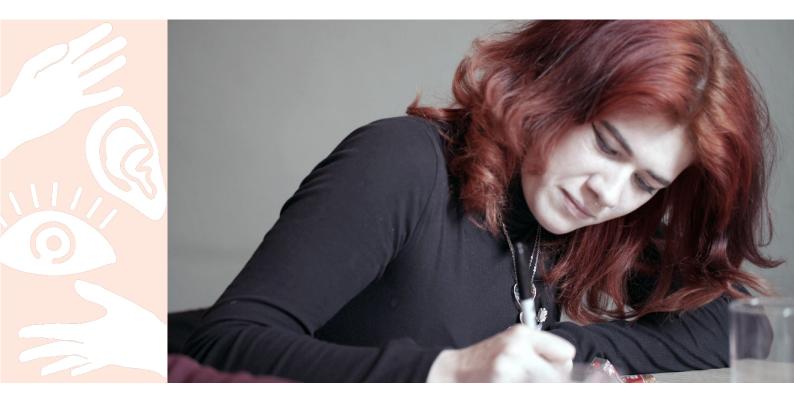
"Also, from my own experience through the healthcare system, for example, I was a support worker. We have the CQC [Care Quality Commission] to police how we're doing, although in my experience, it's not been good enough. What kind of policing body, if not the CQC, would monitor how this capacity assessment is being done?" Session 1

Mixed views on an age requirement

Jury members' views (Table 6²⁸) diverged on whether an assisted death should only be available to adults or whether under-18s should be considered eligible.

TABLE 6: 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

²⁸ 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 to each long list (meaning they had 10 votes in total). This meant that if they felt strongly about a specific point they could put several votes against it.



Some Jury members thought under-18s should be eligible for an assisted death if they have a terminal illness and parental support for their decision. This would be to prevent suffering at the end of life. Some Jury members discussed whether there should be a lower age limit for when a child is eligible for an assisted death. Others reflected 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. A few Jury members proposed that under-18s should only be considered eligible for an assisted death when a judge deems there to be extenuating circumstances.

Other 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 worried 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

Jury members' views diverged on whether residency should be an eligibility criterion for assisted dying in England.

England residents only

Some felt strongly that if the law were changed to permit assisted dying in England, it should be for residents of England only. They would not want to see assisted dying 'tourism' in England and were concerned about the additional pressure this could potentially place on the health service, if assisted dying falls within the NHS.

Concerns included the potential that opening assisted dying services to non-residents could result in private companies attempting to exploit the situation.

"... private companies should not be allowed to exploit AD and become a money-making access available to all wherever you live, wherever you come from, come over here we can end your life without any problems and that shouldn't be allowed to happen." Session 6

Allowing non-residents

A few Jury members thought that people from other countries should be permitted to come to England for an assisted death on condition that they pay for the service and provided it does not put pressure on the NHS. The reasons for proposing this included giving people a choice to have an assisted death in a country where there would be strong regulations, positive personal experiences of the NHS taking care of relatives visiting from overseas, and the potential for generating income for the NHS.

One Jury member compared non-residents travelling to England for an assisted death with people travelling overseas for medical treatments.

"It is in my opinion that residency should not be limited to only those with leave to remain, but to allow for visitors to come and apply to have assisted dying as well. We have people going to Turkey to have treatments done at a reasonable price, we could do the same." Session 6

A few Jury members discussed whether people living in other UK nations might be eligible for an assisted death in England. One person suggested that residents of devolved nations, that do not have their own assisted dying arrangements, such as Wales, should be eligible for an assisted death in England, in the event it is legalised in England.

3.6 If the law is changed - mode of assisted dying

In this section, we summarise the Citizens' Jury findings regarding modes of assisted dying. The following topics are covered:

- The importance of choice.
- Views on voluntary euthanasia (administering) when a healthcare professional administers lethal drugs to an eligible patient with the intention of ending that patient's life.
- Views on physician assisted dying (prescribing) when an eligible patient is prescribed lethal drugs to take themselves (self-administer).
- Method of administration injection and intravenous (IV) versus oral medication.
- Drugs used in assisted dying: regulation, research, and reporting.

The importance of choice

When voting, many Jury members (Table 729) felt that both physician-assisted

²⁹ 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 to each long list (meaning they had 10 votes in total). This meant that if they felt strongly about a specific point they could put several votes against it.

suicide (prescribing) and voluntary euthanasia (administering) should be permitted if assisted dying is legalised in England.

TABLE 7: If the law is changed to	permit assisted dying in Er	ngland, what should it include?
What should it exclude?		

What Should it exclude?		
	Include	Exclude
Both physician-assisted suicide (prescribing) and euthanasia (administering) should be permitted.	16	1

The primary reasons Jury members gave for permitting both modes of assisted dying would be to provide choice and autonomy in decision making, and to ensure no-one (who meets the eligibility criteria) is excluded from having an assisted death who wants one.

In their deliberations, Jury members discussed why they preferred one mode over another, even if on balance they voted for a law that includes both modes.

Voluntary euthanasia (administering)

Many Jury members highlighted advantages to healthcare professionals administering the lethal drugs via injection to patients (voluntary euthanasia), rather than patients taking the 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.
 - "What if someone with a terminal condition had also lost the use of their hands or couldn't swallow. Would they be prevented from having an assisted death? That doesn't seem right and could perhaps harm the people in greatest need." Session 6
- Some Jury members felt there would be people who find it hard to administer a lethal drug themselves and would prefer a medical practitioner to do it for them.
 - "I don't think I could necessarily do a bungee jump. If someone pushed me, that would be easier. I'm the last person that would want to take my own life. It helps if someone does it for you because you're not-- I don't know." Session 4
- Some were 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; they would prefer that these drugs be administered by medical professionals in a controlled environment, ensuring they are managed safely and securely.

"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

A few members of the Jury commented specifically that more people may choose assisted dying if the administration of lethal drugs by a healthcare professional were to be permitted.

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, included:

 It makes it easier for someone to have the option of dying at home, with their family.

"If I was given a prescription, I could do this at home, in peace with my family." Session 6

• 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

Although many Jury members supported the inclusion of physician assisted dying as a mode if the law is changed to permit assisted dying, they would also want to have confidence that the medication used would be fast-acting and without complications.

Some Jury members felt strongly that one or two healthcare practitioners (e.g., a doctor and a nurse) should be present when someone self-administers the lethal drugs as a safeguard to ensure the safe management of the drugs and to support in case of complications.

Method of drug administration – Injection or Intravenous (IV) versus oral medication

Some Jury members felt that an injection or intravenous (IV) drip would be preferable to oral medication because they believe these methods of administration work faster, and would be less likely to result in complications, compared to oral medications.

"IV infusion will go a long way in alleviating suffering as patients can be sedated and later given the dose which would be painless. The aim is to make the experience as painless as opposed to choking and seizures. The evidence is based on reports from colleague who visited Dignitas and experiences the choking effect of the medical drug and how long they take to work." Session 6

Drugs used in assisted dying: regulation, research, and reporting

Jury members raised a number of concerns and made suggestions relating to the drugs used for an assisted death, focusing on the importance of standards, regulation, and research to ensure their efficacy and safe handling.

In the event that assisted dying is legalised in England, Jury members commented on the importance of ensuring that the drugs used are "100% effective", to ensure the final moments are painless, and do not have distressing side effects.

Some Jury members were concerned that there is a lack of research into the efficacy of the drugs used and the process of assisted dying. They called for more research so that improvements can be made, including learning from jurisdictions where assisted dying has been legalised.

Jury members highlighted the importance of the control of drugs used in assisted dying, from drug deposition to storage and safe disposal. They were particularly worried about drugs prescribed for self-administration being kept at home where others could access them. They argued that there needs to be a "robust system and high confidence that deadly drugs are handled safely" (Session 6), in the event assisted dying is legalised in England.

"... You must include a robust control of drugs used, including a fully reported cycle from acquisition, not just prescription, but where they're acquired and traceability right the way through to safe disposal at the end. If they're not used, what happened to them? Are they still on somebody's shelf somewhere? Were they flushed down the toilet?" Session 6

Some Jury members called for mandatory reporting of all assisted deaths, including any complications, in the event it is legalised. They felt that this would be the only way to ensure confidence that the data gathered reflects a "true picture" of assisted dying in practice. They noted that the level of reporting in jurisdictions where assisted dying is currently legal varies, and they were concerned about under-reporting of complications.

Some Jury members highlighted the importance of providing information on the efficacy of different drugs to a person when they are considering an assisted death. They argued that it would be important to know the risk of side effects, even if the chances were very slim, in the same way that people are informed about the side effects of medicines.

"...Patients must be told of the complications that can occur before they make a decision. That's very vital, isn't it? It's like being told about side-effects from the drug that are prescribed for normal illnesses. You have a look at it and if you think, "Oh, I don't know that I really want to take the risk of that particular side effect," and you talk to the doctor about it." Session 6

A few Jury members discussed whether the legalisation of assisted dying in England would be an opportunity to show leadership on research into the drugs and processes of assisted dying, and the effective regulation of assisted dying.

"From what I've seen so far there isn't a lot of good research going on into it, so I think there's an opportunity there for our country to perhaps lead the way into research in the drugs that are used, the processes, how we record data, that kind of thing, you know? I just think it's an opportunity." Session 4

3.7 The process of accessing an assisted death

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

This section covers:

- Listening services, information, and other support
- Requesting an assisted death
- Eligibility and psychological assessments
- Advanced directives
- Cooling off period
- Involvement of medical practitioners
- Involvement of family
- · Location of the assisted death
- Death certificate

Listening services, information, and other support

Jury members discussed the importance of support when considering an assisted death. Recommendations included providing professional counselling, and/ or chaplaincy care, to support decision making before a formal request for assisted dying is made. Many felt that professional counselling should be a formal part of the assisted dying process if the law is changed.





"Because I think everyone, before they make the decision, they should get counselling in place to make sure this is exactly what they do want." Session 6

Some Jury members worried about people deciding on the assisted dying route without adequate support. They saw counselling as part of safeguarding, helping to empower individuals to make a decision that is right for them, without regret.

"As a young, young person, I started abusing drugs, I'll tell you what, the moment you put that tablet into your mouth, then, and only then, do you have this sudden rush of, "Oh, dear, what have I just done?" That's something that I would want to protect patients from. I think that they should have every bit of counselling given to them, that they really understand the full implications of what they're choosing to do." Session 1

Jury members also felt that any person who is considering an assisted death, in the event that the law is changed, should be provided with detailed information about the process. This should also include advice if they decide not to have assisted dying, such as options for end-of-life and palliative care, and wellbeing support.

One person argued that the process should be centred on the whole person, rather than feeling too clinical.

"It all sounds very clinical, "You do this, 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

Requesting an assisted death

A few Jury members discussed the process of requesting an assisted death. They argued that request must be made formally, using an approved format. They commented that it must also be clear that withdrawal of consent to an assisted death can be done at any time.

Eligibility (and psychological) assessments

Some Jury members felt it would be imperative that there are multiple psychological assessments as part of the eligibility assessment (Table 8³⁰). This would be an opportunity to formally reassess and for the person to reaffirm their decision or change their mind.

³⁰ 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 to each long list (meaning they had 10 votes in total). This meant that if they felt strongly about a specific point they could put several votes against it.

TABLE 8: If the law is changed to permit assisted dying in England, what should it include?	
What should it exclude?	

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

Other suggestions relating to the eligibility assessment, made in small group discussions, included:

- 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.
- A formal report should be produced by those who conducted the eligibility assessment, explaining how they came to their decision.

For a few Jury members, legal scrutiny could include that individual cases are also scrutinised by a judge, who would make the final decision. This ties into a common concern that safeguarding measures are robust enough.

"The safeguards have got to be absolutely stringent. I think, as well, we could have, the idea that a particular individual case will go to a judge for assessments, a 'yes' or 'no'." Session 3

Some Jury members worried about potential for bias towards ethnic minorities during the decision-making process. They shared knowledge and experience of medical practitioners not believing or underestimating the severity of the pain experienced by Black patients.

