

# SHOULD ASSISTED DYING BE PERMITTED IN JERSEY, AND IF SO, UNDER WHAT CIRCUMSTANCES?

FINAL REPORT FROM JERSEY  
ASSISTED DYING CITIZENS' JURY

SEPTEMBER 2021

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## FOREWORD – INDEPENDENT ADVISORY PANEL

Debates on assisted dying and the potential introduction of legislation are taking place across the globe. In recent years a number of parliaments have debated the issue; some close to home like Guernsey and the Isle of Man, others much further away, such as New Zealand. Some of these debates have resulted in legislation change, others have voted to maintain the status quo.

In early 2020, the Minister for Health and Social Services made a commitment to commission a citizens' jury, following community interest on assisted dying at a local level. A citizens' jury is a method of deliberation, where a small group of people, broadly representative of the community, come together to carefully consider an issue. Citizens' juries have been used across the world to look at complex issues that are full of moral and ethical considerations to help make recommendations. They help inform the wider debate, and crucially, provide insight for our elected representatives on the community's considered view of a particular issue. The States Assembly are the decision makers with the authority to decide what, if any, changes are made to legislation in relation to assisted dying in Jersey. The Council of Ministers has made a commitment to bring the matter forward for debate before the end of 2021 and these Jury recommendations will form the basis of their report and proposition.

We were selected as members of the Independent Advisory Panel to provide an objective voice to advise, check and challenge throughout the Citizens' Jury process. Having overseen the design of the Citizen's Jury and having observed the delivery of the sessions, we can confirm that it is our view that the Jury process was appropriate, balanced and robust. We were extremely impressed by the way that Involve, and in particular the Lead Facilitator, handled the whole jury process from beginning to end. It is also our view that this report on the recommendations reflects this process.

This report sets out the Citizens' Jury process in full, including further explanation of the role of the Independent Advisory Panel, and all those who contributed to the process. The report also goes on to set out the voting results and recommendations of the Jury.

The Panel would like to thank all those involved in the Jury, including all the speakers who gave their time to share their views, experience and expertise and answer the many questions from the Jury members. And finally, we wish to thank the Jury members themselves for their dedication to the process and their commitment to undertaking such an important role in representing the wider community.

## EXECUTIVE SUMMARY

In Spring 2021, the Minister for Health and Social Services commissioned a citizens' jury of 23 people from across Jersey to consider the question:

“Should assisted dying be permitted in Jersey, and if so, under what circumstances?”

The Jury heard from and questioned a range of speakers on this topic, shared their views in discussions and completed three different votes to provide a final response to the question.

This report describes in detail the work of the citizens' jury, including its oversight structures, how members were recruited, the structure and content of the Jury meetings, and what Jury members thought about the experience of taking part.

The recommendations from the Jury will inform the States Assembly debate on assisted dying before the end of 2021.

### Summary of Recommendations

78% of Jersey Assisted Dying Citizens' Jury members agreed assisted dying should be permitted in Jersey under the following circumstances:

- where a Jersey resident, aged 18 or over, has a terminal illness or is experiencing unbearable suffering and wishes to end their life;
- subject to stringent safeguards including a pre-approval process; a mandatory period of reflection and consideration; with the direct assistance from doctors or nurses only, as opposed to non-medically qualified staff.

## ACKNOWLEDGEMENTS

A very big thank you to Mind Jersey for their unwavering support of the Jury members and the delivery team's mental health and wellbeing throughout this Jury process.

Thanks to all the Independent Advisory Panel; expert and content advisors and Jury speakers who contributed to this process. Particular thanks to Dr Alexandra Mullock and Professor Suzanne Ost for the time they gave to this process.

## 01. INTRODUCTION

The Jersey Assisted Dying Citizens' Jury consisted of 23 randomly selected Jersey residents who worked together across 10 sessions between March to May 2021 to answer the question:

“Should assisted dying be permitted in Jersey, and if so, under what circumstances?”

The Jury heard from and questioned a range of speakers on this topic, shared their views in discussions and across three different votes to provide a final response to the question.

This recommendation will inform a States Assembly debate on assisted dying before the end of 2021.

### 1.1. BACKGROUND

In February 2020, the Minister for Health and Social Services committed to establishing a citizens' jury to consider whether assisted dying should be permitted in Jersey. This followed an e-petition in 2018 signed by 1,861 people calling for the States Assembly to amend Jersey law to allow for assisted dying. There was also an online public survey, a GP and doctors' survey and a public meeting, which indicated that there are people in Jersey who support assisted dying. The development of the citizens' jury was delayed by the Covid pandemic, preparatory work on the design of the jury recommenced in October 2020 and the decision was made to move the process to an online format.

### 1.2. ABOUT ASSISTED DYING

Assisted dying is where a person suffering from a terminal illness or a condition that causes unbearable suffering, is helped to die. They are usually assisted by a healthcare professional who either provides, or administers, lethal drugs.

Agreement on exact definitions of assisted dying varies between individuals, organisations and jurisdictions. It is often used as an umbrella term to encompass both assisted suicide (providing someone the means to end their own life) and voluntary euthanasia (where one person causes another person's death with their consent).

### 1.3. ABOUT CITIZENS' JURIES

Citizens' juries are used all over the world to look at complex issues and make recommendations. It is a method of deliberation, where a small group of people (typically between 12 and 24), broadly representative of the demographics of a given area, come together to carefully consider an issue. Citizens' juries can be used to consider different policy issues and are particularly effective for issues that are full of moral and ethical considerations and controversial questions, where knowledge is contested and there might be important social repercussions. Normally citizens deliberate a clearly framed question.

Throughout the sessions, jury members listen to expert witnesses. These include impartial experts, stakeholders and advocates representing all sides, so that the jury can receive a balanced and complete picture of the issue. There is time allotted for jurors to ask questions of the witnesses and to deliberate what is heard. After all the hearings have been completed, the rest of the time is set aside for the jurors to have final deliberations on the issue and answer the question. They'll reach a decision following deliberation on the issue, either by consensus or voting.

## 1.4. ABOUT THIS REPORT

This report contains the views, ideas and questions shared by jury members during jury sessions and the voting process. It does not seek to interpret the information, other than grouping it into relevant themes. Instead, it presents the thoughts of the Jury members as they deliberated the question “Should assisted dying be permitted in Jersey, and if so, under what circumstances?”.

This report has been shared with all jury members and the Independent Advisory Panel to ensure that the information provided about the Jury process is factually accurate.<sup>1</sup>

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<sup>1</sup> The Jury members’ comments as set out in this report are verbatim comments and reflect individual Jury member’s views and understanding at the point at which the comments were made. As a result some comments may be factually inaccurate but represent Jury members’ views at the time

## 02. HOW THE JURY WORKED

### 2.1. ROLES & RESPONSIBILITIES

The Jersey Assisted Dying Citizens' Jury was supported by an independent advisory panel, content oversight advisers, expert advisers, Sortition Foundation and a delivery team consisting of Involve and Government of Jersey policy officers.

#### Independent advisory panel

An independent advisory panel was set up to oversee the planning and ensure the integrity of the Jury process.

The Panel was established by the Minister for Health and Social Services with members selected based on their previous contributions to the community and their known ability to be impartial and to provide an objective voice to advise, check and challenge the Citizens' Jury process. Those members were:

- Gillian Arthur, MBE
- Michael De La Haye, OBE
- James Le Feuvre
- Dr Helen Miles

The role of the Panel was to maintain the integrity of the Jury process. The Panel provided advice and scrutiny, helping ensure the Jury was balanced, and that the process of evidence selection was both robust and comprehensive.

Further detail including the Panel's Terms of Reference and Panel meeting notes can be found on the Government of Jersey website.<sup>2</sup>

The Panel collectively met five times, plus each Jury session was observed by 1-2 Panel members.

#### Content oversight & expert advisers

The content oversight team consisted of three independent subject matter experts who supported the Independent Advisory Panel in ensuring that the design of the Jury sessions was balanced and comprehensive in terms of content, selection of speakers and evidence presented. The content oversight advisers were selected as leading authorities on assisted dying and for their range of personal positions on the subject. They were:

- Professor Richard Huxtable (University of Bristol)
- Professor Emily Jackson (London School of Economics)
- Professor David Jones (St Mary's University and Director of Anscombe Bioethics Centre, Oxford)

Two further expert advisers assisted the delivery of the Jury in a more 'hands on' role, attending each Jury session to answer questions and provide clarifications on the subject. The expert advisers were:

- Dr Alexandra Mullock, Senior Lecturer in Medical Law at the University of Manchester
- Professor Suzanne Ost, Law School, Lancaster University

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<sup>2</sup> <https://www.gov.je/Caring/AssistedDying/Pages/CitizensJuryOnAssistedDying.aspx>

## Sortition Foundation

The Sortition Foundation promotes the use of sortition (random selection) in participatory democracy processes. The Sortition Foundation was responsible for recruiting people to take part in the Citizens' Jury. Their aim was to ensure the Citizens' Jury was broadly reflective of the island of Jersey.<sup>3</sup>

## Involve

The Involve Foundation is the UK's leading public participation charity, with a mission to put people at the heart of decision-making. Involve ran the Citizens' Jury – facilitating and designing the process by which the Jury members learnt, considered and came to their recommendations.

Involve wrote this report, sharing it with all Jury members and the Independent Advisory Panel to ensure factual accuracy.<sup>4</sup>

## Government of Jersey

The Minister for Health and Social Services commissioned the Jury. Policy officers from the Government of Jersey's Strategic Policy, Planning and Performance Department provided logistical and planning support for the delivery of the Citizens' Jury.

Those policy officers plus staff from Involve collectively formed the delivery team which oversaw the practical arrangements and delivery of each session.

## 2.2. SUPPORTING PARTICIPATION

The Assisted Dying Citizen's Jury took place online. Jury members who were not confident in using online devices and video calls were provided with one-to-one support and training to ensure they could participate fully.

Equipment was made available to those who did not have access to suitable broadband and internet enabled devices.

Other support needs were also met for example, caring responsibilities and any additional communication support or support to access information.

## Recognition of involvement and time commitment

A payment of £300 was made to Jury members to recognise their significant commitment across the 10 Jury sessions, each of which took two to two-and-a-half hours.

## Wellbeing support

Assisted dying is a personal and sensitive topic. This was recognised in the design of the Jury process plus access to a wellbeing and information pack prior to commencement of Jury sessions.

Sessions were designed to allow time for Jury members to process the issues discussed, plus a breakout space was available to provide support to any Jury member that required it. This breakout space was facilitated by Mind Jersey who also led a decompression exercise at the end of each session and offered follow up support outside of the Jury sessions.

Thank you to Mind Jersey for their time, support and commitment to the wellbeing of everyone involved in the Jury process.

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<sup>3</sup> <https://www.sortitionfoundation.org/>

<sup>4</sup> <https://www.involve.org.uk/>

## Independent facilitation

During sessions, Jury members often worked in small groups with a group facilitator. Those who supported the Jury are highly experienced independent facilitators provided by Involve and trained in deliberative processes. The facilitators were there to ensure everyone in the group had an opportunity to contribute to the discussions.

Facilitators also supported Jury members to create a group agreement on how the Jury would work together. Please see [Appendix A](#) for an outline of the key principles of this agreement.

## 2.3. CITIZENS' JURY MEMBERS

4,600 invitations were sent to a random sample of Jersey addresses in January 2021. Anyone aged 16 or over who lived at those addresses was invited to register their interest in participating in the Jury.

In total, 477 Islanders registered their interest. A Citizens' Jury typically consists of 18 to 24 people so not everyone who registered their interest was selected. A process called sortition was used to randomly select which of the 477 interested Islanders would participate, ensuring that those selected would broadly represent the Island's population across the following criteria:

- age (source: Opendata.gov.je 2018 Population Estimate)
- gender (source: Opendata.gov.je 2018 Population Estimate)
- location (source: Jersey Opinions and Lifestyle Survey 2020)
- socio economic status, based on housing tenure (source: Jersey Opinions and Lifestyle Survey 2020)
- place of birth (source: Jersey 2011 census data)
- attitude towards assisted dying (source: British Social Attitudes Survey 34 (2017))

The demographic make-up of Jury members:

Stratification criteria		Jersey population %	Respondents %	Jury Members %
<b>Sex</b>	Male	49.6	32.1	47.8
	Female	50.4	67.7	52.2
	Other	0	0.2	0
<b>Age</b>	16-29	19.9	15.9	17.4
	30-44	25.4	27.7	30.4
	45-64	34.3	37.5	26.1
	65+	20.4	18.9	26.1
<b>Urban / Rural</b>	Urban	35	34.6	34.8
	Rural	43	43.4	43.5
	Semi-Rural/Urban	22	21.4	21.7
<b>Tenure</b>	Owner-occupier	58	61.6	65.2
	States, housing trust or parish rent (social rent)	12	8.4	13
	Qualified private rental	17	21.6	8.7
	Other, non-qualified accommodation (incl. lodging house and staff accommodation)	13	8.4	13
<b>Place of Birth</b>	Jersey	50	43.4	43.5
	British	31	39.4	34.8
	Portugal	7	1.5	8.7
	Elsewhere	12	15.7	13
<b>Should assisted dying be permitted?</b>	Definitely	50	52	52.2
	Probably	29	40	30.4
	Probably not	8	3.6	8.7
	Definitely not	12	4.4	8.7

Jury members did not need prior knowledge about assisted dying but did require a willingness to listen to the information presented and share views with other Jury members.