"What just makes me worry is that historically, Black people have not been considered, their pain is never taken into consideration, when (Black people) say we're in pain, it's never believed." Session 6

Advanced directives for assisted dying

Jury members views diverged on whether assisted dying could be permitted with advance directives. A few saw value in allowing individuals to state their wishes regarding assisted dying in advance, if they have a condition which means they may become incapacitated and unable to communicate at a later stage, such as dementia. They felt that having an advanced directive for an assisted death would give the person a greater sense of control over the end of their life.

Others expressed strong concerns about advanced directives for assisted dying. They worried that a person might change their mind after signing an advanced directive for an assisted death but could potentially be unable to communicate this change. They feared that advanced directives could be misinterpreted and applied in situations where the person did not actually wish to die.

A cooling off period

Many Jury members supported the principle of a cooling-off period that allows the person requesting an assisted death to reflect on their decision.

Some felt 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 were uncomfortable with an inconsistent approach and thought there would need to be a set timeframe which is standardised to avoid ambiguity and to better safeguard individuals.

Views varied on how long the cooling off period should be. Some thought it should be no longer than a week, while others suggested it could be over a few months.

A few Jury members thought it would be sensible for a medical professional to have regular telephone contact with the patient during the cooling off period, so they could monitor whether the individual's decision stays consistent over time and to get a better sense of whether they are being coerced. Some also felt that regular contact would help to ensure the person feels supported and is able to change their mind if they want to.

Involvement of medical practitioners

Involvement when considering an assisted death

Some Jury members felt strongly that a medical practitioner who knows the person should be involved when someone is considering an assisted death. They commented that having a longstanding relationship would allow the medical practitioner to "follow you through the journey" and be a reassurance to the person. However, they worried that people often see different GPs and that consultations are often over the phone. They were concerned that the person considering an assisted death would need to repeat their stories each time they see a different doctor. As a result, they feared that they would 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

However, a few Jury members voted against a requirement for patients to have a long-term relationship with a physician when considering an assisted death. They thought this would complicate matters and would not be possible for everyone.

Presence at the time of an assisted death

Jury members discussed the importance of a medical professional being present at the time of an assisted death, including when a patient is self-administering medication. Some worry about a patient taking the medication when they are alone, or only with family and friends. They felt it would be

important for a medical professional to be present, or in a room nearby, at the time the person self-administers the drugs. They pictured the health care professional helping to make the person comfortable, providing reassurance, and being available "in case something goes wrong". In addition, they would confirm the death and have a vital role in ensuring safe handling of the drugs, from collection to disposal.

Some Jury members argued that two medical professionals should be present. A few Jury members felt strongly that they should not know each other to ensure that protocols are followed and to safeguard against coercion or malpractice.

Location of assisted death

Jury members explored the pros and cons of a range of settings and emphasised the importance of it being a safe environment where the patient feels comfortable.

Home

Many Jury members thought that having an assisted death at home would be preferable, in familiar surroundings, rather than in an institutional setting, such as hospital or a care home. A few caveated this by saying the drugs used must be effective.

Hospital

Some believed a medical setting, such as a hospital, would have the advantage of being a controlled environment. Others thought that hospital would need to be an option for patients who aren't able to leave due to their medical condition or difficulties arranging suitable care at home. However, some felt strongly that assisted dying should not be allowed in hospitals or care homes as a reassurance to people who are fearful of these settings.

"We heard from a palliative care consultant discussing that some people are generally scared and mistrust hospitals/care homes.

Removing AD from these premises will reassure people." Session 6.

Specialist assisted dying facilities

There was unease amongst a few Jury members about the creation of specific assisted dying facilities and a worry they would be seen in a negative light.

Outdoors

One group explored the idea that some people might wish to have an assisted death outdoors, somewhere in nature that they find uplifting.

Death certificate

Amongst the few Jury members that discussed the death certificate, views differed on whether it should record that the cause of death was assisted dying. Some felt strongly that assisted dying should be recorded as the primary cause of death, in addition to secondary reasons. They argued this is important for data collection, research and effective monitoring of assisted dying. However, a few Jury members felt there should be a way to opt out of including assisted dying as a cause of death on the certificate. They felt that if only those with a terminal condition could have an assisted death, then the cause of death should remain that terminal condition rather than the means of their death.

Involvement of family

The involvement of family members of a relative who is considering an assisted death was raised several times during Jury member deliberations. Our analysis suggests a tension between Jury members wanting close family to be involved in a loved one's assisted dying journey, while also being concerned about the risks of people feeling coerced or pressured into an assisted death by members of their family.

Some Jury members felt that close family should be involved in the decision-making process to help ensure that the "right decisions" are made. Additionally, they felt it would help to lessen any "heartache" felt by family and friends who are close to the patient.

"Involve family and friends in decision making as this would be a traumatic time for them as well as the person dying. Make sure all parties who need to be are involved. To make the right decisions and not cause any more heartache than needed." Session 6

However, Jury members also felt it is important that family and friends are not present at all assessments, due to concerns about coercion and experiences of seeing family members showing little regard for older relatives at the end of their lives. They were particularly concerned about patients in more vulnerable situations.

One of the reasons why Jury members supported assisted suicide is so that the person can die at home, with family and friends present. However, a few Jury members worried about the risk of repercussions for family members present at the assisted death if the law does not require for medical practitioners to be present.

Some Jury members commented that safeguarding measures would need to be in place not only for those seeking an assisted death, but also for their families and loved ones who are assisting them, and medical professionals approving and administering the assisted dying drugs.

3.8 Medical practitioners – protections and training

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.

Medical practitioners opting-in or out

For many this included 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 9³¹).

³¹ 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 to each long list (meaning they had 10 votes in total). This meant that if they felt strongly about a specific point they could put several votes against it.

TABLE 9: If the law is changed to permit assisted dying in England, what should it incl	ude?
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 was an issue in itself. These Jury members believed 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 explained 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 were concerned about doctors opting-out feared that this would 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

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 saw 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

Training

Some Jury members were more in favour of opting-in because they believed 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 felt training would be important to ensure that there is a standardised system of assisted dying across England, with appropriate standards in place.

Whilst most Jury members felt that medical practitioner involvement in assisted dying is essential to the process, a few Jury members thought that training could be offered to non-medical staff. These technical specialists would receive training in administering lethal drugs safely. 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

3.9 Safeguarding, governance and regulation

Safeguarding people in more vulnerable situations was a significant issue in Jury member considerations, whether they were 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 was a key concern.

There was 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 worried that individuals may choose this option because they feel a burden or lonely. They worried 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 worried that assisted dying would become normalised. Jury members

therefore called 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 called for the involvement of a range of experts in the development of a safeguarding framework before any legislation is introduced. If this happens, they felt that society would have greater confidence that due process had been followed, and vulnerable people would be effectively 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

"I think there needs to be medical and also legal opinions given surrounding what the best way to safeguard vulnerable people would be. So, you've got the legal perspective of how best to mitigate that, and then the medical perspective on how best to maybe think about capacity, how to ensure that vulnerable or elderly or both people are in fact making their own decisions and not being...not risk them being exposed to abuse essentially." Session 6

Specific safeguarding measures

Specific measures to help safeguard individuals at distinct stages in the assisted dying process were proposed and considered by different Jury members during small group discussions. These potential measures have been referred to already in this section and are summarised below:

- Eligibility assessments with and without family present, over time, in different locations.
- Three specialists involved in the eligibility assessment, two doctors and a psychiatrist.
- Individual cases to be scrutinised by a judge.
- 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 cooling off period.
- Training and support for all involved in delivering assisted dving services.
- Presence of medical professionals when an assisted death takes place.
- Mandatory monitoring and reporting of all assisted deaths, including any complications, with data kept for over two years so lessons can be learnt.

Independent regulatory/ governing body

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

Jury members considered that if the law is changed, having an independent regulatory and/or governing body would be essential. The purpose would be to:

- Ensure that assisted dying is tightly regulated and monitored, and high standards and quality of care are maintained, and to protect the intention of the law.
- Prevent misuse or abuse of the system, and ensure safeguarding measures are adhered 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.
- Build public trust and reassurance in assisted dying processes and procedures.
- Ensure that decisions are unbiased, and processes are followed, so patients have equal opportunities and can appeal or complain about a decision.
- Ensure safe management and disposal of drugs.
- Ensure there is continual learning.
- Keep a record of medical practitioners who are trained and allowed to conduct an assisted death.

A few Jury members argued that the regulatory body would have a key role in controlling commercialisation of assisted dying, in the event private companies are allowed to provide assisted dying services to patients.

"So that the commercial aspect is controlled. I mean, if it's a private company, yes, it is to make profit, but a regulator would ensure that that profit is managed." Session 6

Mandatory reporting and record keeping

Jury members highlighted the importance of mandatory record keeping and reporting throughout the process. One small group of Jury members recommended records are kept for several years so that lessons can be learnt, in the same way tax records must be kept for 7 years.

If assisted dying is legalised, they argued that robust data would:

- Help to ensure that 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 entire process.
- Provide data on how many people are choosing an assisted death, for what reason, and why some patients decide not to go ahead with it.
- Support the monitoring, management, and enforcement of the legislation.

Some Jury members were surprised that some jurisdictions didn't have robust procedures for record keeping and felt it is vital lessons are learnt from other countries.

"And I think it's vital that we learn from mistakes made in other countries where they haven't got any sort of record keeping process in place and our record keeping should be exemplary on the whole process through from the very start, drugs manufacturing, drugs choice, how it's been tested, if it's been tested, complications, all those sorts of things, the whole process from beginning to end." Session 6

3.10 Wider considerations if legalised

Equality of access to assisted dying

Many Jury members who expressed support for a change in the law argued that there must be equal access to an assisted dying service, in the event it is legalised in England.

A few Jury members were concerned that the cost of having an assisted death could be too expensive for some people if it were a service that the public had to pay for and they therefore argued that it should be free to all, in the same way as the NHS.

"I think in this country we've got free healthcare, there should not be any kind of cost saving. That shouldn't come into it, money shouldn't be a factor in it. Give access for everyone regardless of their background, it shouldn't be just something that is affordable to some people, that principle that we have with the NHS of free for all should also be in the assisted dying laws." Session 6

Some Jury members were concerned that people from minority groups and disadvantaged situations may face barriers accessing assisted dying.

"I'm a bit taken aback. We think that there is discrimination in between the sufferers. The poor sufferers, the poor from an ethnic background minority side of it, I'm a bit taken aback by that. We're all going to die, and why should they discriminate again in that area?" Session 4

They also worried about an assisted dying service becoming a postcode lottery, with some areas having better access than others because of doctors opting out.

Others were concerned that the process of assisted dying would be geared towards non-disabled people. They worried that disabled people who wish to have an assisted death could be discriminated against at various stages in the process.

"...I feel like we look at it as a very abled thing to get access, to be able to meet your doctor, be able to have capacity. I do think it's really important to think about those people that may be suffering but may not be physically able to do the things required." Session 4

Jury members who supported a change in the law argued that assisted dying needs to be a fair system that is unbiased and accessible to all that are eligible.

Funding, resources, and costs

In the event that assisted dying is legalised in England, a few Jury members commented on the importance of adequate funding and resources. This would help to ensure high standards and in turn that the process is dignified for all patients who go through the journey of an assisted death. They commented that funding would be needed for the NHS to oversee and manage assisted dying and for an independent regulatory body to ensure the proper implementation of regulation.

Some Jury members questioned how assisted dying would be funded and the cost implications it would have for the NHS, if it is legalised in England. Some thought that the costs would be comparable to palliative care, or that assisted dying could save money.

"Well, if you think about it, right, if these people that go for assisted dying, they would technically be saving the state a lot of money, so the money that would have gone on their palliative care would go towards their assisted dying." Session 6

Other Jury members were concerned it would be an added cost pressure on the NHS at a time when it is "already struggling" and having to make savings.