Jury members were asked to respect the anonymity of all other members.

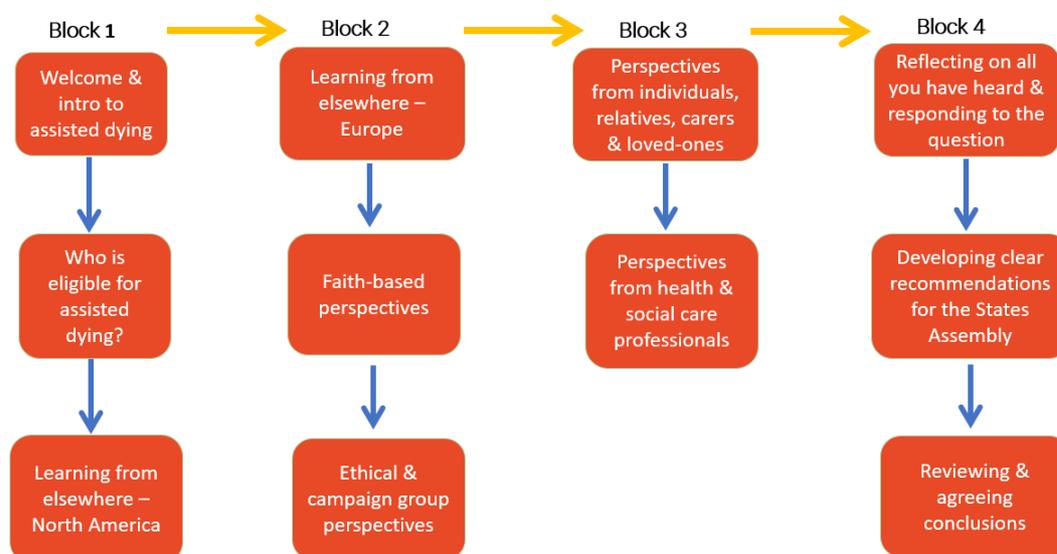
No identifiable details about Jury members will be made public unless any individual member chooses to publicly share their details.

## 2.4. THE JURY SESSIONS

### Overview of Jury sessions & evidence

The Jury met over 10 two to two-and-a-half hour sessions. These sessions included presentations from speakers, discussions with speakers and small group deliberations about what Jury members thought about the topic.

Below is an overview of the 10 Jury sessions which were split into four blocks throughout March – May 2021:



See [Appendix B](#) for detailed outline of sessions<sup>5</sup>

### How evidence was selected

The content oversight team and expert advisers worked closely with the delivery team to identify a range of speakers for the 10 Jury sessions.

The content oversight team was responsible for approval of speakers and evidence provided to the Jury, considering the following criteria:

- Overall balance & diversity of views/experience/backgrounds across all selected speakers
- Experience (lived or professional)
- Profile and/or professional expertise of speaker
- Location – inclusion of local and international voices, including jurisdictions where assisted dying is currently permitted
- Openness – being open to responding to a brief and engaging with participant questions

<sup>5</sup> All presentations to the Jury can be found here:

<https://www.gov.je/Caring/AssistedDying/Pages/JerseyAssistedDyingCitizensJuryMeetings.aspx#anchor-5>

- Presentation skills – ability to present their view/argument clearly and concisely to the Jury
- Speakers to provide context to Jury – i.e. explain whether speaking in a professional capacity, giving personal views or representing groups or cohorts of people (for example, faith groups, campaign groups etc.)<sup>6</sup>

Given the vast number of individuals and experts with experience of the subject, and the focus on deliberation time required during a jury process, it was not possible to invite to speak all those with a view on the subject area.

## 2.5. THE VOTING PROCESS

### Explanation of the voting process

The key function of the Jury was to deliberate and vote on the following question:

**“Should assisted dying be permitted in Jersey? And, if so, under what circumstances?”**

There was a three staged voting process, with different votes taking place following different Jury sessions.

Vote 1: The initial ‘in principle’ vote followed session 8

Vote 2: The vote on the circumstances followed session 10

Vote 3: The final vote was a week after the second vote

Jury members spent time deliberating with each other prior to the voting. Several key votes were used to find out the Jury’s views and preferences.

#### 1. Initial ‘in principle’ vote

The initial vote focused on the first part of the question: *In principle, do you agree or disagree that assisted dying should be permitted in Jersey?* Results from the initial vote shaped Jury discussions in sessions 9 and 10 and the format of the second vote.

As the majority of Jury members answered ‘yes, I agree’ in the initial vote, sessions 9 and 10 focused on the circumstances under which assisted dying should be permitted.

If the majority of Jury members had answered ‘no’ in the initial vote, sessions 9 and 10 would have focused on the reasons why assisted dying should not be permitted and there would have been no further vote on the circumstances.

#### 2. Vote on circumstances

The second vote focused on the second part of the question i.e. the circumstances under which assisted dying should be permitted.

The second vote used a preferential voting process to help identify clear preferences (i.e., some of the questions asked Jury members to indicate their first and second preference, rather than answering ‘yes’ or ‘no’). The second vote was based on voting principles used for other citizens’ juries and citizens’ assembly processes.

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<sup>6</sup> This criteria is published here: [Jersey Assisted Dying Citizens’ Jury meetings \(gov.je\)](https://www.gov.je/assisted-dying-citizens-jury-meetings)

### 3. Final vote

The final vote provided Jury members an opportunity to vote for or against assisted dying, taking account of the circumstances identified via the second vote.

Throughout the voting process Jury members were provided opportunities to:

- issue key messages to States members (as set out in Section 4 of this report), and
- make additional comments on matters included in the voting process.

This allowed for the breadth of views of individual Jury members to be captured throughout the process, including, where individual Jury members did not vote with the majority.

## 03. RECOMMENDATIONS FROM THE JURY

### 3.1. SUMMARY OF RECOMMENDATIONS

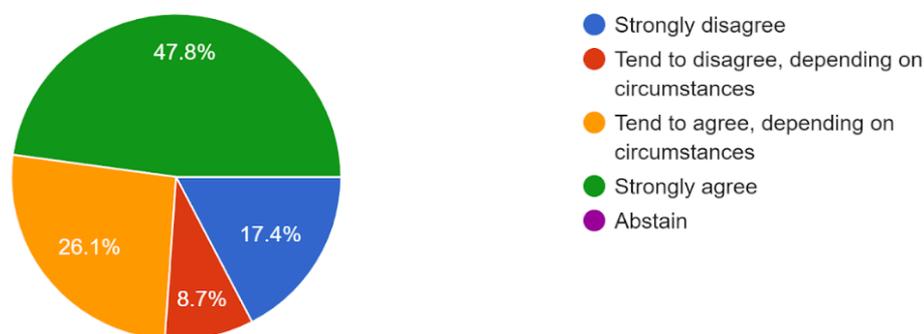
78% of Jersey Assisted Dying Citizens' Jury members agreed assisted dying should be permitted in Jersey under the following circumstances:

- where a Jersey resident, aged 18 or over, has a terminal illness or is experiencing unbearable suffering and wishes to end their life
- subject to stringent safeguards including a pre-approval process; a mandatory period of reflection and consideration; with the direct assistance from doctors or nurses only, as opposed to non-medically qualified staff.

### 3.2. INITIAL VOTE RESULTS: WHETHER ASSISTED DYING SHOULD BE PERMITTED

Jury members were asked the question: “**In principle, do you agree or disagree that assisted dying should be permitted in Jersey?**”

The majority voted in favour of the principle of permitting assisted dying in Jersey, with 48% strongly agreeing and 26% tending to agree.



*Figure 1: In principle, do you agree or disagree that assisted dying should be permitted in Jersey?*

In the session prior to voting, Jury members heard a recap of all the evidence presented during the Jury sessions (see [Appendix B](#)). Members then engaged in group discussions about what would inform their answer to the Jury question, and explored the reasons underpinning their intended answer.

Jury members covered the following areas in these discussions: implications for medical staff; support around the assisted dying process; what further information Jury members wanted; people's quality of life; cost and funding the process; ethical issues; how this issue relates to other scientific developments; governance and decision-making around the assisted dying process; palliative care; personal stories and people needing to have a choice. More detailed notes from these group discussions are included in [Appendix C](#).

Jury members were also asked to provide additional comments on the voting forms in response to each question if they wanted to. [Appendix D](#) sets out in full those additional comments.

### 3.3. SECOND VOTE RESULTS: THE CIRCUMSTANCES UNDER WHICH ASSISTED DYING SHOULD BE PERMITTED

The second vote focused on the circumstances under which Jury members felt assisted dying should be permitted in Jersey.

Jury members were asked to vote on eight questions. The voting results for each question are set out below, followed by a summary of the group discussions that preceded each vote.

The results from the second vote are split into three sections which reflect the structure of the final Jury sessions:

- eligibility criteria
- mode
- regulations & safeguards.

#### Assumptions related to regulations & safeguards

Prior to discussing the circumstances in which assisted dying should be permitted, the Jury was asked to assume that the following safeguards would be put in place if assisted dying was permitted in Jersey.

The assumed safeguards are consistent features of assisted dying legislation or regulations in other jurisdictions. They include:

- conscientious objection clause for medical professionals
- certain approved locations: e.g. at home, hospital, specialist facility/ pre-approved location
- format of request: usually a written, witnessed request
- withdrawal of request: permitted at any time
- reporting: general reporting on assisted dying in Jersey would take place on a regular basis (with no disclosure of individual identifying details)

#### Eligibility Criteria

There were three questions related to assisted dying eligibility criteria focusing on residency, health and age.

##### Residency criteria

Jury members were asked the question: ***“Should assisted dying only be for Jersey residents?”***

The majority of the Jury voted for yes, assisted dying should only be for Jersey residents.

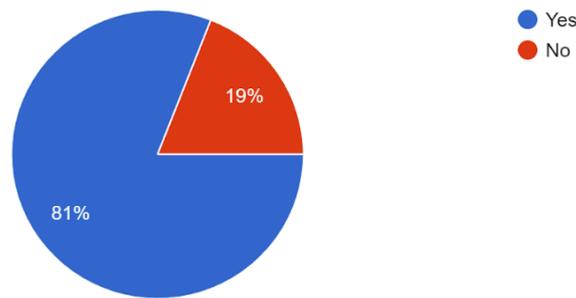


Figure2: *Should assisted dying only be for Jersey residents?*

Jury members had group discussions on the question of residency criteria. These discussions covered the advantages and disadvantages of a wide range of themes that are summarised below.

Jury members discussed the possibility of assisted dying tourism, whether it was Jersey's responsibility to provide this service for other countries and complexities around Jersey residency definitions. This was also linked with the possibility of negative media coverage that assisted dying tourism could bring.

The possibility of this being a staged process was discussed with only Jersey residents first and then the service offered more widely. Jury members gave the example of Jersey being a closer option for some people (for example UK residents) than somewhere like Dignitas.

Jury members talked about the issue of accessibility of the service too. This included whether it could help prevent people having to travel abroad and allowing people to have their family nearby if they did want an assisted death. Linked to this, the cost implications were considered around how many people would use the service and level of infrastructure in place to support fair access to the service.

Jury members talked about how residents-only access is the most common model in other countries and explored regulation and monitoring implications too.

They also discussed how closer links with local health professionals could be possible along with the potential implications for Jersey health professionals if the service was introduced.

The detailed notes of the residency criteria discussion are captured in [Appendix E](#). Additional comments Jury members added to the second vote form are in [Appendix F](#).

### Health criteria: Part 1

Jury members were asked a two-part question related to health criteria. For Part 1, Jury members were asked: ***“Who should be eligible for assisted dying related to health?”***

The Jury's overall preference was for either those with a terminal illness (with limited life expectancy) or those experiencing unbearable suffering to be eligible for assisted dying.

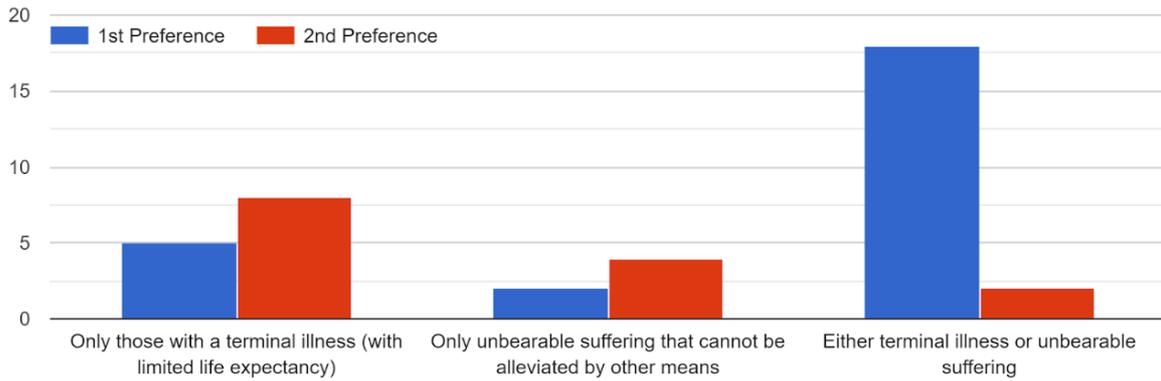


Figure 3: Part 1: Who should be eligible for assisted dying related to health?

Options	1st Preferences	Percentage
Only those with a terminal illness (with limited life expectancy)	5	21.7
Only unbearable suffering that cannot be alleviated by other means	2	8.7
Either terminal illness or unbearable suffering	16	69.6

### Health criteria: Part 2

Jury members were asked: ***“If they chose unbearable suffering, should this include suffering caused by a mental condition?”***

The Jury voted that the eligibility criteria for health should not include suffering caused by a mental condition.

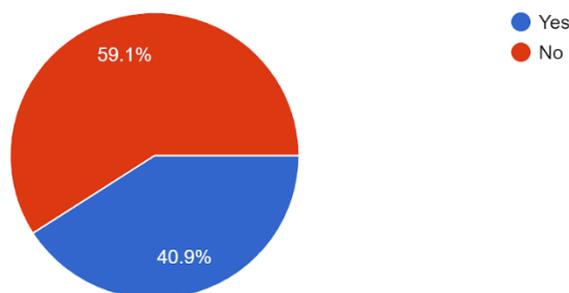


Figure 4: Part 2: If you chose unbearable suffering, should this include suffering caused by a mental condition?

Jury members explored this question in depth prior to voting. Their discussions covered many different questions and perspectives on the issue of health criteria. They discussed how challenging this issue is and the need to break down types of conditions, and if mental conditions/illnesses were included.

Jury members talked through considerations around timing of a diagnosis and the possibility of inaccurate diagnosis or medical trials that could have an impact on an individual's condition.

The groups discussed the need for people to have a sense of empowerment, choice and control on the whole process and a chance to alleviate unbearable suffering and have peace of mind. Jury members discussed how the decision around which health criteria decisions are based on for permitting assisted dying might impact on making the process fairer and more accessible too.

Jury members raised cautions around this question including concerns that vulnerable people may fall between the net or individual's circumstances can change and how that would be managed. They also talked through wider implications for family involvement in both positive (inclusive) and negative ways (families having their own agenda/coercion).

The Jury talked about questions around definitions and the need for clearer definitions of mental capacity, unbearable suffering, terminal illness and incurable/irreversible conditions. They also looked at considerations around starting with a narrow remit for the process of assisted dying or whether it is better for people in Jersey to have a clear understanding from the outset of the possible widest remit of assisted dying (including unbearable suffering). Linked to this point, Jury members also discussed whether there should be a focus on physical and terminal illness only. This was in case including other conditions/illnesses might prevent assisted dying being possible at all due to the increased bureaucracy these additional aspects might create.

Jury members explored further whether assisted dying should be physical conditions only or mental conditions too. They discussed the implications of including a greater number of conditions or fewer conditions. They also considered the impact on suggesting assisted dying to those who had not considered it; safeguarding concerns and whether there was potential for a slippery slope in future around this area. The groups talked through questions of inclusivity if only some mental health conditions are included. Jury members also discussed examples such as the Canadian model which will [in 2023] include both mental and physical conditions in the criteria and looked at the implications of how a mental condition can manifest into a physical condition and vice versa.

Additional points from this discussion are captured in [Appendix E](#). Additional comments Jury members added to the second vote form are in [Appendix F](#).

## Age criteria

Jury members were asked: ***“Who should be eligible for assisted dying relating to age criteria?”*** (Jury members were asked to state their first and second preferences).

If Jury members' first preferences alone are taken into account, the Jury voted for “Over 18s only” but this option does not achieve an overall majority.

If Jury members' second preferences are also considered, the vote results in a near tie between “Over 18s only” and “Anybody of any age”. Therefore the Jury recommendation is not definitive.

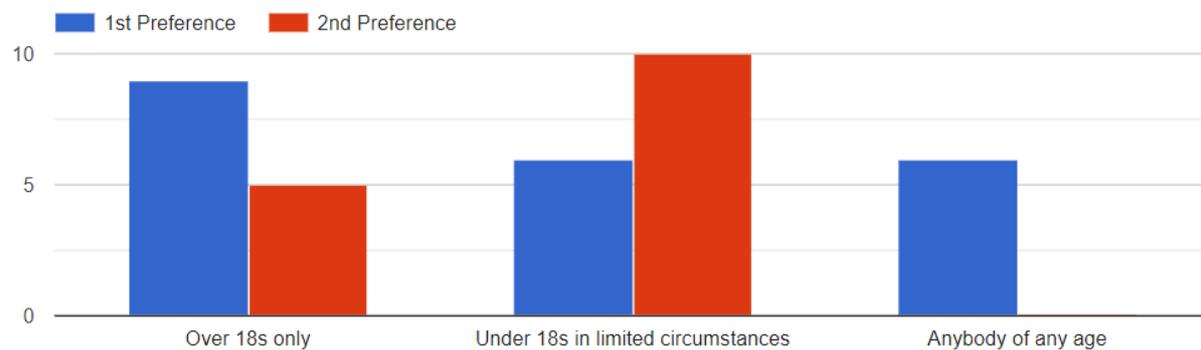


Figure 5: Who should be eligible for assisted dying relating to age?

Options	1st Preferences	Percentage
Over 18s only	9	42.9
Under 18s in limited circumstances	6	28.6
Anybody of any age	6	28.6

Jury members discussed age criteria based on assisted dying being permitted for over 18s only; for under 18s as well and for under 18s only in limited circumstances.

The Jury considered what existing laws allow or don't allow for under 18s and discussed different stages of assisted dying being introduced. The question of choice, children being heard and whether children should have the same sense of ownership as adults over their lives were all discussed.

Jury members talked about whether those with terminal illness and under 18 should be given different considerations and how this would be managed including the question of consent (the child's consent, parental consent and medical consent). Different age thresholds were also suggested too.

The Jury covered concerns around risk appetite and a whole range of different vulnerability considerations for people under 18 including physical and psychological development and concerns around safeguarding. Jury members raised concerns about how challenging this question is to consider whether assisted dying should be possible for children or not.

The groups also connected this question with who should be allowed to decide discussing the role of medical professionals, parental decision-making and the voice of the child here too.

Additional detailed points from the discussion are captured in [Appendix E](#). Additional comments Jury members added to the second vote form are in [Appendix F](#).

## Mode

Jury members were asked: *“What mode of assisted dying should be permitted in Jersey?”* The majority of Jury members supported both Physician Assisted Suicide (PAS) and euthanasia as the mode of assisted dying that should be permitted.

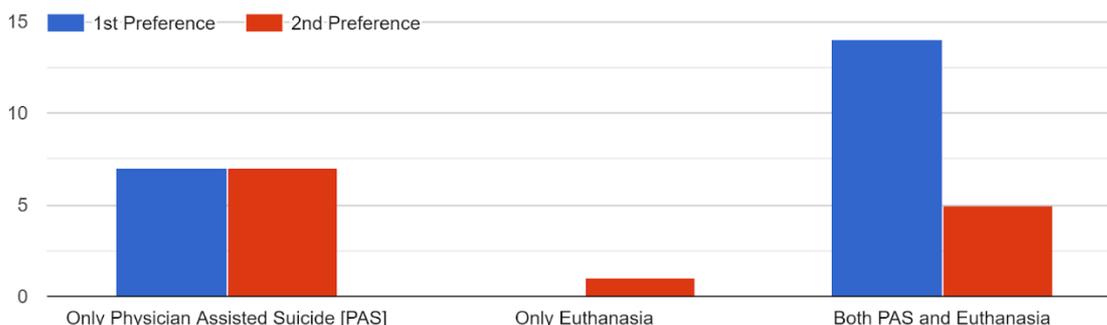


Figure 6: What mode of assisted dying should be permitted?

Options	1st Preferences	Percentage
Only Physician Assisted Suicide [PAS]	7	35.0
Only Euthanasia	0	0.0
Both PAS and Euthanasia	13	65.0

The Jury discussed the different modes of assisted dying in depth before voting.

Allowing choice, autonomy and a person to be in control, connected with the other number of hurdles an individual may need to go through to be eligible for an assisted death, came up in the Jury members' discussions.

These discussions also linked to the question of who should administer or assist in an assisted death including whether someone should be medically qualified or not. This was also linked to implications and safeguards for medical staff too and whether medical staff would want to be part of the process or not.

The Jury discussed questions around what is involved in the different modes of assisted death and the possible advantages and disadvantages of each. This included the impact of timings of when the prescription is given and taken; safeguards required and the efficacy of the different modes and examples from other jurisdictions.

Jury members talked through the implications of a patient having to administer a prescription themselves and questions around consent were also considered too.

The groups also explored the implications of both modes being permitted looking at this providing different options for people and which mode might be preferable. Jury members again discussed the question of the role and involvement of family members in the process too.

Additional points from the group discussions are captured in [Appendix E](#). Additional comments Jury members added to the second vote form are in [Appendix F](#).

## Regulations & Safeguards

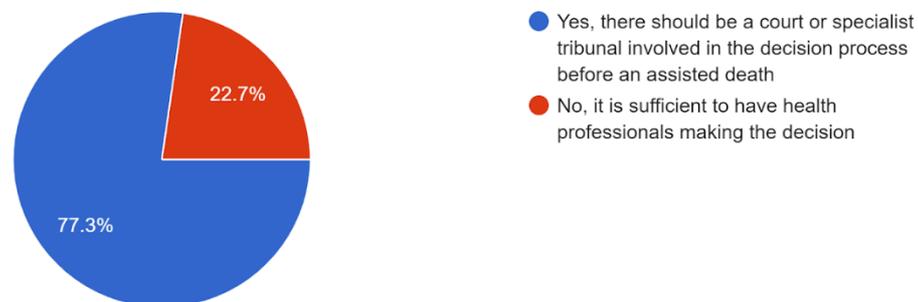
Jury members were asked four questions related to assisted dying regulations and safeguards:

- Court or tribunal involvement
- Assisting/administering assisted dying
- Cooling off period
- Advanced decision-making

### Court or tribunal involvement

Jury members were asked: ***“Should a court or specialist tribunal be involved in the decision process before an assisted death?”***

The majority of the Jury voted for yes, there should be a court or specialist tribunal involved in the decision process before an assisted death.



*Figure 7: Should a court or specialist tribunal be involved in the decision process before an assisted death?*

The group discussions before Jury members voted on these questions covered the implications for medical professionals who would need to be involved in this process. This included regulation on the profession; whether medical professionals would want to do this or not and whether someone’s GP may know an individual well or not.

Jury members talked about the number of people involved in the decision-making process and who those people should be including suggestions of a judge, charities, medical and non-government professionals being on tribunals. The Jury also covered whether the implications of the personal beliefs of those on the panel could affect decision making too.

The groups discussed the type of legal review needed and whether a legal layer of sign off was an advantage (a safeguard) or disadvantage (expensive and possibly bureaucratic).

Jury members also talked about whether there should be ongoing review and if every case should be scrutinised.

Additional points from the group discussions are captured in [Appendix E](#). Additional comments Jury members added to the second vote form are in [Appendix F](#).

## Assisting/administering assisted dying

The next question on assisted dying regulation and safeguards Jury members answered was: “*Who can assist/administer assisted dying?*”

The majority of Jury members voted in favour of doctors and nurses being those who assist/administer assisted dying.