"...If the assisted dying law was to go ahead, then there will be separate doctors, there will be separate prescriptions. If the NHS is already struggling with what we currently have, the government will have to put in more funding whether that would be done in an appropriate way or not." Session 4

A few Jury members also noted there would be costs associated with the regulation and oversight of assisted dying in England, in the event it is legalised.

"... we keep talking about we don't have enough money to improve palliative care, but then setting up a separate regulatory body, that's not going to be a volunteer position, is it, that's going to cost money as well." Session 4

Addressing how a change in law could affect society

A few Jury members were concerned about the impact a change in law would have on society. They expressed concern that assisted dying could become normalised and result in too many people feeling it is a possibility, particularly if there is widespread media coverage.

"I'm just thinking, the British press and TV, if something comes up, they start normalising it by advertising, putting it in EastEnders, putting it on the TV to make it sort of normal, and I think that's what he says. When it's fed to us on TV, we start accepting it and we normalise it, and I think that is the worry. I can see a movie or something happening, everything, you accept it from TV." Session 6

If the law is changed to permit assisted dying in England, some Jury members commented that the associated communications should be low key, so that it does not attract too much attention, to prevent too many people choosing assisted dying, while appreciating that achieving this would be difficult. Others argued that it would be important to communicate proactively about what the eligibility criteria are.

Some Jury members were concerned about the impact a change in the law could have on disabled people, terminally ill people and older people. They worried about people feeling undervalued by society and pressured into considering assisted dying. One Jury member recommended a government communications campaign which makes it clear that no-one should feel pressured into assisted dying, and that everyone counts.

"Yeah, you can just say, when the new law comes out, you know the government sometimes puts up those adverts, right, one of the adverts could literally be, you know, although this new legislation has passed, for people who are terminally ill or disabled, "Don't feel pressured into it," you know, "You are not a burden on society and you are not worth less than an able bodied person. Your value does not decrease because you are terminally ill or disabled." Session 6

The legislative process

As part of their discussions on a potential change in the law, Jury members raised wider points about the legislative process around assisted dying. They appreciated the 'Assisted dying policy timeline' and the presentations on the current policy landscape in the UK, which informed their deliberations.³²

Jury members acknowledged that decision and policy making on this issue is complex; discussions have been ongoing over many years, and it can take time for a Bill to pass to the implementation of a law. Jury members referred to political and cultural factors which contribute to this complexity, such as electoral cycles, existing legislation and the integration of religion within our political processes.

"Within the House of Lords, there are quite a number of heads of religion, and our King is the head of the Church. It's going to be a bit of an uphill struggle in this country by comparison to Holland where religion and politics are completely separate." Session 3

Jury members emphasised the importance of drafting legislation tightly, including on terminology and definitions, so that safeguards are robust, monitored and regularly and independently reviewed. For some Jury members this would be enough to prevent the possibility of a legislative slippery slope.

"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

³² 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

"The fear of the unknown freaked quite a few people out. The idea that it could become out of control, but if it's in legislation and if it's governed by a separate body, then it would be very difficult for it to go that direction". Session 4

As discussed in section 3.11 on travelling abroad, Jury members considered current legislation to be 'wishy-washy' with a lack of clarity on whether the law will be imposed if someone chooses to travel abroad for an assisted death.

The way 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.

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

"...is there scope for us to do better, to learn from all of these other jurisdictions and have a regime that would be better suited for us?" Session 3

There doesn't seem to be any global forum for all of these jurisdictions to come together to share good practice or share data (...) surely it would be a really good idea..." Session 3

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. They also believed strongly that 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.



"It's important that we get across to policymakers that, just because Jersey and other countries have or are bringing in new laws for assisted dying, there's no reason why we should have to follow suit as a country. (...) we should have the guts if we really feel that it's not for us" Session 1

3.11 Jury considerations on the end of life

Whether or not the law is changed, Jury members strongly agreed about the importance of improving end-of-life care. They suggested that improvements should be made 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. As well as Jury members calling for more open public discourse about death and dying in general, there was a clear appetite for national conversations on assisted dying to feed into decision making. During their discussions, Jury members reflected on the legislative process, international comparisons, and the experience of being part of a Citizens' Jury. The following points are covered in this section:

- Public conversations about death and dying.
- Travelling to other countries for an assisted death.
- Improving health, social and palliative care.

Public conversations about death and dying

A key theme throughout the Jury deliberations related to the need for more public discourse around death and dying, including assisted dying, and the difficulties that arise from people being unaccustomed to talking about the end of life.

"We are all going to die and we don't talk enough about death." Session 6

There was particularly strong support amongst Jury members for a recommendation to continue public conversations around assisted dying, and about death and dying more generally. 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. This includes being able to talk about assisted dying, and access to it overseas.
- To raise awareness about assisted dying and related issues and legalities, so that informed public conversations can continue to evolve and feed into decision making.

"There needs to be a national conversation and communication about assisted dying with wider society, before a decision is made." Session 6

Jury members were keen to recommend more opportunities for public deliberation, like the Citizens' Jury, irrespective of whether the law in England is changed. They were interested in this to ensure wider public understanding of this complex topic. They saw 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, Jury members think that deliberation supports 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

Travelling to other countries for an assisted death

Jury members called for the act of helping a loved one travel abroad to access assisted dying to be decriminalised, even if the provision of assisted dying in the UK is not legalised.

The current law in relation to accessing assisted dying services abroad was seen by Jury members as 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 to 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

Jury members also saw the current law as unfair and lacking in compassion. It obliges people accessing assisted dying abroad to travel alone despite their ill-health, and to die without family members or friends present. In their view it "punishes" families or friends for assisting with their loved one's dying wishes.

"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

"It really is awful to think that people will have to go on their own and they can't take relatives with them because they might be arrested, and put through the mill" Session 6

Jury members felt 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.

"Remove the veil of secrecy from Dignitas and the need for protection of family members." Session 6

Jury members pointed out that terminally ill people would continue to travel abroad to access assisted dying while that possibility exists. They also believed it is unfair that only those who can afford the high costs can access assisted dying abroad.

Regardless of their stance on assisted dying, many Jury members expressed empathy for those involved in these kinds of end-of-life decisions and feel that those considering travelling abroad to access assisted dying, and their friends or families, should have access to support.

Jury members suggested that a more compassionate safeguarding procedure should be established in place of criminal investigations. This procedure should take place before a person travels to access assisted dying. Including the 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.

"If someone's decided they want to go to Dignitas, let the police interview them, and make sure it's clear, firm decision on their part, and who they want to take with them, and name them, so that they are then not involved in any prosecution risk." Session 6

Improving health, social and palliative care

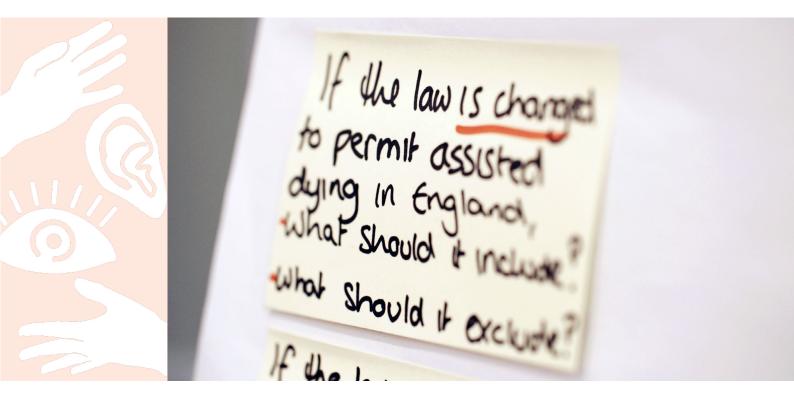
From their own lived experiences, and from specialist presentations and personal testimonies during the workshops, Jury members were aware of a crisis in health and social care, and the implications for those with a terminal diagnosis. Jury members, whether in favour of a change in the law or not, called for support networks across multiple settings to provide consistent care, guidance and emotional assistance to everyone nearing the end of their life or caring for someone with a terminal diagnosis.

Jury members believed that people at the end of their life should have a guaranteed continuity of care through a social care plan and a named GP. There was also strong backing from Jury members for the government to provide more support and guidance for home carers. As an example of the kind of support needed, Jury members pointed out that carers need more information about particular conditions, how they are likely to progress, and how to manage this progression.

"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 think illnesses need to be explained better." Session 6

Jury members also emphasised the need for improvements in pain management to be made across different settings, through training for specialist nurses for example:

"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



Particular concern was raised by some Jury members about end-of-life provision in care homes. Irrespective of whether the law on assisted dying is changed or not, care homes should, in their view, be inspected and regulated more effectively to ensure consistent quality of end-of-life care.

"A lot of people get worried about the care that is provided (in care homes), so if the law is not changed, maybe regulate the care that is provided." Session 6

The need for better and more consistent emotional or spiritual support across all settings was important to Jury members. Counsellors or social workers should be on hand to support both people nearing the end of their lives, as well as their friends and families. Some Jury members felt that chaplaincy support should be offered to all nearing the end of their lives, regardless of any declared faith. Many Jury members also feel that people who are considering assisted dying, or supporting someone considering assisted dying, should have someone to turn to for support and advice, without fear of judgement or repercussions.

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

Jury members called for improvements in 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 were concerned about how palliative care and assisted dying provision could negatively impact each other. Some Jury members believed that a future assisted dying service could divert focus and funding away from already stretched end-of-life care, or away from research into terminal illness. Jury members also raised concerns about inadequate end-of-life care contributing to a person's decision to consider assisted dying.

4. Analysis of the survey findings

This public engagement programme set out to explore public views on assisted dying in England using a mixed methods approach: two nationally representative surveys and a Citizens' Jury.

The key difference between these two methods is that survey respondents answer on their own, without receiving additional evidence or having the opportunity to discuss the topic with specialists and fellow respondents over time. Furthermore, survey respondents cannot be asked why they have answered as they have as Jury members can.

The analysis in Section 4 of this report draws on two summary reports on each of the surveys published by NCOB in September 2024³³, and compares key findings with the Citizens' Jury analysis above. Survey 1 was used primarily to inform the recruitment of Citizens' Jury members. Survey 2 was conducted after the Citizens' Jury to explore the Jury findings with a wider group of the English population. As such, Survey 2 is drawn on more frequently in this analysis.

³³ Nuffield Council on Bioethics/ M·E·L Research/ Hopkins Van Mil Survey one (February 2024) and Survey two (September 2024), both available at: https://www.nuffieldbioethics.org/publication/surveys-exploring-public-views-on-assisted-dying/

4.1 Key findings

Overall support for the legalisation of assisted dying

A majority of the public in England responding to both Surveys 1 and 2 agreed that assisted dying should be legalised. The proportion of the public in England that support and oppose the concept of assisted dying remained substantially unchanged between February 2024 (when Survey 1 was conducted) and September 2024 (when Survey 2 was conducted).

This stability in findings is notable given the increase in exposure to social and broadcast media messages on this subject over this period.

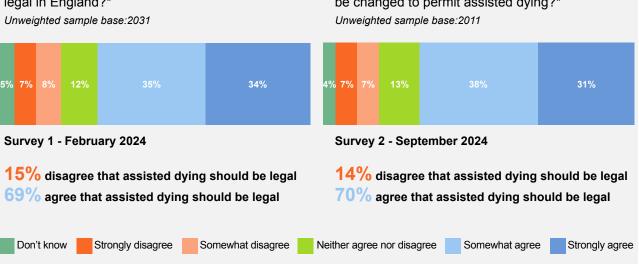
In Survey 1, those in the older age groups, whose ethnicity is White, and those with no religion were more likely to agree with the view that assisted dying should be legalised in England. Those from ethnic minorities, younger age groups, those of Muslim faith, and those working in end-of-life care were less likely to agree. The findings for Survey 2 were broadly similar, with variation across demographics in those who would like a change in the law. Those most supportive of such a change were male, aged 55-74, who identified as White and with no religion, and those living outside of London.

Figure 3: Comparisons between Survey 1 and Survey 2 on the question as to whether the law in England on assisted dying should change.

Agreement that assisted dying should be legal in England Survey 1 vs Survey 2

Survey 1: A4. To what extent, if at all, do you agree or disagree that assisted dying should be legal in England?*

Survey 2: Q2. To what extent, if at all, do you agree or disagree that the law in England should be changed to permit assisted dying?*



^{*}Please note that the wording changed in this question between Survey 1 and Survey 2

The findings from Survey 1 and 2 on the question "To what extent, if at all, do you agree or disagree that assisted dying should be legal in England" were broadly similar to the results of the Citizens' Jury votes in Session 5 and 6 or the process. Across both methods, more members of the public supported a change in the law to permit assisted dying in England than opposed it.

Views on possible scenarios in which assisted dying could be provided

In Survey 2, respondents were given scenarios to assess as they considered whether assisted dying is appropriate in specific situations. These scenarios were created from Citizens' Jury deliberations and some of the situations they had identified as being particularly hard to reach a clear view on. The scenarios are set out in Figure 4.

Figure 4: Scenarios on assisted dying to which Survey 2 respondents responded.

SCENARIO 1a | 6 months

Please imagine a person aged 18 years or older who has a terminal illness who has been told they can reasonably be expected to die within 6 months.

Two healthcare professionals have assessed them as being mentally competent to make decisions on their health.

They have repeatedly asked for an assisted death over several months.

They are a resident of England.

SCENARIO 1b | 12 months

Please imagine a person aged 18 years or older who has a terminal illness who has been told they can reasonably be expected to die within 12 months.

Two healthcare professionals have assessed them as being mentally competent to make decisions on their health.

They have repeatedly asked for an assisted death over several months.

They are a resident of England.

SCENARIO 2

Please imagine a person aged 18 years or older who has a physical medical condition that is not terminal but is expected to cause them what they describe as intolerable suffering.

Two healthcare professionals have assessed them as being mentally competent to make decisions on their health.

They have repeatedly asked for an assisted death over several months.

They are a resident of England.

SCENARIO 3

Please imagine a person under the age of 18 who has a terminal illness.

Two healthcare professionals have assessed them as being mentally competent to make decisions on their health.

They have repeatedly asked for an assisted death over several months.

They are a resident of England and their parent(s) support their wish to have an assisted death.

SCENARIO 4

Please imagine a person under the age of 18 who has a physical medical condition that is not terminal but is expected to cause them what they describe as intolerable suffering.

Two healthcare professionals have assessed them as being mentally competent to make decisions on their health.

They have repeatedly asked for an assisted death over several months.

They are a resident of England and their parent(s) support their wish to have an assisted death.

SCENARIO 5

Please imagine a person aged 18 years or older who has a terminal illness.

They are not a resident of England and have heard that a change in the law means that assisted dying is legal in England. As a result, this person is planning to travel to England for an assisted death at a private clinic at their own expense.

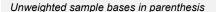
Two healthcare professionals have assessed them as being mentally competent to make decisions on their health.

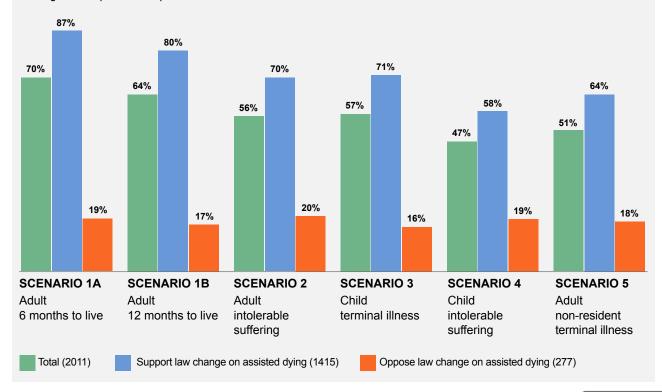
They have repeatedly asked for an assisted death over several months.

In Survey 2, support for assisted dying in each scenario is highest amongst those who support assisted dying as a general concept (Figure 5 - the blue bar). Support is generally much lower amongst those who said earlier in the survey that they do not support assisted dying, between 16% and 20% of these people gave a supportive response for each scenario (orange bar). The green bar in Figure 5 are the responses for everyone who completed the survey.

Figure 5: Responses by Survey 2 respondents to scenarios on assisted dying

Q5-Q9. In this scenario, do you think that the law in England should allow this person to choose an assisted death?





Box 6: Connections to the Citizens' Jury analysis – key findings

Citizens' Jury members did not come to an agreed view on the timeframe for terminal diagnosis, the age of the patient and whether those who are not resident in England should be eligible for assisted dying. However, most Jury members shared the view that intolerable suffering for a non-terminal condition or mental illness should not be included in the eligibility criteria.

4.2 Most important reasons for a change in the law

In Survey 2, all survey respondents (irrespective of their support or opposition in principle) were asked to rank the importance of a set of seven potential arguments in support of a law change in England to permit assisted dying, taken from the Citizens' Jury recommendations. Of these arguments, the

ability to end suffering, the right to choose, and issues of dignity were deemed most important. All seven possible reasons provided had a mean importance score of at least 7 out of 10 (Figure 6).

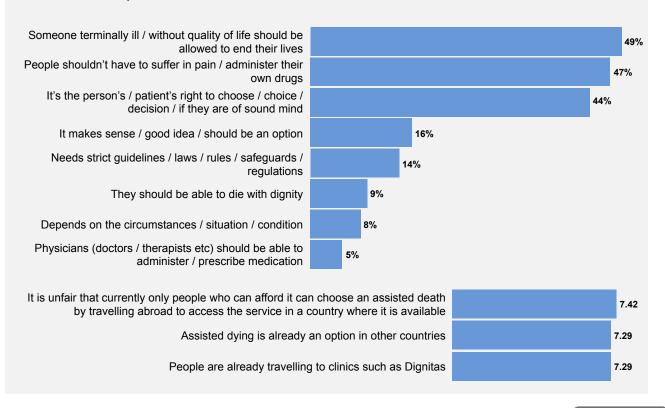
When those who supported a change in the law were asked to give the reasons for their view in their own words, the most commonly given explanations were that someone terminally ill or without quality of life should be allowed to end their life (49%), that people should not have to suffer (47%), and that people should have the right to choose (44%).

Figure 6: Survey 2 – selecting possible reasons for a change in the law in England (all survey respondents)

Q2a. Please explain in your own words your reasons for saying this: those who **agree** that the law in England should be changed to permit assisted dying.

Unweighted sample base: 1415

Response given by 5% or more of respondents shown on the graph. Note that comments may have been allocated to more than one theme.



Box 7: Connections to the Citizens' Jury analysis – most important reasons for a change in the law

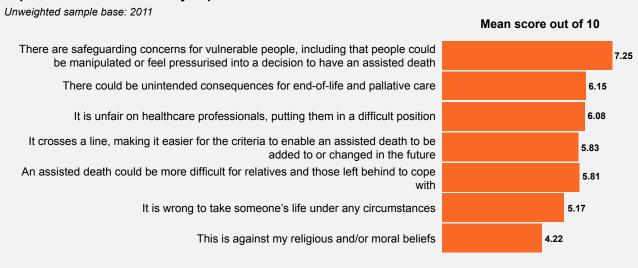
The findings from Survey 2 regarding the reasons for a change in the law align with the findings of the Citizens' Jury, which prioritised being able to end pain, having the option to end one's own life, and knowing that you can die with dignity (see <u>Table 1</u>).

4.3 Most important reasons against a change in the law

In Survey 2, when all survey respondents were presented with potential arguments against a change in the law (derived from the Citizens' Jury deliberations), the reasons ranked as most important were safeguarding concerns for vulnerable people, unintended consequences for end-of-life and palliative care, and impacts on healthcare professionals (Figure 7).

Figure 7: Survey 2 – selecting possible reasons for opposing a change in the law (all survey respondents)

Q4. Below is a list of reasons that could explain why the law in England **should not** be changed to permit assisted dying. For each reason, please say how important you think it is, where **1 in not important** at all and **10 is very important**.



The sentiment that, 'it is wrong to take someone's life under any circumstances' came through particularly strongly amongst those that oppose a law change (Figure 8).

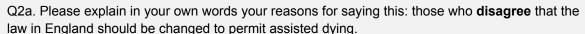
Figure 8: Survey 2 – selecting possible reasons for opposing a law change on assisted dying. Survey responses are shown with separate bars for respondents who support the law change (blue) and those who oppose it (orange).

Q4. Below is a list of reasons that could explain why the law in England should not be changed to permit assisted dying. For each reason, please say how important you think it is, where 1 in not important at all and 10 is very important.



In Survey 2, when those who opposed a change in the law were asked to explain in their own words the reasons that best explain their viewpoint, the most commonly cited were: religious beliefs (22%), the belief that assisted dying is wrong (21%), and the belief that life is sacred (20%).





Unweighted sample base: 277

Response given by 5% or more of respondents shown on the graph.

Note that comments may have been allocated to more than one theme.



When respondents to Survey 2 were asked, "Are there any other important reasons why you think the law in England should not be changed to permit assisted dying?", the following reasons were listed:

- Misdiagnosis or errors by healthcare professionals could lead to unintended deaths
- Conflicts with Hippocratic Oath.
- A change in the law could divert resources away from palliative care or research focused on curing terminal illnesses.
- Individual involved could regret decision.
- Fears that assisted dying could be politically prioritised to save money.
- Fears that assisted dying could become part of an unregulated/ profit-driven industry.
- Legalising assisted death sends a message that some lives (e.g. disabled, elderly) are less valuable.
- Could create a society where death is seen as more acceptable than care.



Box 8: Connections to the Citizens' Jury analysis – most important reasons against a change in the law

The findings from Survey 2 regarding the reasons for a change in the law align with the findings of the Citizens' Jury, which particularly highlighted concerns over the law being used for the wrong reasons if safeguarding is not in place; misinterpretations causing challenges for the legal system; and less funding for palliative care (see <u>Table 3</u>). In common with survey respondents, Jury members were also concerned about assisted dying becoming 'normalised', with unintended consequences, for example making it swing too much towards being universally seen as an alternative to care.

4.4 Public understanding and awareness of the issues

In Survey 1, a majority of respondents indicated a good understanding of assisted dying. When respondents were asked to describe their understanding before being provided with any information on the topic, most used language that aligned with the principles of assisted dying (e.g., ending life with lethal drugs). 82% also correctly identified specific definitions of assisted dying that had been included amongst other statements about end-of-life care.

Most respondents understood that palliative care is not the same as assisted dying. However, there was some confusion about the meaning of 'withdrawal of life support' with 39% erroneously believing it to be the same as assisted dying. Similarly, 28% of respondents thought that dying adult patients who exercise their existing and legal right to refuse life-prolonging treatment is the same as assisted dying.

Based on the survey findings, public awareness of assisted dying has increased during 2024. In February 2024 (Survey 1), 59% of the public had seen, read or heard about assisted dying via media sources or through inperson conversations. This rose to 82% in September 2024 (Survey 2), likely reflecting the increased media coverage, interest and parliamentary focus on the topic during the year. Increased exposure to messages about assisted

dying on social and broadcast media did not appear to have affected the balance of public opinion in England towards assisted dying, with levels of support and opposition remaining consistent between February 24 (Survey 1) and September 24 (Survey 2).

Box 9: Connections to the Citizens' Jury analysis – understanding and awareness of the issues

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Survey 1 and 2 findings on understanding of assisted dying offer valuable insights on challenges in communicating these concepts to the wider public, particularly in areas where confusion may arise (e.g., 'withdrawal of life support'). In contrast, Jury members were given detailed information on key terminology and had access to expert witnesses and Jury Friends to address their questions, which reduces the potential for such misunderstandings.