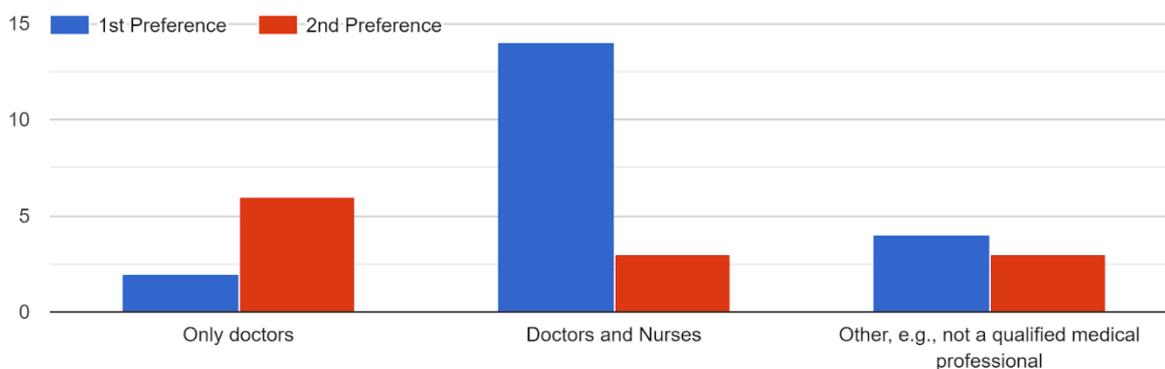


Figure 8: Who can assist/administer assisted dying?

Options	1st Preferences	Percentage
Only doctors	2	10.5
Doctors and Nurses	13	68.4
Other, e.g., not a qualified medical professional	4	21.1

Jury members discussed the role of medical professionals in particular and mental health professionals in this process. They explored areas such as the level of qualification required and whether an existing relationship with the patient is needed or not.

The Jury again looked at the role and involvement of an individual’s family when discussing this circumstance too.

Groups talked through different suggestions such as whether the person administering should be pre-approved by a panel, whether there should be approved locations for people to go for the lethal dose to be administered properly and how the process would be monitored overall.

Discussions held by the Jury also covered safeguarding requirements and what law change may be required for suggested individuals to carry out the administering of the assisted death.

The Jury talked about who could be present at someone’s assisted death free from fear of prosecution.

Additional points from the group discussions are captured in [Appendix E](#). Additional comments Jury members added to the second vote form are in [Appendix E](#).

## Cooling off period

Jury members were asked: “*Should there be a requirement for a cooling off period if assisted dying were permitted in Jersey?*”

The Jury voted in favour of a cooling off period. There was also quite strong support for this being dependent on the circumstances of the individual too.

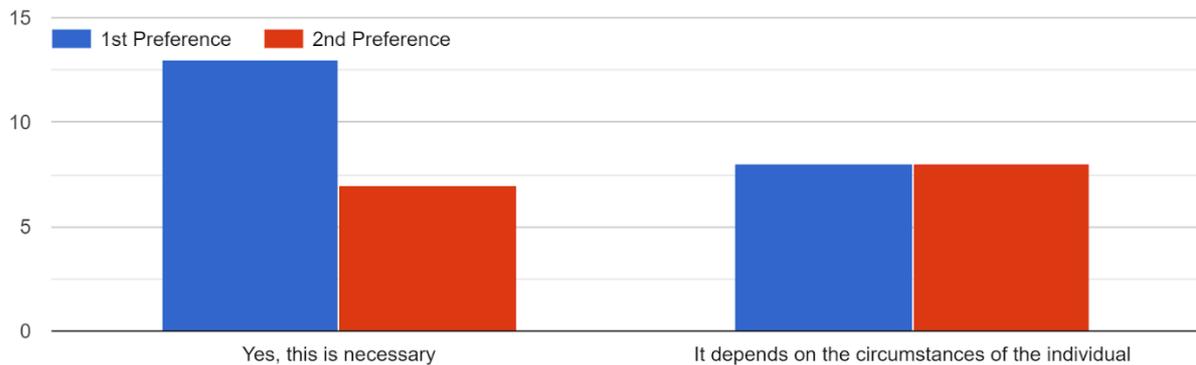


Figure 9: Should there be a requirement for a cooling off period?

Options	1st Preferences	Percentage
Yes, this is necessary	12	60.0
No, this is not necessary	0	0.0
It depends on the circumstances of the individual	8	40.0

The groups looked at the different types and lengths of cooling off period and what implications these might have. These considerations were linked to the context of different situations people may face for example where death is imminent or someone is in constant pain.

Jury members talked about the possible empowerment and control this circumstance could provide including the option for an individual to change their mind without feeling forced within a timeframe. Linked to this, Jury members talked about whether coercion and possible abuse could still be an issue.

The Jury also discussed the way that any cooling off period was recorded and what a second request process would involve.

Additional points from the group discussions are captured in [Appendix E](#). Additional comments Jury members added to the second vote form are in [Appendix F](#).

### Advanced decision-making

Jury members were asked: ***“Should assisted dying be possible with an advance decision after losing capacity?”***

An advance decision in the context of assisted dying is a statement, made by a person with capacity, in which they make an advance request for assisted dying to apply in a future situation in which they will lack decision-making capacity.

The Jury voted in favour of assisted dying being possible with an advance decision after losing capacity but under certain circumstances.

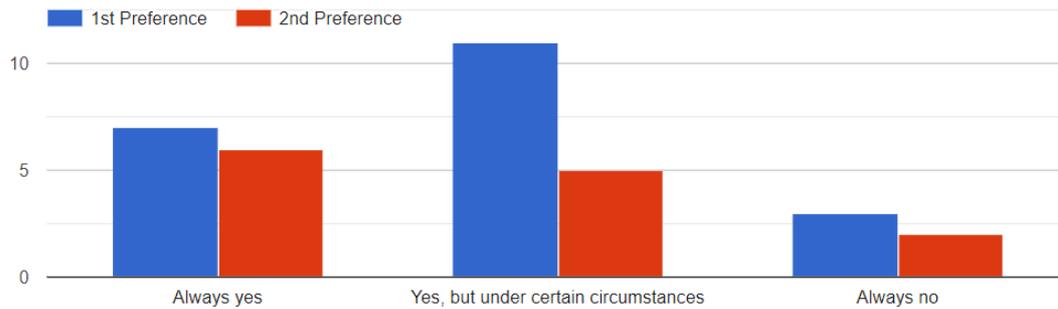


Figure 10: Should assisted dying be possible with an advance decision after losing capacity?

Options	1st Preferences	Percentage
Always yes	7	33.3
Yes, but under certain circumstances	11	52.4
Always no	3	14.3

The Jury discussed a range of factors around this area. They explored the question of who can make decisions and the role of other people in the decision for an individual's death. The groups looked at risks around coercion and safeguarding in this process. The question of autonomy and the ability for an individual to make a decision were discussed too.

Jury members talked about how death is experienced by different people depending on their condition or situation. The Jury explored different considerations around whether an advance decision should be allowed for someone with dementia specifically and referred to the experiences in other jurisdictions they had heard through the Jury process. Linked to this, the question and challenges around defining mental capacity came up again too.

Jury members also looked at emotional wellbeing as a factor to consider in this process and explored what might happen if someone changes their mind at different times.

The Jury discussed whether this should be possible under specific circumstances too including for someone who has complications after a procedure with known high risks.

Additional points from the group discussions are captured in [Appendix E](#). Additional comments Jury members added to the second vote form are in [Appendix F](#).

### 3.4. FINAL VOTE RESULTS: SHOULD ASSISTED DYING BE PERMITTED IN JERSEY BASED ON THESE CIRCUMSTANCES

Jury members undertook a final vote which asked “*Based on the agreed circumstances from the second vote, should assisted dying should be permitted in Jersey?*”

A clear majority voted in favour of assisted dying being permitting in Jersey based on the agreed circumstances.

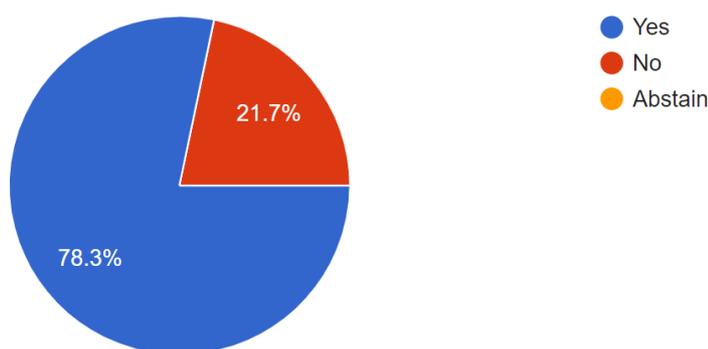


Figure 12: Based on the above circumstances, should assisted dying be permitted in Jersey?

Please see [Appendix G](#) for the Jury members’ additional comments on the final voting form.

### 3.5. OPPOSING VIEWS – SUMMARY STATEMENTS FROM JURY MEMBERS OPPOSING THE OUTCOME OF THE JURY

Involve explained during the Jury sessions that there would be space in the final report for summary statements from any Jury members who voted in opposition to the overall outcome of the Jury, should a Jury member wish to submit a statement. This is referred to in several Jury member comments in this report.

One Jury member informed Involve they would like to do this following the process. Sadly, due to a recent bereavement, they are not in a position to do this at the time of writing the report. The Jury member asked for a note to be included in this report that they will submit a separate statement to the States Assembly outlining their views in September 2021.

## 04. KEY MESSAGES FROM THE JURY FOR THE STATES ASSEMBLY

As part of the second vote process, Jury members were asked if they had final or key messages to send to the States Assembly. Those messages have been loosely grouped into the themes below.

Some of the Jury members discussed this question in their groups during the final session of the Jury. Notes from these discussions are in [Appendix H](#).

### 4.1. DYING WITH DIGNITY

- It is about compassion and letting people die with dignity.
- Hinduism says death is inevitable and is a way to attain nirvana or moksha (the ultimate freedom). We as conscious educated citizens of Jersey should at least let citizens have the choice of a dignified death. Let the soul pass without torment and in peace. Let everybody rest in peace, should the time come.
- People should be allowed to die with dignity. I hope you take all of the Jury's points into consideration.
- I volunteered myself into this Jury with no fixed idea of how I would vote in the end. I had an idea of wanting to be pro-choice however I could never have fully imagined the journey that we've been on. This topic is far bigger than a 10-session citizen jury, and I think as an island we need to talk about death, reviewing our palliative care, access to health services as well as hospice care and listen to people that have experienced them both, but also would have considered assisted dying. I believe all life is precious, and I believe we must aspire to offer world class personalised health services. For some this will not be enough. As technology advances, we can artificially extend life, but that in some cases is not life. Some people will experience pain, suffering, and have no prospect of life. They may be sedated to reduce pain, but again is being under sedation living? For those who wish to take this course of pain relief and sedation to remain alive, they should continue to be fully supported to do so. But for those who want their pain and suffering to end, they should be given the option for their suffering to end, with them remaining in control of their destiny and as has been said throughout this process, afforded the option of dying with dignity. For Assisted dying to function, we need to protect the vulnerable in our society, those who would be at risk of abuse of such arrangements as assisted dying, so if we are to offer assisted dying we need a robust, secure and compassionate process that is multidisciplinary in nature with safeguarding being the key focus. If we're not confident in the process and the safeguards, the assisted dying debate needs to continue.

### 4.2. PERSONAL CHOICE

- Person's choice.
- I believe assisted dying is a personal choice I cannot believe it is to let people suffer when they cannot cope anymore. Choice is the word!
- I would ask The States Assembly to support our recommendation to introduce assisted dying to Jersey. I believe there is a majority support from Islanders for such a legislation and while those who may be opposed may never choose to take advantage of the option, for those select few who may unfortunately become eligible in the future, the comfort of knowing such an option would be available to them, could make their final weeks or months so much easier. With adequate criteria and safeguards in place, combined with a robust reporting and scrutiny framework post event, there is no reason to believe the option would be abused. Having volunteered as a jury member, fortunate enough to have not needed to give the subject matter

much consideration before, hearing the evidence and testimonials has led to my now strong support. While a minority of the population may remain opposed, personal beliefs, religious or otherwise, should not be imposed on others, nor impact on their personal choices. A decision to oppose this legislation would be to oppose progress and inclusion. This is a pro-choice decision. Thank you.

- There is no compulsion for assisted dying it is the patient's CHOICE.
- Please put aside your personal views. This is to give people a choice.
- The patient is the one that should be given the right to a choice where there are no others left. We should not be the ones to decide what choice they have, only how to best make sure they live in the best way possible whilst making it absolutely clear that their life is precious, and we wish to offer the best care possible.
- Palliative care needs improved levels of funding with assisted dying as a choice following a documented discussion within the range of options available for individuals. In the past 5 years I have lost 3 members of my close family where the last 2-3 weeks have been very painful with no ability to increase the method of pain relief. People would like the ability to decide if and when to choose to end their life with dignity and pain free.
- Death is a part of life. We are all born, we make our way down life's many paths and we die. Some will live blessed lives and pass away gently in our sleep. But some will contract awful painful diseases that despite our brilliant physician's skill will result in lingering painful death. This doesn't have to be the case if terminally ill patients are given the right to an assisted death on their terms and at the time of their choosing.
- I feel that allowing assisted dying in Jersey is not just a humane route but one that allows people the peace of mind in the last stages of their life whether they chose to use it or not. Situations where people feel they have to travel overseas to have the death they want seems cruel when they could be at home with their families at such a difficult time. We live our lives as we choose, and we should have the right to end our lives as we choose.
- Everyone should have the option of choosing to avoid distressing potentially painful death.
- Please give the people of Jersey the choice.
- We have reviewed many cases, testimonials, data, views, and difference of opinions. Ultimately, we always come to the starting point, is all about choice. We need to give our citizens control over their death (within parameters), the time and place. Assisted dying should form part of the current medical practice in conjunction with palliative care.

### 4.3. VIEWS AGAINST ASSISTED DYING

- This space for my statement about my reasons for voting against assisted dying is not really big enough. If anyone is interested in my reasons for voting against assisted dying, I have written a document which I would gladly share.<sup>7</sup>
- I have chosen to disagree on these circumstances as I feel that palliative care within Jersey should take paramount and become stronger therefore providing residents with more support. Alongside supporting both nurses and doctors - we as individuals have to take into account that our health professionals take an oath to support the living and although sadly some people wish to leave on their own terms due to circumstances it's unfair to put this on our incredible health professionals. In addition, Jersey law needs to change to support those who still wish to travel to Dignitas and their families without prejudice and repercussions upon their arrival home. I feel a relationship needs to be developed with ourselves and potentially

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<sup>7</sup> Jury members were invited to share any additional statements into this Final Report. Please see section 3.5 for more information.

Dignitas: other places that offer this to those who wish it and provide islanders with support and wellbeing on their return. I feel ultimately Jersey does not need adopt this legislation and implement it - due to extensive complex variables - including conflict of legislation/ money/ space/ religion/ etc. - but Jersey does need to facilitate Islanders towards this decision and support them through every aspect during a difficult time such as what an individual may face. Jersey is a place where many come to retire and die with dignity. We as an island do not need to do this directly, we just need to do what we do best. Facilitate and support Islanders.

- Do not pass this law when there is ample evidence why not which I will be forwarding in my statement. This Jury was not a satisfactory debate in my opinion which I will also be making my reasons for this known once why not to and Jersey doesn't even need it. I will be putting my full statement forward as to why not.<sup>8</sup>

#### 4.4. PROTECTING VULNERABLE PEOPLE

- Protect the vulnerable.

#### 4.5. LISTEN TO THE JURY

- To review EVERY aspect of our case, put aside your religious and other beliefs and "listen" to what we are saying, you have chosen US, the Jury, to undertake the in-depth research and emotional journey as an INDEPENDANT panel. I hope you make the correct decision. Thank you.
- Over the last few months, myself and 25 other jury members have listened to evidence from both sides of the debate on assisted dying.<sup>9</sup> It has been an interesting and sometimes very emotional journey which all points from both sides have been taken into account. I ask that you listen to the findings of the Jury and not take any personal feelings such as your faith into your final decision. I respect everybody's faith but if this does sway your decision then you should state this during the debate. Please remember that not everybody follows a religion. I really hope you listen, especially to the late Alain Du Chemin, it's people like him who would have relied to you to follow the Jury. If you do pass this, I would feel that in memory of Alain the law should be called Alain's law. Many thanks.

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<sup>8</sup> Jury members were invited to share any additional statements into this Final Report. Please see section 3.5 for more information.

<sup>9</sup> Correction for this report: there were 23 jury members in total.

## 05. MEMBERS' EXPERIENCE OF THE JURY

### 5.1. REFLECTIONS ON THE JURY PROCESS

Jury members were asked to reflect on their experience of being part of the Jury. They did so at the start of the final block of Jury sessions. Below is a summary of key points Jury members shared about their experience and what they learnt.

#### General vote

- Hope that any group on the opposite side of a vote is not alienated...
- I was worried about the summary - looks like those who don't agree with the majority won't necessarily get their opinion recognised in the final session.
- Important to remember that the Jury is only 23 people, and just because the vote goes one way or another, the vote isn't final...

#### Personal stories

- Dreadful to hear about Alain [du Chemin, Jersey resident who campaigned for assisted dying to be permitted in Jersey].
- Sad news of Alain, good family was with him, but not way he wanted.

#### Looking forward

- Look forward to decision.
- Interesting to see where it goes.

#### Complexity

- A lot more complicated than first thought. Not as simple as I thought.
- How big a question it is - particularly in what circumstances.
- Not as straightforward or black and white as initially thought.
- Made me think a bit more...a lot of things we didn't think of...how complex dying is...different views and ideals... massive learning curve.
- Assisted dying is [a] complicated question, like life really...focusing on death is an issue.

#### Quality of information

- Now in a better position to take an informed position.
- Team done well.
- A decision is only as good as the information it is based on.
- Overload at times.
- So much information digesting it all.
- For every problem there is a solution.

#### Questions/concerns on legislative process

- Some upset and/or surprised by what govt said– [Head of Policy, Government of Jersey said] ...state member could put forward another proposition before the Health Minister...quite surprised.
- For Health Minister to have the last say...don't agree...it would be quite biased on the view of one person....given his personal circumstances.....
- [Head of Policy, Government of Jersey] said our thoughts would go to John LF what qualifications does he have to consider this first? I heard it was the Health Minister. [In the pre-recorded video Head of Policy noted: "Involve will write up [the Jury's] initial

recommendations...once those initial recommendations have been written up by Involve, they will be sent to the Health Minister."]<sup>10</sup>

- Clarification on doctors & nurses registration has helped a lot.

### Value of group work

- Very important to be exposed to those views whether agree or not...become more accepting of other views.
- We need everybody's input. Serious stuff....talking about people in a vulnerable position...about death...how do we approach death?
- The jury is from different walks of life so any decision made would be a well-rounded decision...

### Jury process & impact

- Will we be accused of doing things the Jersey way again? It's not best practice...
- The wider public have been more engaged - this is a good forum for maintaining some kind of voice.
- Idea - Jury members to speak the decision. To have more impact.

### Accessibility of assisted dying

- Accessibility and the cost - will it be accessible for everyone who is living in Jersey - is it just for citizens of Jersey or for people like me I live in Jersey, but I'm not a citizen so what will it cost?
- Taxpayers and resident should be allowed to access this as well - this needs to be thought about - we could become a tourist destination for assisted dying.
- Maintain a safe but relatively accessible process.

### Dilemmas

- How would we deal with underage people?
- Other connected issues we are not supposed to think about, but they have an impact on this, but some of these issues are really, really important e.g. mental health, palliative care.
- Mental capacity - advanced/living will - if you lose capacity at the end do you lose the choice and what can be done about this - represent previous wishes.. it's complex.
- The safeguards are important - probably not going to change my mind - worried the safeguards are too much it's not possible for anyone - there is a risk we tie ourselves in knots and don't get anywhere.

### General

- Religious leaders - tunnel vision, passionate about their subject.
- Different approaches in different jurisdictions.
- Some are against because of the potential for abuse.
- Other presenters emotionally moved by Alain - were they swayed?
- Enjoyed learning and the case studies.
- definitely been more intense...last two sessions more than others...
- Met powerful and inspiring people.
- Privileged to be part of this. Glad to be chosen.
- Seeing this through telescope of death and not life.....disagree with that approach.

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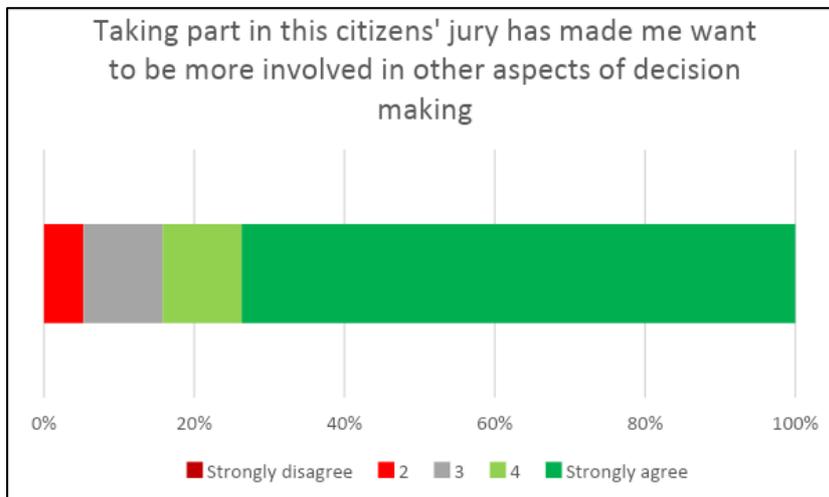
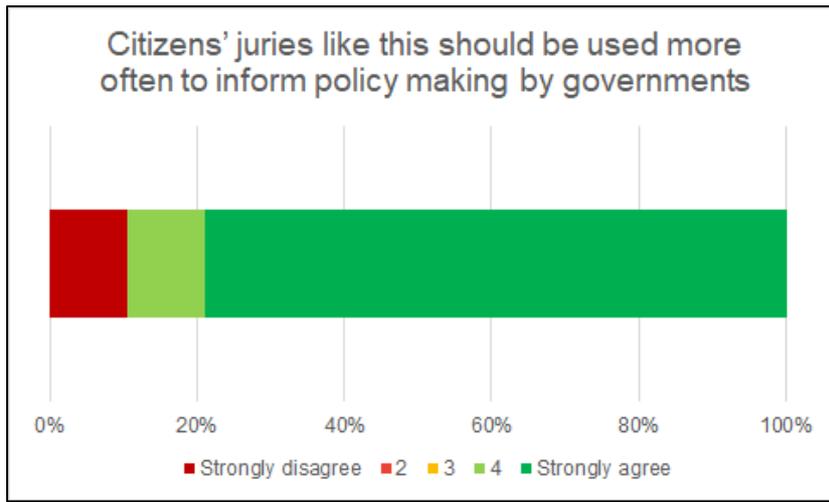
<sup>10</sup> [Jersey Assisted Dying Citizens' Jury meetings \(gov.je\)](#)

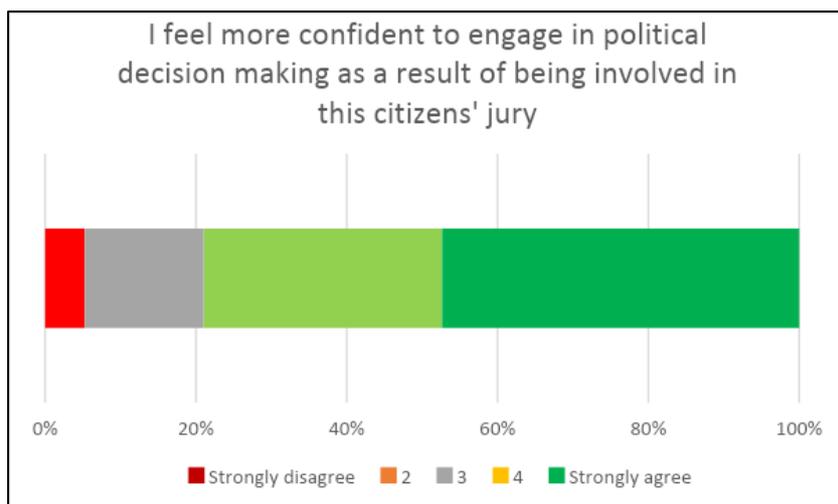
- Covid has brought this topic to life.
- Benefits of process despite the outcome.
- This could be the start of a conversation about dying either way.

## 5.2. FINAL EVALUATION OF THE JURY

The delivery team asked Jury members for feedback at the end of each block of Jury sessions, allowing for ‘real time’ improvements to be made. Jury members also completed a final evaluation of the whole process after the final Jury sessions. This section outlines a summary of Jury members’ feedback.

The following feedback is based on responses from 18 out of 23 Jury members.





Jury members were also asked to rate a series of questions from 1 to 5, with 1 being the lowest and 5 being the highest.