4.5 If the law is changed - eligibility criteria

In this section we explore what eligibility criteria survey respondents say would be important to include in a new law on assisted dying. The following topics are covered:

- Health status (e.g., terminal (physical) conditions, intolerable (physical) suffering, assisted dying for mental illness)
- Mental capacity
- Age requirement
- Residency status

Health status

In Surveys 1 and 2, there was greater support for assisted dying for terminal conditions than for non-terminal (physical) conditions. For example, in Survey 2, 70% of respondents supported assisted dying in a case where a medical condition is terminal with a 6-month prognosis. This support reduced to 56% in a case where a medical condition is not terminal but is likely to cause intolerable suffering.

Box 10: Connections to the Citizens' Jury analysis – eligibility: health status

3 3

As in the Surveys, members of the Citizens' Jury showed greater support for restricting assisted dying to terminal conditions than for expanding the criteria to include non-terminal (physical) conditions that cause intolerable suffering.

Terminal prognosis timeframe

In Survey 2, there was slightly more support for assisted dying being available when someone has a terminal illness with a prognosis of 6-months to live (70%), than for assisted dying being available when someone has a 12-month prognosis (64%).

Box 11: Connections to the Citizens' Jury analysis – eligibility: timeframe

The picture from the Citizens' Jury regarding the terminal prognosis timeframe was more mixed, with Jury members' views diverging on whether it should be 6-months, 12-months or a terminal condition with no specific timeframe.

Assisted dying for mental illness

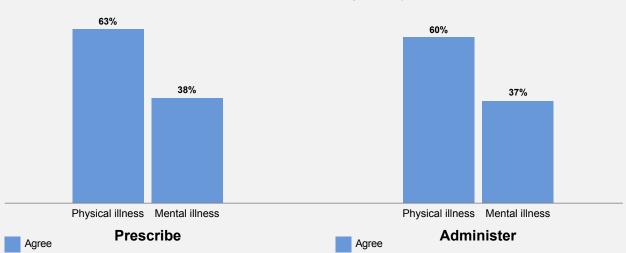
When considering mental illness, the prospect of a healthcare professional prescribing or administering lethal drugs for those with a mental as opposed to a physical illness was supported by only a minority of Survey 1 respondents (38% and 37%). This is shown in Figure 10.

Figure 10: Survey 1 – respondents who agree/ disagree with 'prescribing' or 'administering' drugs for those with a non-terminal mental illness.

A7. To what extent, if at all, do you agree or disagree that the law should be changed to permit healthcare professionals to prescibe drugs for eligible patients to take themselves to end their own life who are not terminally ill but are...? *Unweighted sample base:2031*

A8. To what extent, if at all, do you agree or disagree that the law should be changed to permit healthcare professionals to administer drugs with the intention of ending an eligible patient's life for those who are not terminally ill but are...?

Unweighted sample base:2031



Box 12: Connections to the Citizens' Jury analysis – eligibility: mental illness

Similarly, a few Jury members supported including mental illness as an eligibility criterion in the event assisted dying is legalised in England. Most Jury members who discussed mental illness did not think it should be included as an eligibility criterion.

Mental capacity

In Survey 2, 44% of respondents saw mental capacity as a prerequisite for an assisted death when asked to explain in their own words their reasons for supporting a change in the law to permit assisted dying.

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Jury members also argued that having the mental capacity to make your own decision about assisted would be one of the priority eligibility criterion. This for many Jury members is related to the importance they place on safeguarding and ensuring no one is coerced into making a decision on assisted dying.

Views on age requirement

While 57% of Survey 2 respondents supported assisted dying being possible for someone under the age of 18 with a terminal condition, this level of support is lower than that recorded for adults with a terminal condition (70%). For a child who is experiencing intolerable suffering without a terminal condition, support for assisted dying dropped further, to below half (47%).

Box 14: Connections to the Citizens' Jury analysis – eligibility: mental capacity

Jury members' views diverged on whether an assisted death should be available only to adults or whether under-18s should also be considered eligible.

Views on residency status

Around half (51%) of Survey 2 respondents were supportive of non-residents of England with a terminal illness being permitted to travel to England for an assisted death, if they pay for this care. However, this level of support was almost 20% lower than the support for allowing an assisted death for residents of England with a terminal condition (70%).

39% of Survey 2 respondents opposed non-residents of England being allowed to travel to England for an assisted death.

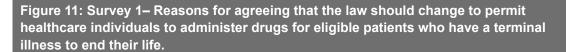
Box 15: Connections to the Citizens' Jury analysis – eligibility: mental capacity

The views of Jury members diverged on whether non-residents of England should be allowed to travel to England for an assisted death in the event the law is changed to permit assisted dying in England.

4.6 If the law is changed - mode of assisted dying

The majority of Survey 1 respondents supported the provision of both modes of assisted dying: physician-assisted dying (healthcare professionals prescribing lethal drugs to eligible patients to take themselves) and voluntary euthanasia (healthcare professionals administering lethal drugs to eligible patients, at their request, with the intention of ending that patient's life). However, there was marginally less support for administering lethal drugs (67%) than for prescribing them (71%).

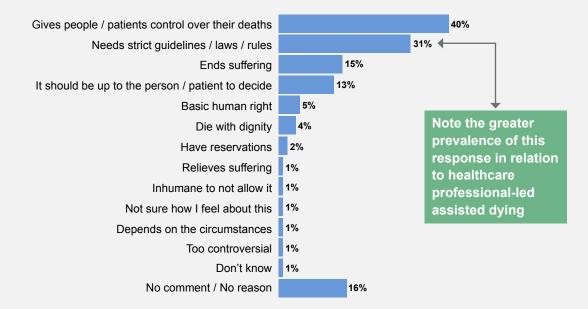
Needing strict guidelines is mentioned by more respondents in Survey 1 in relation to healthcare professionals administering lethal drugs, than it is for healthcare professionals prescribing assisted dying drugs (Figure 11).







Sample base: Those who agree with healthcare professional administered option for terminal illness: 1365



Box 16: Connections to the Citizens' Jury analysis – mode of assisted dying

Many Jury members also supported both modes being available if the law is changed. However, they tended to highlight the advantages they saw in healthcare professionals administering lethal drugs to patients when compared with patients taking lethal drugs prescribed by healthcare professionals. They focused on the efficacy and management of drugs used in assisted suicide.

4.7 The process of accessing an assisted death

Involvement of medical practitioners

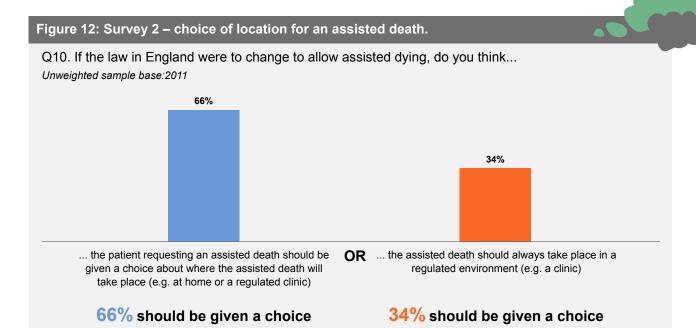
The majority of Survey 1 respondents (74%) supported healthcare professionals always being involved in the process if assisted dying is legalised in England.

Box 17: Connections to the Citizens' Jury analysis - accessing assisted dying

Jury members also felt that healthcare professional (e.g. doctor or nurse) should be involved in the process of assisted dying, if it is legalised in England.

Location of assisted death

66% of Survey 2 respondents supported those requesting an assisted death having a choice in the location where it takes place (Figure 12).



Box 18: Connections to the Citizens' Jury analysis – location

Jury members discussed what they perceived as the pros and cons of different settings during their deliberations, during which they also highlighted the importance of choice. They particularly wanted to ensure that the patient is in a safe environment where they feel comfortable.

4.8 Safeguarding, governance and regulation

Amongst all Survey 2 respondents, safeguarding concerns, unintended consequences for end-of-life and palliative care, and the impacts on healthcare professionals, were selected as the most important considerations when deciding whether the law on assisted dying in England should change. When those Survey 2 respondents who supported a change in the law were asked to explain, in their own words, the reasons that best explained their viewpoint, 14% proactively called for strict guidelines, laws, rules, safeguards, and regulations.

Box 19: Connections to the Citizens' Jury analysis – safeguarding, governance and regulation

Survey respondent and Jury members' views align here, with Jury members having called for a range of specific safeguarding measures, including the development of a safeguarding framework. They also called for effective, robust legislation, governance and monitoring of assisted dying services to ensure that high quality care is given to all those involved.

4.9 Considerations on the end of life

Public conversations about death and dying

Findings from Survey 2 confirmed a clear public appetite for wider discussions to take place and feed into the legislative process (Figure 13). In Survey 2, 37% of respondents thought that the usual procedure would be appropriate for making a decision about assisted dying in England (i.e., a new law is proposed by the government, debated, and voted on by MPs). However, 54% of respondents disagreed and felt that there should be wider public deliberation and discussion before a new law is passed.

Figure 13: Survey 2 – the importance of wider public discussions. Q12. When new laws are passed they are usually proposed by th government, debated, and then voted on by MPs in Parliament. Is this procedure appropriate for assisted dying? Unweighted sample bases in parentheses 70% 54% 50% 44% 37% 21% 9% 8% 1% No - there should be wider public Yes Other Don't know deliberation / discussions first 1% Other: Total (2011) • Public vote / referendum · Should involve the NHS, medical staff, charities Support law change on assisted dying (1415) • Public enquiry / review led by a judge before it goes to politicians Oppose law change on assisted dying (277)

Box 20: Connections to the Citizens' Jury analysis – public conversations

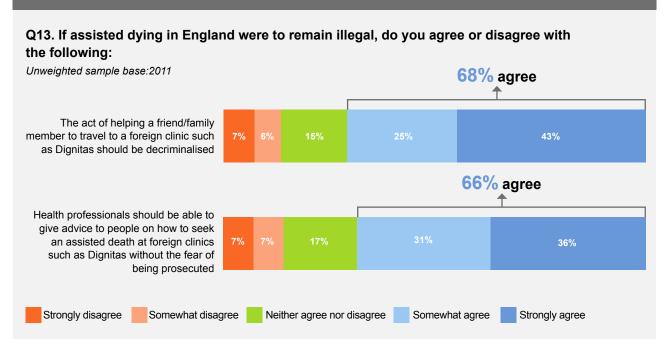
Whether or not the law is changed, Jury members recommend more open public discourse about death and dying in general, and there was also a clear appetite for continued national conversations around assisted dying to feed into decision making. They shared their view that whether the law in England is changed or not, there should be more opportunities for public deliberation. If the law is changed, they see a role for the public voice to refine the detail of the legislation and how it is implemented.

Travelling to other countries

If assisted dying were to remain illegal in England, 68% of Survey 2 respondents supported the decriminalisation of friends and family members who support someone to attend a clinic in another country such as Dignitas in Switzerland. A similar number also supported the idea that health

professionals should be able to advise on how to seek an assisted death at a foreign clinic without fear of being prosecuted (Figure 14).

Figure 14: Survey 2 – Supporting a family member to access a foreign clinic/ health professional providing advice on clinics overseas.



Box 21: Connections to the Citizens' Jury analysis – travelling to other countries

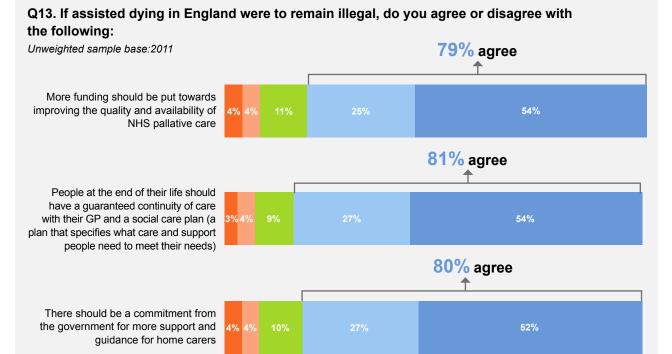
These Survey 2 findings align closely with Citizens' Jury findings. Many Jury members supported decriminalising helping a friend/family member to travel access assisted dying services abroad and allowing health professionals to give advice to people seeking an assisted death in those countries where it is legal. Many also expressed empathy for those involved in such decisions and felt those considering travelling abroad to access assisted dying, along with their friends or families, should have access to support.