Question	Answer
If the Government of Jersey/States' Assembly were to run another citizens' jury in the future on a different topic, how likely are you to recommend to friends and family that they participate in it?	4.68

Question	Answer
I had enough information to participate effectively	4.79
I understood almost everything that was presented by speakers	4.58
The organisers ensured I was properly prepared to participate	4.84
The small group facilitators helped to make sure everyone could contribute	4.68
The lead facilitator managed the process effectively	4.84

Question	Answer
The information I have received has been fair and balanced	4.74
I had the chance to ask questions of the speakers	4.84
I had ample opportunities in the small group discussions to express my views	4.68
Our group discussions & decisions were accurately captured by the organisers	4.79
I understood almost everything that the other members of my small group said during our small group discussions	4.74
My fellow participants respected what I had to say, even when they didn't agree with me	4.63

Question	Answer
I have learned a lot during the citizens' jury on assisted dying	5.00
My views about the topic of assisted dying have changed as a result of participating	2.95
I know how the decisions and recommendations jury members have made are going to be taken forward by the States' Assembly	4.74
I feel my participation in this citizens' jury will have an impact	4.00

Question	Answer
The online sessions were an appropriate length	4.42
I was satisfied with the gaps between each block of sessions	4.68
The online format was an appropriate way of delivering the process	4.63
We had enough sessions to fully consider the evidence that was shared with us	4.47

## 06. CONCLUSION

The Jersey Assisted Dying Citizens' Jury met over 10 sessions from March – May 2021. 23 Jury members, recruited through sortition, came together to address the question of:

***“Should assisted dying be permitted in Jersey, and if so, under what circumstances?”***

The Jury members spent almost 25 hours listening and questioning evidence on the topic and deliberating to come to their final position on the question.

In the final vote on the Jury question, 78% of Jury members concluded that assisted dying should be permitted in Jersey under the following circumstances:

- where a Jersey resident, aged 18 or over, has a terminal illness or is experiencing unbearable suffering and wishes to end their life.
- subject to stringent safeguards including a pre-approval process; a mandatory period of reflection and consideration; with the direct assistance from doctors or nurses only, as opposed to non-medically qualified staff.

This report explains the process the Jury members went through to get to those recommendations. It includes the notes from the group discussions Jury members had illustrating the depth and level of detail the Jury went into.

The Council of Ministers has committed to lodge a report and proposition asking the States Assembly if they agree, in principle, with the Jury that assisted dying should be permitted in Jersey subject to appropriate safeguards. This report will inform that Council of Ministers' report and proposition.

We will conclude by reiterating the overwhelming message from Jury members of the importance of discussing complex, emotive and challenging topics such as this.

## 07. APPENDIX

### APPENDIX A - HOW WE WILL WORK TOGETHER



## APPENDIX B - OUTLINE OF THE JURY EVIDENCE & SPEAKERS<sup>11</sup>

	Content	Speakers	Link to Voting Questions
<b>Session 1: What is assisted dying?</b>	Key background information on assisted dying, including definitions, language and the Jersey context.	<ul style="list-style-type: none"> <li>Hugo Forrester, Mind Jersey</li> <li>Dr Alexandra Mullock and Professor Suzanne Ost</li> <li>Ruth Johnson, Government of Jersey</li> </ul>	<ul style="list-style-type: none"> <li>Understanding terminology and the different modes of assisted dying.</li> </ul>
<b>Session 2: Which people may be eligible for assisted dying?</b>	An introduction to eligibility criteria, processes, safeguards and authorisations	<ul style="list-style-type: none"> <li>Dr Isra Black, University of York</li> <li>Professor Rob George, Kings College London, Guy's and St Thomas' Hospital, St Christopher's Hospice</li> <li>Professor Raphael Cohen-Almagor, University of Hull</li> </ul>	<ul style="list-style-type: none"> <li>Pro and against perspectives</li> <li>Eligibility criteria questions</li> <li>Mode of assisted dying</li> <li>Advance directives</li> <li>Who can administer assisted dying</li> <li>Decision-making: court/tribunal involvement or not</li> <li>Cooling off period</li> </ul>
<b>Session 3: Learning from elsewhere: North America</b>	Cases studies from Canada and Oregon	<ul style="list-style-type: none"> <li>Professor Jocelyn Downie, Dalhousie University</li> <li>Professor Trudo Lemmens, University of Toronto</li> <li>Dr Nancy Berlinger, Hastings Center</li> <li>Robert Preston, Living and Dying Well</li> </ul>	<ul style="list-style-type: none"> <li>Pro and against perspectives</li> <li>Eligibility criteria questions</li> <li>Advance directives</li> <li>Who can administer assisted dying</li> <li>Decision-making: court/tribunal involvement or not</li> <li>Cooling off period</li> </ul>
<b>Session 4: Learning from elsewhere: Europe</b>	Cases studies from Belgium, Netherlands, Switzerland & Germany	<ul style="list-style-type: none"> <li>Professor Sigrid Sterckx, Ghent University</li> <li>Professor Emily Jackson, London School of Economics</li> </ul>	<ul style="list-style-type: none"> <li>Pro and against perspectives</li> <li>Eligibility criteria questions</li> <li>Advance directives</li> <li>Who can administer assisted dying</li> </ul>

<sup>11</sup> <https://www.gov.je/Caring/AssistedDying/Pages/JerseyAssistedDyingCitizensJuryMeetings.aspx>

			<ul style="list-style-type: none"> <li>• Decision-making: court/tribunal involvement or not</li> <li>• Cooling off period</li> </ul>
<b>Session 5a: Different perspectives</b>	Religious and faith-based organisations	<ul style="list-style-type: none"> <li>• Professor David Jones, Anscombe Bioethics Centre</li> <li>• Rev Drew Waller, Jersey Evangelical Alliance</li> <li>• Robert Ince, President for the International Association for Religious Freedom</li> </ul>	<ul style="list-style-type: none"> <li>• Pro and against perspectives</li> </ul>
<b>Session 5b: Different perspectives</b>	Campaigning Groups	<ul style="list-style-type: none"> <li>• Andrew Copson, Humanists UK</li> <li>• Dr Jacky Davis, Dignity in Dying</li> <li>• Michael Talibard, End of Life Choices Jersey</li> <li>• Dr Gordon MacDonald, Care Not Killing</li> </ul>	<ul style="list-style-type: none"> <li>• Pro and against perspectives</li> </ul>
<b>Session 6: Different perspectives</b>	Individuals, loved ones and carers	<ul style="list-style-type: none"> <li>• Alain Du Chemin [pre-recorded]</li> <li>• Paul Lamb [pre-recorded]</li> <li>• Baroness Tanni Grey-Thompson [attended in person]</li> <li>• Anne Pryke [attended in person]</li> </ul>	<ul style="list-style-type: none"> <li>• Pro and against perspectives</li> <li>• Eligibility criteria</li> <li>• Advanced directives</li> </ul>
<b>Session 7: Different perspectives</b>	Health and care professionals	<ul style="list-style-type: none"> <li>• Rose Naylor + Dr Patrick Armstrong, Government of Jersey</li> <li>• Dr Carol Davis, Palliative care consultant Southampton University</li> <li>• Dr John Stewart-Jones, Retired GP and Freedom Church Pastor</li> <li>• Dr Nigel Minihane, GP and chair of Primary Care Body</li> <li>• Professor Sam Ahmedzai, University of Sheffield</li> </ul>	<ul style="list-style-type: none"> <li>• Pro and against perspectives</li> <li>• Who can administer assisted dying</li> </ul>
<b>Session 8: Recap</b>	Reflecting on all the evidence & weighing up	<ul style="list-style-type: none"> <li>• Professor Richard Huxtable, University of Bristol</li> </ul>	<ul style="list-style-type: none"> <li>• Pro and against perspectives</li> </ul>

	position on the Jury question		
<b>Session 9: Decision-making</b>	Hearing result of initial vote & discussing more detailed recommendations	<ul style="list-style-type: none"> <li>• Professor Suzanne Ost</li> </ul>	<ul style="list-style-type: none"> <li>• Eligibility criteria questions</li> <li>• Mode of assisted dying</li> <li>• Advance directives</li> <li>• Who can administer assisted dying</li> <li>• Decision-making: court/tribunal involvement or not</li> <li>• Cooling off period</li> </ul>
<b>Session 10: Decision-making</b>	Discussing more detailed recommendations	<ul style="list-style-type: none"> <li>• Dr Alexandra Mullock</li> </ul>	<ul style="list-style-type: none"> <li>• Eligibility criteria questions</li> <li>• Mode of assisted dying</li> <li>• Advance directives</li> <li>• Who can administer assisted dying</li> <li>• Decision-making: court/tribunal involvement or not</li> <li>• Cooling off period</li> </ul>
<b>Additional Meeting – Voting Results</b>	Hearing the final vote results and & reflecting on Jury Members’ experience of the process overall		

## APPENDIX C – INITIAL VOTE ADDITIONAL DISCUSSION NOTES

These are the notes from the group discussions Jury members had before the initial vote.

### Medical staff

- Would it make medical staff very nervous, not got a lot of comfort from medical staff that presented.
- Not put them in a compromising position.

- Would it impact medical staffing here? Would have a problem if it affected us recruiting medical staff.
- What support would be in place for the medical staff if vote goes ahead?
- See additional point under “Governance” below.

## General support needed

- Support for families if someone chose to go down the AD route?
- Mental Health side, support network for mental health sufferers.

## Missing information

- Have we just skimmed the surface, have we gone deep enough?
- Have we covered a spiritual viewpoint (not religious)? Science now being looked at and discovered, near death experiences being logged and recorded.
- Lack of actually understanding fully the process of AD and failings in the process.

## Quality of life

- Some do not have a joyful life near their end.
- Where does your mind go in the process of dying...focus on the joys of life has been totally missed.
- This process has not focused on life and the joys of life.
- No quality of life.

## Cost

- Still unsure if it goes ahead, how does the funding work?

## Ethical issues

- Wouldn't want to be a burden on self or others [this was a reason in favour not against].
- All life is special.
- Death isn't always beautiful, we need to talk about it and educate about it.
- Thought of having to travel to Switzerland to die is awful as person has to be slightly healthier. Dying at home is preferable.
- Only a small number will use it.

## Scientific developments

- Man is already stepping in to keep people alive.
- Are we in this position because we are intervening so much already e.g. machines?
- We are already intervening with advancements in medicine and use of machines to keep people alive artificially with little quality of life.

## Governance

- The governance and the possibility of properly governing the process.
- Safeguarding ALL vulnerable people, not used to advantage.
  - I would second that point, I worry that it might be abused to a certain extent.
- To me the most important point are...is the number of medical staff suitable and are there enough to make it viable? Is there the possibility of a good governance process, is safeguarding likely to be suitable - linked to the social issues that people have mentioned re the reasoning for wanting to use the process & are our own social structure suitable?
- Need robust processes, but there will always be vulnerable people.

- Can we actually do this? Jersey hasn't got the resources to do what we want them to do. Cannot look after kids, never mind vulnerable people.
  - AD is a very difficult road to go down.

## Palliative care

- Can't lose the point that we don't have enough resource in that area [palliative care] and that it needs to be a hand in hand discussion.
  - Not a palliative care OR AD discussion (PC needs more money!), should be run in parallel.
  - Not mutually exclusive.
  - Palliative care & AD can coexist.
  - Palliative care and Assisted Dying should be part of a suite.
- Hospice doesn't cover all illnesses.
- Palliative care is not for everyone.
- Most health care professionals see it in different camp: Palliative care and Assisted Dying.
- For some people hospice care is not fantastic. Give them another option.
  - Life is precious, need more than one option.
- Being able to die at home is important as part of palliative care or Assisted Dying.
- Personal view not important. It is about giving people a choice of Palliative Care or Assisted Dying. No one to be forced.

## Personal stories

- Imagining myself in the same position.
- Personal accounts from both sides have really hit hard. Overall, what I want to happen, only positive things going forward.

## Choice

- Pro choice.
- I would want the choice.
- People want the option of AD if everything else hasn't worked.
- Individuals will exhaust other options first - they just want assurance that it is a choice if they need it.
- We think it is the right thing to do for animals, but we don't give humans the same respect.
- Unbearable suffering.
- Relief from suffering should be available to people. People should be allowed to make the decision themselves.
- Death is painful - do I continue with the suffering, or do I have a choice to say that now is enough?
- People respond differently to their pending death. Their own experience informs their choice.
- Should be able to stop the suffering when sane and able.
- Respect different choices and religious views but... Why should someone have to live a few months in agony because another person says they should?
- Your choice not to distress your family - good memories for everyone not harrowing ones.
- We should be allowed to have the death we choose.
- It should be a choice. Not everyone would want AD or palliative care.
- Alain Du Chemin. How can anyone make a decision on how he chose to die.
- It's about choice.
- We must have both options - palliative care and/or assisted dying.
- Your choice not to distress your family and loved ones.

- Allowing a person to die with dignity.
- Why should someone else tell you that you have to continue suffering, because their views are different to your own.
- If someone wants to go to Dignitas we will support them (rather than set it up here).

### Other comments

- We cannot trust these people [it was not clear in the notes who this was referring to but Jury members were encouraged throughout the process to contact the delivery team with any questions and the Independent Advisory Panel were present to observe sessions for fairness if this was regarding the process].

## APPENDIX D - INITIAL VOTE COMMENTS

These are the comments Jury members added to their initial vote forms sharing their individual perspectives on the question.