Improving health, social and palliative care

In Survey 2, as shown in Figure 15, the majority of respondents wanted to see increased funding to improve the quality and availability of NHS palliative care (79%), guaranteed continuity of care with their GP and social care plan at the end of life (81%) and a government commitment to support home carers (80%).



Figure 15: Survey 2 – Improved NHS palliative care and end of life care



Box 22: Connections to the Citizens' Jury analysis – improving health, social and palliative care

Somewhat disagree

Strongly disagree

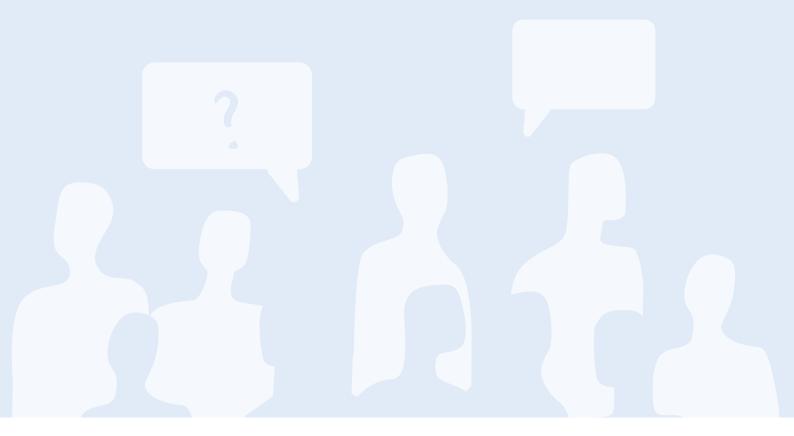
These Survey 2 findings mirror concerns expressed by many Jury members about the need for more funding for NHS palliative care and having guaranteed continuity of care with GP and a Social Care Plan at the end of life, alongside support for home carers. It also links to the concern expressed by some Jury members that establishing assisted dying services will take resources away from social and palliative care.

Neither agree nor disagree

Strongly agree

Somewhat agree

5. Key themes and conclusions



This report provides insights into how the public in England feel about the possibility of the legalisation of assisted dying. The findings provide a new and greater depth of insight having been drawn from the first Citizens' Jury in England on assisted dying, as well as two nationally representative surveys.

The report provides this evidence at a critical time for policymakers as they weigh up the significant issue of whether or not the law on assisted dying should change and, if it does change, what parameters and safeguards should be in place. In light of this, the primary recommendation for policymakers is to ensure that public priorities and concerns shape decisions around future assisted dying legislation and its implementation.

The evidence presented within this report will be useful for policy and decision making on the detail of assisted dying legislation. It will support those contributing to the current national conversation on assisted dying to root their discussions in not only what people in England think about the legislation, but why they think it.

Understanding the key themes and conclusions set out in this report and summarised below has the potential to contribute to trusted policy making on this key societal issue.

Should the law in England be changed to permit assisted dying?



Yes, the majority of survey respondents and most Citizens' Jury members responded that the law in England should be changed to permit assisted dying.

Safeguarding and tight governance were highlighted. Jury members proposed the involvement of a range of experts in the development of a safeguarding framework before any legislation is introduced. To give societal confidence and to protect vulnerable people.

What are the most important reasons for a change in the law?



When thinking about in-principle reasons for a change in the law participants in both elements of the project draw similar conclusions:

- The prevention of pain.
- Ending suffering for those at the end of life with a terminal condition.
- Offering the reassurance of choice.

What are the most important reasons against a change in the law?



Similarly, when thinking about in-principle reasons against a change in the law, participants shared the view that:

- Safeguarding the vulnerable in society is paramount but could be very hard to achieve, or even prove impossible, if the law is changed.
- That approving a change in the law could lead to assisted dying being seen as an normal alternative to end-of-life care which they felt was unacceptable.

Some expressed the view that it is always wrong to take a life.

If the law is changed - what eligibility criteria should apply?



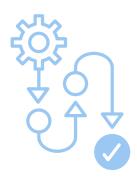
Both survey respondents and Jury members showed support for:

- Restricting assisted dying to those with terminal conditions with survey respondents supporting a 6 month prognosis, and the Jury reaching no clear agreement on time frames.
- Mental illness to be excluded as an eligibility criterion.
- People having the mental capacity to request an assisted death a capacity which is tested during the approval process.

There was less agreement on whether the following should be allowed to request an assisted death:

- Under 18s
- People who are not residents of England.

If the law is changed what modes and process of assisted dying should be permissable?



Many Jury members agree that:

- Both physician-assisted dying (prescribing) and voluntary euthanasia (administering) should be permitted.
- Healthcare professionals should be involved in the process of assisted dying.
- People should have a choice on where the assisted death can take place.
- Listening services, information and other support should be available to those seeking and eligible for an assisted death and to their family members where appropriate.
- There is a need for a formal process for requesting an assisted death.
- Repeated psychological assessments are essential to ensure that the patient's view is settled, and to test for coercion
- A cooling off period would allow the person requesting an assisted death to reflect on their decision.

A range of views on advanced directives were expressed, with some seeing a value in being able to state a preference before a condition is terminal and others fearing that the request could be misinterpreted or be too inflexible preventing people from changing their minds nearer the time.

What are the most important reasons for a change in the law?



Jury members and Survey respondents called for:

- Substantial improvements to health, social and palliative care through funding and more equitable distribution of services.
- An ongoing public conversation about death, dying and assisted dying. This is to raise awareness, inform policy and its implementation, and to ensure that palliative care remains high on the policy agenda.
- The act of taking a friend or family member to travel to an assisted dying clinic in another country to be decriminalised, ending uncertainty.

Deliberation, over time, through a Citizens' Jury process, is a powerful tool which supports understanding of what matters to people across society when given accurate evidence on the issues and the time to reflect on it.

This report is intended to provide a helpful set of recommendations to inform future assisted dying legislation and its implementation should it be written into law. The project provides robust, granular, insights into public opinions on assisted dying in England.

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, thoughtfulness and kindness. Their commitment to their 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 that 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. We also thank those we <u>interviewed</u> in the planning phase of the project for giving their time to speak to us.

We would also like to thank 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.

We are very grateful to all our expert witnesses and speakers, panel discussion members, and those who provided filmed lived experience interviews. They generously gave their time to ensure that Jury members heard evidence and a 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.

Appendix 1: Advisory Board and Content Group members

Advisory Board

Chair: Anne Kerr

Professor of Science & Technology Studies and Head of School of Social & Political Sciences, University of Glasgow; Member of the Nuffield Council on Bioethics

Clare Chambers

Professor of Political Philosophy, University of Cambridge; Member of the Nuffield Council on Bioethics

Sarah Cunningham-Burley

Chair of the Nuffield Council on Bioethics and Professor of Medical & Family Sociology / Dean of Molecular, Genetic & Population Health Sciences, The University of Edinburgh

Suzanne Hall

Director of Engagement, The Policy Institute, King's College London

Rachel Lopata MBE

Freelance researcher

Malcolm Oswald

Director, Citizen' Juries c.i.c.; Honorary Research Fellow in Law, University of Manchester

Michael Reiss

Professor of Science Education, Institute of Education, University College London; Member of the Nuffield Council on Bioethics

Holly Rogers

Head of Engagement, Academy of Medical Sciences

Selena Stellman

General Practitioner; former Member of the Nuffield Council on Bioethics

Content Group

Richard Huxtable

Professor of Medical Ethics and Law, University of Bristol

Emily Jackson OBE

Professor of Law, London School of Economics and Political Science

Trudo Lemmens

Professor and Scholl Chair in Health Law and Policy at the Faculty of Law and the Dalla Lana School of Public Health, University of Toronto

Claud Regnard FRCP

Retired Consultant in Palliative Care Medicine

Appendix 2: Stakeholder interviewees

Andrew Copson

Chief Executive, Humanists UK

The Baroness Grey-Thompson

Cross bench peer and Director, Living and Dying Well

Ben Colburn

Professor, University of Glasgow School of Humanities

David Albert Jones

Professor in Bioethics at St. Mary's University, Director of the Anscombe Bioethics Centre

Jasvir Singh CBE

Barrister, Vice Chair of Faiths Forum for London, Co-Chair of City Sikhs

Kamran Mallick

CEO, Disability Rights UK

Lloyd Riley

Director of Policy and Research, Dignity in Dying

Mark Pickering

Chief Executive, Christian Medical Fellowship

Nancy Berlinger

Senior Research Scholar, The Hastings Centre

Robert Butcher

Ethics consultant, Canada

Sam Royston

Executive Director for Policy and Research, Marie Curie

Veronica English

Head of Medical Ethics, British Medical Association

Appendix 3: Expert witnesses and speakers

Adam McCann

Associate Professor of Criminal Law and Criminal Justice, University of Reading

Alan Renwick

Professor of Democratic Politics and Deputy Director of the Constitution Unit, University College London

Alexandra Mullock (Jury Friend)

Senior Lecturer in Medical Law, University of Manchester

Andrew Green

Chair of BMA medical ethics committee and MEC lead on physician assisted dying

Annabel Price

Consultant Liaison Psychiatrist, Addenbrooke's Hospital; Visiting Researcher, Department of Psychiatry, University of Cambridge; Associate Specialist Director for Palliative Care, Cambridge Institute of Public Health.

Carol Davis

Board member, Living and Dying Well; Consultant in Palliative Medicine, University Hospital Southampton and Visiting Consultant in Palliative Medicine Jersey Hospice Care

David Albert Jones

Professor of Bioethics at St Mary's University, Director of the Anscombe Bioethics Centre Oxford

Gordon Macdonald

CEO, Care Not Killing

Isra Black

Associate Professor, UCL Faculty of Laws

Jamilla Hussain

Consultant in Palliative Medicine at Bradford NHS Trust, Honorary Senior Research Fellow, Hull York Medical School

Lloyd Riley

Director of Policy and Research, Dignity in Dying

Lydia Dugdale

Professor of Medicine and Director of the Centre for Clinical Medical Ethics, Columbia University

Mary Shariff

Professor Faculty of Law, Director of Master of Human Rights Program, University of Manitoba

Miro Griffiths

Lecturer in Social Policy and Disability Studies, University of Leeds

Nancy Berlinger

Senior Research Scholar, The Hastings Centre

Nathan Stilwell

Assisted Dying Campaigner, Humanists UK

Sarah Chan

Chancellor's Fellow and Reader in Bioethics at the Usher Institute, University of Edinburgh

Shaykh Yunus Dudhwala

Head of Chaplaincy, Barts Health NHS Trust

Suzanne Ost (Jury Friend)

Professor of Law, Lancaster University

Thomas McMorrow

Associate Professor and Undergraduate Program Director of Legal Studies, Ontario Tech University

Tom Shakespeare

Professor of Disability Research, London School of Hygiene and Tropical Medicine

Links to the expert witness and speaker presentations is available in the Citizens' Jury Evidence and Information Pack.³⁴

³⁴ Nuffield Council on Bioethics/ Hopkins Van Mil (September 2024) *Information and evidence pack*, available at: https://cdn.nuffieldbioethics.org/wp-content/uploads/Infomation-and-Evidence-pack-FINAL.pdf

Appendix 4: Expert witness brief example

This briefing contains:

- 1. Contact information
- 2. About this Citizens' Jury
 - a. Definitions of assisted dying
 - b. Jury questions
 - c. Jury process and dates
 - d. Supporting the Citizens' Jury to deliberate
- 3. Expert witness speaker brief
 - a. Accessibility
 - b. Your slides: using the Jury template and sharing them in advance
 - c. Your Q&A with Jury members
 - d. Informants and advocates
 - e. Impartiality and balance
 - f. Transparency
- 4. Briefing for specific Jury sessions

Contact information

Thank you for agreeing to be an expert witness for the Citizens' Jury exploring public views on assisted dying. Please read the information contained in this briefing carefully as it provides essential information on providing evidence to the Jury.