### Governance/management/safeguards

- I don't think it's possible to govern it to an acceptable standard.
- Safeguarding of vulnerable people is an absolute must.
- Safeguards need to be put in place and people's choice respected.
- I think that strict regulation and a robust multi-disciplinary team (MDT) process are needed to safely and appropriately offer an assisted dying service here in Jersey. I also believe an audit of palliative care and hospice care should also be completed with public consultation on their experiences.
- Assisted dying should be permitted with safeguards.
- That strong safeguards are to be put in place from a medical perspective to protect the vulnerable people looking to participate in assisted dying.
- Assisted Dying should be permitted and accessible to the population, although, strong guidelines and procedures should be put in place to protect the vulnerable.

### Cost

- Government of Jersey IF approved must have NOTHING to do with it other than necessary funding if required. No involvement otherwise they will bugger it up like everything else on the "old boys' network" 😞.

### Choice

- I think that people should be given the choice. Nobody should be told how to die by others.
- Everyone should have a choice to how they die.
- The right to choose should be available.
- The key is the individual's free choice.
- I believe in the human right of choice.

### Views against assisted dying

- Further to last night's meeting I would like to convey my concerns at some of the comments made. patronising comments and leaving your sound unmuted and sighing loudly because one mentions faith or religion is not an open debate. clearly this is a pro jury from the start and as far as I'm concerned very little debate has taken place, despite overwhelming evidence that safeguarding measures are not and have not been implemented satisfactorily in countries that practice euthanasia, yet the jury members seem to think somehow this can be addressed adequately in Jersey with as yet no convincing alternatives. One comment was made that this debate is about death not life. I find this extraordinary when in fact for many of the population in Jersey this is exactly what this is about, life the very sanctity of life and how every single life has a value right up to the end. I find it disappointing that somehow faith and afterlife have little or no room in this debate. A subject so profound cannot in my opinion be taken so

lightly and at the very least demands Island wide debate and the opportunity of the citizens of Jersey to see and hear some of the truly shocking consequences of passing such a law. There has been clear evidence from relevant speakers that this is not a matter for the medical profession but clearly if there were to be any form of euthanasia it is put in the hands of judges under the legal system.

### Palliative care/other options

- As long as this does not, under any circumstances, diminish the importance of options/palliative care.
- I have chosen to disagree on these circumstances as I feel that palliative care within Jersey should take paramount and become stronger therefore providing residents with more support. Alongside supporting both nurses and doctors - we as individuals have to take into account that our health professionals take an oath to support the living and although sadly some people wish to leave on their own terms due to circumstances it's unfair to put this on our incredible health professionals. In addition Jersey law needs to change to support those who still wish to travel to Dignitas and their families without prejudice and repercussions upon their arrival home. I feel a relationship needs to be developed with ourselves and potentially Dignitas: other places that offer this to those who wish it and provide islanders with support and wellbeing on their return. I feel ultimately Jersey does not need to adopt this legislation and implement it - due to extensive complex variables - including conflict of legislation/ money/ space/ religion/ etc. - but Jersey does need to facilitate islanders towards this decision and support them through every aspect during a difficult time such as what an individual may face. Jersey is a place where many come to retire and die with dignity. We as an island do not need to do this directly, we just need to do what we do best. Facilitate and Support islanders.
- I think that Assisted Dying should be available for people in Jersey but that alongside the island needs greater Palliative provision.
- See additional point under "Governance/management/safeguards" section too relating to palliative care.

### Importance of discussing this topic

- Death isn't always beautiful we need to talk about it and educate about it and not be frightened.

### Weighing up either side of the argument

- I wanted to strongly agree, but I feel that the circumstances need to be addressed. The way the answers are put does leave me sitting between the 2.
- This is my view after assessing all the information that we have been given.

### Encouraging States Assembly to listen

- I have listened with respect to the argument for and against Assisted Dying. I hope the States of Jersey take the findings of this jury as seriously as we have when coming to their conclusion.

## APPENDIX E – SECOND VOTE ADDITIONAL COMMENTS

These are the notes from the group discussions Jury members had before the second vote.

### Eligibility Criteria

#### Residency

Pros	Cons
<b>Yes, residents only</b>	
<ul style="list-style-type: none"> <li>You wouldn't have death tourism.</li> <li>Save Jersey residents having to go abroad.</li> <li>Family can be around people when they die.</li> <li>Easily monitored if Jersey only</li> <li>It would stop tourism of people coming to Jersey for AD.</li> <li>Followed by most except Switzerland.</li> <li>Up to other countries to provide AD for their citizens.</li> <li>Less chance of things slipping between the net.</li> <li>Patient will need/ have relationship with doctor, social workers, others.</li> <li>Know individuals well, their journey.</li> <li>Only 3 -4 people would request AD in Jersey - taken from Dignitas collective record.</li> <li>Could start in Jersey, embed the process and THEN open it out wider, say to the UK etc. - staged process.</li> </ul>	<ul style="list-style-type: none"> <li>Cost element - the cost of maintaining and having may be better suited if more people could take up the option - it could be an argument for.</li> <li>Repercussion for health professionals and relationship with reg bodies. Do not want them to be impacted.</li> <li>Definite NO to offer AD to anyone who is non-UK resident.</li> <li>Ending life is murder - don't want to be a holiday destination. I will challenge all the way! [relates to non-residents &amp; residents].</li> <li>People moving to Jersey to use AD process - term and length of residency.</li> <li>Residency law is complex.</li> </ul>
<b>No, not residents only</b>	
<ul style="list-style-type: none"> <li>For some it's easier to come to Jersey than Switzerland.</li> <li>Cost element - the cost of maintaining and having may be better suited if more people could take up the option - it could be an argument for.</li> </ul>	<ul style="list-style-type: none"> <li>People coming from UK to here - this will be extenuated by Covid - there is a backlog of people waiting for care so people may feel more pushed to come to Jersey for healthcare or assisted dying.</li> <li>Being part of 'British Isles' community. If not allowed to come we are not participating in a 'community spirit'.</li> </ul>

<ul style="list-style-type: none"> <li>• Don't like idea of making people travel far and incur inconvenience of seeking AD.</li> <li>• Open up AD to UK residents as a first step.</li> <li>• UK residents - able to die in a nice way surrounded by family. Lower costs. Dignified.</li> <li>• Less expense for UK resident to travel to Jersey.</li> <li>• We rely on NHS esp. Southampton Hospital when cannot be treated in Jersey. Issue of fairness.</li> <li>• Jersey has faced controversy before. Finance sector.</li> <li>• Private non-resident people to make it financially viable for Jersey residents.</li> <li>• But by sharing the WHY, Jersey could be seen as forward thinking....*</li> </ul>	<ul style="list-style-type: none"> <li>• Information re. patients could be lost between UK and Jersey - notes may not marry [with] miscommunication about healthcare across different jurisdictions.</li> <li>• Non-residents who are suffering may not have the access they want.</li> <li>• Currently if you need an operation, you could be stuck on a waiting list - you wouldn't want a similar situation with AD.</li> <li>• For some people in Jersey - people are going to England.</li> <li>• Jersey does not want to be seen as the death island.</li> <li>• Ending life is murder - don't want to be a holiday destination. I will challenge all the way! [relates to non-residents &amp; residents].</li> <li>• Concern about infrastructure, funding etc.</li> <li>• You won't know what access to services people have had.</li> <li>• Ludicrous.<sup>12</sup></li> <li>• Cooling off period may be sped up.</li> <li>• 'Tourism' aspect, and it's an awful phrase...</li> <li>• Tin of worms for people living in Jersey... and certain groups.</li> <li>• Limited No. of consultants in Jersey, may put more stress on our resources than what we gain financially.</li> <li>• If we opened it up it would probably gain a lot of negative attention/media. BUT would this be only temporary?*</li> </ul>
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## Residency - Additional points from the discussion

### Only Jersey residents

- After 6 months of living on Jersey healthcare is open to you if it's only for 6 months you could have people moving to the island for assisted dying.

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<sup>12</sup> A participant asked for further clarity on the meaning of this point during the participant review stage of the report. There was no further context in the discussion notes to explain more context to this comment therefore it is difficult to infer the exact meaning of this comment.

- Hopefully it will reduce suicides.
- With assisted dying I don't think people should be allowed to go private - it's not fair.
- Ensure it is not a money-making service.
- Jersey is a Crown dependency and linked to the NHS so do we want to exclude the UK? UK has helped Jersey enormously during the pandemic. Unsure of numbers involved.
- If hospices are involved it would add a layer of control. Unsure if they want to be involved.
- Important issue. Family (Jersey born and non-Jersey born) need to be able to accompany the dying without legal threat of aiding and abetting if offered to Jersey and/or non-Jersey residents.

### **Not Jersey residents only**

- Real clarity needed on residency status to avoid opportunistic residency application for AD.
- Happy to offer to UK residents but not sure whether they would accept it as currently illegal.
- Would it be legal for UK resident to come to Jersey? Problematic - Like travelling to Dignitas currently.
- Condition - Diagnosis while living and working in Jersey. Shouldn't show intent to move to Jersey for the purpose of AD.
- Suggestion re residency - Could be similar system to accessing health services (whether qualify).
- Condition - palliative care team should be involved, people clear on options.
- Wider social issue re: not looking after some in society.
- Polish & Portuguese community are being abused - poor housing etc. How will we look after them?<sup>13</sup>
- Issue for Jersey residents as well, poor conditions etc.
- Thought it would be an easy decision, but it's not... in order for it to be available to Jersey residents there might have to be an in between, to make it financially viable...?
- Given size of population of Jersey, we might need to open it up... BUT would have to be put in a wait list and not be 'higher' up the list if they pay.
- What are the numbers from the UK using Dignitas?
- Alain pointed out how expensive it was to use Dignitas, and it was out of reach financially to many, would it be so for Jersey?
- Where would it take place?

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<sup>13</sup> A participant asked for further clarity on the meaning of this point during the participant review stage of the report. There was no further context in the discussion notes however we would point readers to themes around safeguarding throughout the report to add further context from wider Jury discussions. This includes the [Key Messages to the States Assembly](#) section and “Safeguarding & Support” section in [Appendix H](#).

## Health

Pros	Cons
<b>Terminal illness</b>	
<ul style="list-style-type: none"> <li>• If they have just been diagnosed - people can recover, have extended life, but if it's close to end of life it feels more appropriate.</li> <li>• Given people a sense of empowerment. With their level of suffering they don't feel they have much control.</li> <li>• Assisted dying can include families in the dying and grieving process. It can be empowering for the family, if they can die at home.</li> <li>• Word choice is so critical as some can have same condition but opt for different things.</li> <li>• There is a predicted end to their life, that is where it is going.</li> <li>• Prefer cautious approach - keep it limited.</li> <li>• Fear of excluding whole thing [AD as option] therefore focus on physical &amp; terminal illness.</li> <li>• It means people don't have to go to Dignitas earlier than they would want to.</li> <li>• Fairer as currently poor are excluded as [they] can't afford to go to Dignitas.</li> <li>• All agreed this should be included as an eligibility requirement.</li> <li>• Should be for both Terminal and unbearable suffering... Should be about choice.</li> </ul>	<ul style="list-style-type: none"> <li>• Maybe the ability to trial something that may reverse decision.</li> <li>• You could outlive your diagnosis considerably.</li> <li>• Mental capacity to decide - what is the level of mental capacity that is needed to make the decision?</li> <li>• 6 months is tricky.</li> <li>• 6 months - doctors can get it wrong, people can live longer.</li> <li>• Issue can work both ways.</li> <li>• Family members can have own agenda - can focus on 6 months. [Concern re abuse and coercion]</li> </ul> <p><b>Cons for both terminal illness &amp; unbearable suffering</b></p> <ul style="list-style-type: none"> <li>• Vulnerable people die before their time if they fall between the net - examples from other countries with AD [general concern about AD].</li> <li>• Things change &amp; seem dark at one moment, but they may get better [general concern against AD].</li> <li>• AD doesn't always work and may not be dignified [general concern about AD].</li> </ul>
<b>Unbearable suffering</b>	
<ul style="list-style-type: none"> <li>• Alleviate unbearable suffering.</li> <li>• It's good for people who are severely disabled to know they are recognised in this - they should be allowed to make the choice if they are ready.</li> </ul>	<ul style="list-style-type: none"> <li>• Ethical question for doctors can muddy the waters as they have to form an opinion of what is unbearable suffering.</li> <li>• Unbearable suffering can be different for different people - the question of what is unbearable suffering is more difficult to define.</li> </ul>