If you have any questions about the content of your presentation and how to present please contact:

Henrietta Hopkins, Director of Hopkins Van Mil and lead facilitator for the Jury **henrietta@hopkinsvanmil.co.uk** cc'ing in her colleagues Hally Ingram, Senior Associate, and Kate Furber, Researcher.

Please also send your draft slides to this team (see slide sharing).

For questions about the logistics for speaking to the Jury including Zoom links and outlook invitations please contact: Louis Mylne, Research Assistant, Hopkins Van Mil

About the Citizens' Jury

The Citizens' Jury 'Exploring public views on assisted dying' has been commissioned by the Nuffield Council on Bioethics (NCOB) working with the deliberative social research agency Hopkins Van Mil (HVM). The NCOB is an independent body that examines and advises on ethical issues. The NCOB does not have a position on assisted dying and will not be taking one as part of this project.

2a. Definitions of assisted dying

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'.

It was made clear to survey respondents and Citizens' Jury members that assisted dying is not currently legal in England.

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, is not intended to endorse or reflect any particular stance on the law on assisted dying.

The law: Assisted dying is not legal in England.

2b. Citizens' Jury overarching questions

The overarching questions the Jury will consider are:

- 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?

The Jury will deliberate on these questions during six Jury sessions, four of these are held online using Zoom and two are in-person sessions. The Jury dates are set out in the following section.

2c Citizens' Jury process and dates

The Citizens' Jury 'Exploring public views on assisted dying' will meet between April and June 2024. 30 people have been recruited to the Jury to broadly represent the demographic mix of the population of England (and specifically age, gender, ethnic group, disability, educational attainment and geographical location). The group will also be sampled to broadly match views on assisted dying based on the results of a nationally representative survey conducted as part of this project. The Jury will meet online using Zoom on five occasions and in-person for two sessions in London. They will hear evidence from a variety of expert witnesses, deliberate together and answer a set of overarching Jury questions on assisted dying (set out in section 2.b).

Our overall programme

17th April 15th May Webinar: Jury session 3: · An introduction to our 14th June · A range of perspectives purpose and topic · Campaigning and organisations Jury session 5: Religions 24th April · Reviewing all we have heard Jury session 1: 22nd May 15th June • The UK context Jury session 4: Jury session 6: · A range of perspectives · Final deliberations 8th May · Lived experience · Creating and sharing · Disabled people recommendations Jury session 2: · Palliative care · International context Clinicians · Case studies Online In person

The Jury dates and broadly the content that will be covered in each session are as follows:

- Webinar: 6-8pm Wednesday 17th April 6-8pm Jury purpose and topic
- Jury session 1: 6-9pm Wednesday 24th April The UK context
- Jury session 2: 6-9pm Wednesday 8th May Global jurisdictions
- Jury session 3: 6-9pm Wednesday 15th May A range of perspectives
- Jury session 4: 6-9pm Wednesday 22nd May A range of perspectives
- Jury session 5: 6-9pm Friday 14th June Reviewing and reflecting on the evidence
- Jury session 6: 10am-4pm Saturday 15th June Jury concluding deliberations and recommendations.

2d. Supporting the Citizens' Jury to deliberate Independent counselling and signposting

The topic of assisted dying is complex and sensitive. HVM's independent counsellor, Sandeep Ganatra, will provide a listening service to the Jury. He will be present at all Jury sessions and Jurors can also book a separate appointment with him if they wish to discuss any of the issues discussing the topic raises for them outside of the Jury sessions.

In addition, the Jury handbook will signpost organisations to contact if Jurors are affected by the issues being discussed.

Technical support

A tech support session will be run in the week before the Jury begins. This is to provide information and guidance to Jurors who are unsure how to use Zoom, or would like a refresher on it. Jurors who do not have suitable equipment to join the Jury are offered the loan of equipment such as tablets, webcams, headsets, and Wi-Fi boosters/ hot spots.

Each Jury session is also attended by an HVM tech support team member who supports Jurors if their technology is not working properly during a session. A dedicated HVM event support person attends each of the in-person sessions to support Jurors with the practicalities of their participation.

Facilitation

The Citizens' Jury is being facilitated by the expert team at Hopkins Van Mil. The sessions will be Lead Facilitated by the HVM Director, Henrietta Hopkins. The skilled facilitation team will include HVM Senior Associates Hally Ingram, Suzannah Kinsella and Pauline Harris. Jurors will be supported by this team to work together and deliberate amongst themselves before reaching their recommendations and conclusions.

In addition to the Jury members and the session facilitators, others who are likely to be present during the Jury are Jury Friends who will be present at all Jury sessions and available to answer questions and observers, present to ensure the independence of the process.

Expert witness speaker brief

You are asked to provide evidence as an expert witness to the Citizens' Jury 'Exploring public views on assisted dying'.

We would like you to speak for **no more than 10 minutes** at Jury session 4 on Wednesday 22nd May. The session is online using Zoom. Further details on speaker times and content are in the briefing for specific jury sessions at the end of this document. Alongside this briefing document, we will also arrange a speaker briefing call held on Zoom with you so that we can discuss the contents of this brief. This will be arranged with you in the coming week.

3a. Accessibility

As the Jury will have people with different levels of educational attainment, including people with no educational qualifications and people with university degrees, and include people who may have not heard about the topic before please:

- Explain things as simply as possible;
- Avoid using acronyms and do not use jargon;
- If you cannot avoid using complex terminology please explain it to the Jurors clearly;
- Do not assume that the audience has any prior knowledge of the subject you are presenting on;
- Do use PowerPoint (or similar) slides as this gives Jurors a simple way of focusing on your key points.

Two of the Jury members have hearing loss. Please speak clearly and slowly into your computer microphone on Zoom and ensure your mouth is visible on screen.

3b. Your slides: using the Jury template and sharing them in advance Please use the template we have shared with you for your slides. We are providing a template for transparency, clarity, and consistency. In the slide template we are asking you to please:

- Create a presentation slide pack that addresses the specific brief and questions set out for your presentation here in this brief.
- Introduce yourself to Jurors.
- You have been asked to share conflicts of interest. If you have something
 that may be perceived as a conflict of interest, you will be asked to discuss
 this with Henrietta Hopkins, and, assuming this is not a barrier to you being
 a witness, add it as a bullet point to your introductory slide for the Jury
 members so it is declared openly.
- Start your slides with a list of the key points that you are going to cover.
- Structure your presentation so that it covers the detail required on each of these points in order.
- Please do not try to cover too much information in each slide, 1 minute per slide and a maximum of 10 slides is a useful rough guide.
- Do use bullet points and visuals, but remember that participants will be reviewing the slides after the session, so images with no contextual text are unhelpful.
- Where appropriate, relate what you say explicitly to the relevant <u>Jury</u> guestions
- Illustrate your points with examples where you can.
- Take into account the information being presented by other witnesses (where identified in this briefing document).
- Avoid making factual statements where the evidence is uncertain or disputed.
- Stick to the information in your slides when presenting without introducing new information.
- End your presentation with the same slide you began with to recap your key points.
- Be aware that your presentations will be recorded, and that your slides and a video of the presentation will be made available:
 - to Jurors to review again immediately after the session.
 - and made publicly available on the web when we publish the Jury report.

All speaker slides **must be reviewed** at least a week before the presentation is made. To enable this, please upload your draft slides to this folder Speaker slides for review by 5pm on **Wednesday 15th May**. We cannot allow speakers whose slides we have not reviewed to present, so please do ensure the slides are uploaded promptly. The slides will be reviewed so we can take the opportunity to bring to your attention any material which does not appear to be relevant to your brief, is not easy to understand, or which might be considered biased. We will confirm in advance of your presentation if we think any of the slides need adjustment and agree with you the final presentation.

The schedule for review, feedback and confirmation of final slides is as follows. For presentations to be made on:

Wednesday 17th April

- Friday 12th April slides uploaded to the SharePoint
- COP Monday 15th April feedback given
- Midday Tuesday 16th April final slides confirmed

Wednesday 24th April

- Wednesday 17th April slides uploaded to the SharePoint
- COP Friday 19th April feedback given
- COP Monday 23rd April final slides confirmed

Wednesday 8h May

- Wednesday 1st May slides uploaded to the SharePoint
- COP Friday 3rd May feedback given
- COP Monday 6th May final slides confirmed

Wednesday 15th May

- Wednesday 8th May slides uploaded to the SharePoint
- COP Friday 10th May feedback given
- COP Monday 13th May final slides confirmed

Wednesday 22nd May

- Wednesday 15th May slides uploaded to the SharePoint
- COP Friday 17th May feedback given
- COP Monday 20th May final slides confirmed

When speaking please stick to time, we will have to stop any speakers that go beyond the allotted time so as to give our Jurors enough time to ask questions and to deliberate on what they have heard in each session.

3c. Your Q&A with Jury members

After listening to the presentations from you and other speakers Jury members will discuss what they have heard in their small groups. This will be followed by a Q&A session and a Juror from each of the small groups will ask you and the other speakers the most important questions identified by their group. The Lead Facilitator, Henrietta Hopkins, will facilitate this Q&A session to ensure that all speakers get an equal opportunity to respond to the questions and to keep the session to time.

It is important to note that some jurors may lack confidence, so please respond positively to any question you receive. When answering questions, try to make your answers clear and concise, and if you do not know the answer to a question, please say so. As previously mentioned, two of the Jurors have hearing loss, please speak clearly and slowly into your computer microphone on Zoom and ensure your mouth is visible on screen. If you think you may encounter any technical difficulties with your online presentation (e.g. poor broadband, background noise), please raise this with Henrietta Hopkins.

3d. Informants and advocates

The Jury will hear a variety of evidence in order to reach informed recommendations and conclusions about the questions they are considering. There are two types of speakers as set out in Table 1.

3e. Transparency

We anticipate there being significant interest in this Citizens' Jury. It is important therefore that it is fully transparent. For these reasons we will:

- Upload the speaker presentations to the Nuffield Council on Bioethics and Hopkins Van Mil websites; and
- Make speakers' presentation slides available in pdf form when we publish the Jury report.
- We may also publish the outline agendas for each Jury session and an example of this speaker briefing.

If you have any concerns or questions about these plans please raise them with Henrietta Hopkins.

TABLE 1		
Role	During your presentation	During your Q&A
Informant	Please explain the range of views, options and opinions that exist on the topic(s) we have asked you to cover in your presentation. We aim to provide a range of information and views on the topic to the Jury. We will do this partly by selecting speakers with diverse perspectives, but also ask you to explain the reasonable range of views/ options that exist. It is important that you confine your presentations to descriptive information rather than any valueladen claims. You should try to describe the world rather than judge it.	Some questions may have straightforwardly factual answers. Please answer these questions with a clear fact. Where this is not the case, please explain, as far as you can, the range of opinions that exist. Where the evidence is uncertain, provide an answer to the best of your knowledge, mentioning the uncertainty. But if you do not know, say so.
Advocates	Please present your personal opinion, or, where relevant, the opinion of the organisation you are there to represent. In presenting your opinion please do not share points that are factually inaccurate. You are invited to make a case for a particular position without misrepresenting the facts or otherwise misleading their audience. Hearing these arguments can be useful to jurors, although the process is also designed so that jury participants use their own values and knowledge to weigh the evidence they are given.	Some questions may have straightforwardly factual answers. Please answer these questions with a clear fact. Where this is not the case your answers can reflect your personal opinion, or, where relevant, the opinion of the organisation you are there to represent. Again, in presenting your opinion please do not give answers that are factually inaccurate.

Appendix 5: Key themes from the analysis

Key themes

Key finding

Survey responses³⁵

Citizens' Jury responses³⁶

Key theme: Should the law in England be changed to permit assisted dying?

The majority of survey respondents and most Citizens' Jury members responded that the law in England should be changed to permit assisted dying.

A minority of survey respondents and some Citizens' Jury members disagree with this position.

Survey 1:

69% agree that assisted dying should be legal.

15% disagree that assisted dying should be legal.

Survey 2:

70% agree that assisted dying should be legal.

14% agree that assisted dying should be legal.

In the final vote

20 Jury members strongly or tend to agree that assisted dying should be legal; 7 tend to or strongly disagree that assisted dying should be legal.

1 Jury member was undecided at the end of this process.

Key theme: Most important reasons for a change in the law

Participants in both elements of the project draw similar conclusions on the main reasons for a change in the law with the prevention of pain and ending suffering for those at the end of their life as main reasons. Reassurances on having the choice of an assisted death is important to survey respondents and Citizens' Jury members.

When those who supported a change in the law in Survey 2 were asked to give the reasons for their view the most commonly given explanations were that someone terminally ill/ or without quality of life should be allowed to end their life (49%), that people should not have to suffer (47%), and that people should have the right to choose.

Citizens' Jury members prioritised stopping pain, having the option to end your own life, and the knowledge that you can die with dignity if the time comes as the main in-principle reasons for a change in the law.

Jury members highlighted the need for a change in the law to be considered through the lens of public benefit.

³⁵ Survey 1 unweighted sample base 2,031 respondents. Sample 2 unweighted sample base 2,011 respondents.

^{36 30} Citizens' Jury members attended Jury Sessions 1-5 inclusive. The final in-person Session (Session 6) was not attended by 2 Jury members due to illness.

Key theme: Most important reasons against a change in the law

Respondents and participants in both methods have common the main reasons against a change in the law focused on safeguarding concerns for vulnerable people.

Some Survey 2 respondents and Jury members also expressed the view that it is always wrong to take a life.

Both groups share a view that approving a change in the law could lead to assisted dying being seen as an acceptable alternative to end-of-life care which they felt was not acceptable.

In Survey 2, all respondents were presented with potential arguments against a change in the law. The reasons that were most important were seen as safeguarding concerns for vulnerable people.

In Survey 2 when those opposed to a change in the law were asked to explain their viewpoint they said religious beliefs (22%), the belief that assisted dying is wrong (21%) and the belief that life is sacred (20%) were the key parts of their opinion.

Jury members raised the following reasons against a change in the law:

- Assisted dying being used for the wrong reasons e.g. pressurising vulnerable people
- The law being misinterpreted
- Reducing the funding available for palliative care.

Some Jury members reflected indepth on the spiritual dimensions of the topic, particularly suffering. A few said their religious beliefs meant they could not agree with a change in the law.

Key theme: If the law is changed - what eligibility criteria should apply

Health status

Both survey respondents and Jury members showed greater support for restricting assisted dying to those with terminal conditions.

Survey respondents showed clearer support for a fixed timeline for eligibility (6 months).

Survey respondents and Jury members both expressed a preference for mental illness to be excluded as an eligibility criterion. In Surveys 1 and 2, there was greater support for assisted dying for terminal conditions than for non-terminal (physical) conditions. In Survey 2, 70% of respondents supported assisted dying in a case where a medical condition is terminal with a six-month prognosis. Support reduced to 56% in a case where a medical condition is not terminal but is likely to cause intolerable suffering.

Survey 1 respondents showed less support for healthcare professionals prescribing or administering lethal drugs for those with a mental illness.

Most Jury members thought only people with a terminal condition should be eligible for assisted dying. There was less support for non-terminal conditions which cause intolerable suffering being eligible.

Jury members' opinions diverged on a specified timeframe for eligibility. 6 months, 12 months and no-frame were all discussed.

Most Jury members excluded mental illness as an eligibility criterion as help to live well was still possible for many, and the person suffering may not have the capacity to decide for themselves.

Mental capacity

We see agreement between the Survey responses and Jury findings on mental capacity, although Jury members place more emphasis than Survey respondents.

In Survey 2, 44% of respondents saw mental capacity as a prerequisite for an assisted death.

Jury members said that having the mental capacity to choose an assisted death should be a priority criterion.

Age

There is little agreement on whether those under 18 should be allowed to request an assisted death if the law in England is changed.

In Survey 2, while 57% support assisted dying being possible for someone under the age of 18 with a terminal condition, this level of support is less than recorded for adults with a terminal condition (70%). For a child who is experiencing intolerable suffering, but does not have a terminal condition, support for assisted dying drops further to below half (47%).

Citizens' Jury members did not come to an agreed position on assisted dying for those under 18. Some Jury members thought under-18s should be eligible for an assisted death if they have a terminal illness and parental support for the decision. This would be to prevent suffering at the end of life. Other Jury members expressed concern about the capacity and maturity of those under 18 making such an important decision.

Residency

There is no clear agreement in either the Survey or Jury responses on whether non-residents should be eligible for assisted dying in England.

In Survey 2, 51% of respondents were supportive of non-residents of England with a terminal illness being permitted to travel to England for an assisted death – if they pay for this service. 39% of respondents were opposed to non-residents being eligible for an assisted death, while 10% said they didn't know if people not resident in England should be able to travel there for an assisted death.

The views of Jury members diverged on whether non-residents should be allowed to travel to England for an assisted death. Some thought that this should be possible if they paid for the service, others were against it under any circumstances.

Key theme: If the law is changed - mode of assisted dying

Most Survey respondents and Jury members agree that if the law is changed both physicianassisted suicide (prescribing) and euthanasia (administering) should be permitted.

The majority of Survey 1 respondents supported both modes of assisted dying being available, although there was marginally less support for administering lethal drugs (67%) than for prescribing them (71%).

Although many Jury members supported both modes of assisted dying being available (because of their strong belief in choice), they tended to highlight the advantages they saw in healthcare professionals administering the lethal drugs, focusing on the efficacy and management of these drugs (which they want to see tightly monitored and regulated).

Key theme: The process of an assisted death

Involvement of healthcare professionals

Both Survey respondents and Jury members expressed the view that healthcare professionals should be involved in the process of assisted dying in England if legalised. The majority (71%) of Survey 1 respondents said healthcare professionals should always be involved in the process of an assisted death. Many Jury members felt that healthcare professionals (specifically a doctor or a nurse) should be involved in the process of assisted dying. For some it was important that the patient had an existing relationship with this healthcare professional.

Location of assisted dying services

Location of assisted dying services

66% of Survey 2 respondents supported those requesting an assisted death having a choice on the location where it takes place.

Jury members discussed the pros and cons of various settings for an assisted death during their deliberations. They highlighted the importance of choice, particularly wanting to ensure that the patient is safe and where they feel comfortable.

Other elements in relation to the process of an assisted death

In addition, Jury members also highlighted the importance of other elements within the process of an assisted death including:

- That listening services, information and other support should be available to those seeking and eligible for an assisted death and to their family members where appropriate
- The need for a formal process for requesting an assisted death
- The importance of repeated psychological assessments to ensure that the patient's view is settled, and to test for coercion
- A range of views on advanced directives with a few Jury members seeing a value in allowing people to state their wishes
 in advance of a diagnosis for a terminal condition and others fearing that advanced directives could be misinterpreted
 and potentially used in circumstances where the person did not actually wish to die by means of assisted dying
- Many Jury members were in favour of a cooling off period, allowing the person requesting an assisted death to reflect on their decision.

These issues were raised only by Jury members and were not covered in either of the two Surveys.

Key theme: Safeguarding, governance and regulation

For Survey respondents and Jury members safeguarding concerns were highlighted and views on the importance of tight governance and regulation were in alignment.

Jury members spent considerable time discussing what they saw as the significant issue of safeguarding people in more vulnerable situations throughout the Jury process.

Among all Survey 2 respondents safeguarding concerns, unintended consequences for end-of-life and palliative care and the impacts on healthcare professionals were highlighted as important considerations. When those Survey 2 respondents who supported a change in the law were asked to explain, in their own words, the reasons for their viewpoint, 14% proactively called for strict guidelines, laws, rules, safeguards and regulations.

All Jury members were concerned to discuss the embedding of safeguards in the process of assisted dying.

Some Jury members called for the development of a safeguarding framework by medical and legal specialists to protect vulnerable people.

The Jury also proposed a range of specific safeguarding measures, including on eligibility assessment. A few Jury members discussed including the scrutiny of any decision on assisted dying by a judge.

Jury members considered that if the law is changed having an independent regulatory and/ or governing body would be essential.

The mandatory reporting of assisted deaths and robust record keeping on the operation of the system was seen as a key factor for many Jury members in running the process in a robust way

Key theme: Considerations on the end of life

National conversations on death, dying and assisted dying

Whether or not the law is changed, survey respondents and Jury members highlighted the need for there to be ongoing public conversations about death, dying and assisted dying.

In Survey 2 54% of respondents said that there should be wider public deliberation and discussion on assisted dying.

Jury members recommend more open public discourse about death and dying in general. They demonstrated a clear appetite for continued national conversations around assisted dying to feed into decision-making, including further public deliberation on the detail of any new legislation and its implementation.

Travelling to other countries to access assisted dying

In both components of the project, support was shown for the act of taking a friend or family member to travel to an assisted dying clinic in another country to be decriminalised.

Both also endorsed the view that medical professional advice should be available to those who wish to travel abroad.

68% of Survey 2 respondents supported the decriminalisation of friends and family members who support someone to attend a clinic in another country.

66% of Survey 2 respondents agreed that health professionals should be able to give advice to people on how to seek an assisted death at a clinic in another country.

Many Jury members supported decriminalisation of friends and family members in this context.

They also wanted health professionals to be able to give advice to people seeking an assisted death at an assisted dying clinic in another country. They expressed empathy for those involved and wanted support for those in this situation. They want the law to be clear on whether prosecutions will be made.

Improving health, social and palliative care

Survey respondents and Jury members called for substantial improvements to health, social and palliative care, irrespective of whether assisted dying is legalised in England.

This should include improvements to quality, provision and funding.

In Survey 2, the majority of respondents wanted to see increased funding to improve the quality and availability of NHS palliative care (97%), guaranteed continuity of care with their GP an social care plan at the end of life (81%) and a government commitment to support home carers (80%).

Jury members, whether in favour of a change in the law or not, called for support networks across multiple settings to provide consistent care, guidance and emotional assistance to everyone nearing the end of their life or caring for someone with a terminal diagnosis.

They specifically called for improvements in palliative care: more evenly distributed funding from government to ensure that NHS palliative care provision is equitable and of a high standard.

Jury members were concerned that establishing an assisted dying service in England could take funds away from social and palliative care.

Appendix 6: Reflections on being part of the Citizens' Jury

The independent evaluation of the Citizens' Jury has shown that Jury members found the experience to be interesting, enjoyable and positive. At the end of the final Jury session, members were asked: 'Overall, what was it like participating in the Citizens' Jury?' The 'word cloud' below shows all of the responses provided. Larger text represents multiple answers

Responses from Citizens' Jury members to the evaluation question on what it was like to participate in the process.



Jury members shared how important it felt to them to be part of a Citizens' Jury and take eight weeks to reflect on this complex topic meaningfully. They said that receiving a range of evidence and information was an essential part of the process. They appreciated that this included expert witnesses and speakers 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 thinking 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 project³⁷, 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

A full independent evaluation report will be published on the Nuffield Council of Bioethics' website in spring 2025.

³⁷ YouTube (11 November 2024) NCOB Citizens Jury on Assisted Dying 2024, available at: https://www.youtube.com/watch?v=cpXvJNy5KFw.



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