<ul style="list-style-type: none"> <li>• Should the families suffering be taken into consideration? If they are looking after someone who has a severe disability. There are different level of disabilities.</li> <li>• It gives people peace of mind - I don't need to worry about how painful it's going to be in the end.</li> <li>• Important addition to the Canadian model. At least 2 requests for AD and there is a clear interval of time between them.</li> <li>• Section 6c of Canada - unbearable suffering resulting from a physical condition and not purely mental health.</li> <li>• Prefer the Canadian model but NOT include the latest mental health additions coming in force in 2023. Specificity of the 6 eligibility criteria.</li> <li>• People should have the choice.</li> <li>• The ability to make own choice makes life precious.</li> <li>• It's because it is what I would want.</li> <li>• Pro &amp; suggestion: Better to have a full understanding from the outset (and include unbearable suffering), rather than having a small / narrow remit (i.e., just terminal illness) that expands over time.</li> <li>• Sanctity of life means you can make your own decision.</li> <li>• Years of a chronic illness can be just as bad as terminal.</li> <li>• If it were unbearable AND incurable and/or irreversible - Acts as a safeguard...</li> <li>• No prognosis it would get better for them.</li> <li>• Should be for both Terminal and unbearable suffering... Should be about choice.</li> </ul>	<ul style="list-style-type: none"> <li>• Difficult to define unbearable suffering.</li> <li>• A safeguard for depressed person changing their mind from one day to the next. If someone cancels their first request for AD, then they have to completely restart the process (i.e., make a fresh new first request).</li> <li>• Subjective e.g. pain.</li> <li>• It's complicated.</li> <li>• Safeguarding more challenging.</li> <li>• Pain is subjective and life is precious.</li> </ul>
<b>Physical conditions only, or mental conditions also?</b>	
<ul style="list-style-type: none"> <li>• More conditions that are included the more it can help. There is a caution here re safeguarding.</li> </ul>	<ul style="list-style-type: none"> <li>• Concern palliative care could be neglected in terms of resourcing.</li> </ul>

<ul style="list-style-type: none"> <li>• For physical conditions only.</li> <li>• Should be only available to physical conditions.</li> <li>• All agreed that it should be for physical conditions.</li> </ul>	<ul style="list-style-type: none"> <li>• The more conditions you include the more doors it opens. - lots of paper work for people to go through.</li> <li>• It could be perceived as suggesting options to people who may not have considered it before - not sure this is a good thing.</li> <li>• People with dementia - family could say they told me..., but the patient may not remember or vice versa.</li> <li>• Healthcare professionals may see it as a way of saving budget.</li> <li>• No to those with mental conditions. Initially offered to those with physical conditions.</li> <li>• Very difficult with dementia - condition goes up and down. Some live quite happy lives. Music is a great joy; it triggers memories.</li> <li>• Mental Health considerations too difficult to tackle.</li> <li>• Mental conditions are a minefield; would need to be split down even more under what we MEAN by mental conditions, many different parts of mental health?</li> <li>• Too BROAD - if we were to include mental conditions HAS to be broken down further.</li> <li>• Dementia, depression, schizophrenia etc...</li> <li>• Person has to be of sound mind; if you have a mental condition, are you of sound mind, what would be the legal standing?</li> <li>• A mental condition can manifest into a physical condition so acts as a 'bridge', could be used as a way round the criteria.</li> <li>• It is not a terminal illness.</li> <li>• You aren't fully there.</li> <li>• Major concern.</li> <li>• Concern that this could happen over time (slippery slope).</li> </ul>
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	<ul style="list-style-type: none"> <li>• Safeguarding concern.</li> <li>• People will gradually demand this, which is a concern (slippery slope).</li> </ul>
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## Health – Additional points from the discussion

### Terminal illness & unbearable suffering

- Need to find a balance between Death should be imminent and level of suffering.
- I don't think it should be 1, 2 /3 it should be a group of things.
- Having doctor's view weigh more heavily in cases where they have a short time to live.
- Need for a multi-stakeholder robust safeguarding process (not like the Belgian model). To ensure people are not being forced especially in cases involving disability.
- Decision making must be over a prolonged period of time.
- Need reflection period [having decided to choose an assisted death].
- Speak to palliative care so aware of options.
- Need legal process, and many people involved, it shouldn't be an easy option.
- Depression cases are difficult to assess. Need to look at time frame for 2 requests. Avoid making the decision when they are at their lowest and most vulnerable.
- Would need a very robust process in place...
- Should not be that anyone with a disability should be considered if not meeting the unbearable, incurable and irreversible...
- Have to be in unbearable suffering - which is subjective in itself.
- The conversation [about AD in Jersey] doesn't stop here [with the Jury].

### Mental health conditions

- The choice should be able to [be] made so long as there is a good standard of palliative care alongside the decision-making process. It should be available as an option alongside palliative care.
- Feel all these should be rolled into one and each case should be considered on its merits.
- We need a living will for people with dementia - if I have this ... I want this outcome. There is a need to consider the quality of palliative care - drugging people to numb/ to manage them is not a good way to treat people.
- I definitely think it should be a choice for people with dementia!
- Ensuring states budget is put into mental health.
- Anything to do with power of attorney should NOT be recognised in AD process.
- Some MAY be concerned if certain mental conditions are excluded, such as dementia, but some of these conditions DO become physical in later stages?
- CARE re inclusivity if we agree it's only for certain MH conditions...?

- Being too scared to do or agree something in itself is excluding as you're not giving the option.

### Age

Pros	Cons
<b>Over 18s only</b>	
<ul style="list-style-type: none"> <li>• Yes. Initially only for over 18s.</li> <li>• Under 18s with terminal illness can be looked at in the future. But not initially.</li> <li>• This fits with current law.</li> <li>• All agreed should be over 18s.</li> </ul>	<ul style="list-style-type: none"> <li>• It's not choice if U18's can't choose.</li> </ul>
<b>Under 18s</b>	
<ul style="list-style-type: none"> <li>• Gives children the same sense of ownership as adults would get.</li> <li>• Would enable children to be heard.</li> </ul>	<ul style="list-style-type: none"> <li>• People have a different perception of risk to adults - less risk averse. They tend to think in the moment.</li> <li>• Children don't verbalise - everything to them is a big deal - they don't have the knowledge of language to verbalise things in the same way.</li> <li>• Hormonal changes and impact on growing bodies adds extra vulnerability to young people.</li> </ul>
<b>Under 18s in limited circumstances</b>	
<ul style="list-style-type: none"> <li>• Terminally ill with significant suffering in last period of life.</li> <li>• Someone who is under 18 should have the option not to experience suffering when they have a terminal illness.</li> <li>• BUT conditions should be much tighter...</li> <li>• Have to include parental consent.</li> <li>• It should go back to incurable, unbearable suffering and irreversible?</li> <li>• 15 as a reasonable threshold.</li> <li>• Age could be lowered, not always talk about 18 year old - often used as an entry level age?</li> </ul>	<ul style="list-style-type: none"> <li>• If parents are not available, where does consent end?</li> <li>• What about orphans?</li> <li>• Where do you draw the line re age?</li> <li>• Should not be a medical professional's decision?</li> </ul> <p><b>Also for 'Under 18s'</b></p> <ul style="list-style-type: none"> <li>• If legislation says under 18 don't have capacity (capacity and self-determination law) then it shouldn't happen.</li> <li>• Doesn't sit comfortably - children's brains are not fully developed.</li> </ul>

	<ul style="list-style-type: none"> <li>• Children don't ask to be put to death on hospital wards.</li> <li>• Horrific and awful.</li> <li>• Concern other people would be making choice on behalf of child and worry about safeguarding.</li> <li>• Everyone fights for a child's life.</li> <li>• Worry about putting child through pain but on balance no to under 18s including in limited circumstances.</li> <li>• Allowing child to be put to death is murder.</li> </ul>
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### Age – Additional points from the discussion

#### Over 18s only

- Age is a hard way to look at it - people grow up at different times.
- Very sensitive point, as a society we protect our 'minors'. Who would have the final say for a person under 18? Parents or doctors

#### Under 18s

- Who would have the final say for a person under 18? Parents or doctors.
- Question about foster children or children in care? who would represent their views?
- Has to be looked at on a case by case basis.
- What about a 16 year old, that has a child, can make a parental decision but can't make a decision for themselves?!
- NO suffering is less or more for an U18.
- Should we treat U18's any differently to adults?
- No difference re capacity to make a decision for a 15 - 18-year-old to an adult, choice should not be taken away from them.

#### Under 18s in limited circumstances

- I don't see why we should treat a child differently if they have terminal illness or if they are suffering unbearably. It needs to be considered on case by case basis because children mature differently.

## Mode

Pros	Cons
<b>Only physician-assisted suicide (PAS)</b>	
<ul style="list-style-type: none"> <li>• This allows people who are able to decide when and how they take the medicine.</li> <li>• Someone medically qualified (Dr/nurse) to make sure it is done correctly.</li> <li>• Person is in control to the very end.</li> <li>• You hold the final choice - every opportunity to change your mind.</li> <li>• Prefer person to administer it themselves.</li> </ul>	<ul style="list-style-type: none"> <li>• Concerns that Jersey ends up with a death doctor - only one doctor who would administer - need to safeguard the healthcare professionals.</li> <li>• They could keep the prescription - would have to be done with a physician in the room. Question why not? Can't have deadly drugs in your home, need to set a date on when you would like to die.</li> <li>• May not complete the event / it may not work.</li> <li>• Liquid doesn't always work.</li> <li>• Suicide by another name [Against PAS &amp; AD].</li> <li>• There are positive stories of people coming out of it (PAS not working), and then deciding that they don't want to take their life.</li> <li>• Look at other countries and where it hasn't worked and the suffering that it has caused.</li> <li>• Safeguarding - pills go missing, careful it can't be stored!</li> <li>• What if patient can't administer?</li> <li>• Can't make a physician provide the medicine.</li> <li>• How to manage risk: it could be stolen or given to someone else.</li> </ul>
<b>Euthanasia</b>	
<ul style="list-style-type: none"> <li>• I see euthanasia more for people on life support.</li> <li>• Need it done properly and with peace and dignity.</li> </ul>	<ul style="list-style-type: none"> <li>• May not be health professions who would be willing to do it.</li> <li>• Patient in a coma cannot consent to euthanasia.</li> </ul>

<ul style="list-style-type: none"> <li>• But only with agreement or pre-agreement (voluntary).</li> </ul>	<ul style="list-style-type: none"> <li>• A lot of people are not familiar with death so may find it painful and uncomfortable.</li> </ul>
<p><b>Both PAS and euthanasia</b></p>	
<ul style="list-style-type: none"> <li>• Group generally feel they'd like to support both.</li> <li>• Both - caters to people in comas.</li> <li>• Autonomy is important especially given all the hurdles they have to go through.</li> <li>• If you can't swallow you would need an injection?</li> <li>• PAS is more preferable, but euthanasia for those unable to take control.</li> <li>• There is a risk the first one might fail [pills don't work], therefore good contingency to have euthanasia.</li> <li>• It is a fail-safe - there has to be a follow up plan in case PAS doesn't work.</li> <li>• Should be both.</li> <li>• Combination of both.</li> <li>• Should be both, but assisted, not euthanasia, should be the default.</li> </ul>	<ul style="list-style-type: none"> <li>• You need to believe it works. You need to decide which it is - you can't have both.</li> <li>• Humans aren't meant to end other people's lives - who would do it?</li> <li>• Family members may influence or force family members.</li> </ul>

Mode – Additional points from the discussion

**Other points from the discussion – only PAS**

- I think there should be a physician to pronounce you are dead.
- Patient needs all the information first - including that the pill may not work.
- Safeguards are essential.
- Judiciary needs to be involved (not doctors).

**Other points from the discussion – euthanasia**

- I think you should set a date for when you take the medicine.
- Question about when and where the medication be taken. Would it be a booked appointment or would you have total freedom to take it when you choose?
- Need to inform a medical profession that death is imminent to pronounce them dead.
- Dosage has to [be]used within a distinct time period or returned to a safe location.
- Managing euthanasia can be a deep rabbit hole.

- Person does not full autonomy about when they can die. Need someone else present. Limiting but necessary to control what happens to dosage.

### Other points from the discussion – both PAS & euthanasia

- Needs to be more than one person who hears the case / on the Board; it would be good if the "board" had some independence - there needs to be a structure in place to start with and then it could be reviewed once more is understood about the scale.
- The process would start by going to your family doctor/ should there be a certified board who would assess your decision. We have volunteers to be on the board!!
- Family being involved is your decision.
- The form of lethal dose is important. Liquid form is less open to abuse than a pill.
- There would need to be an advanced decision process in the event it doesn't work. [PAS doesn't work]
- Would there be cost differential if you choose one over the other?
- In both circumstances would still need medical professional/physician present.
- If we had the advanced notice, you will need a euthanasia option.

## Regulations & Safeguards

### Court or tribunal involvement

Pros	Cons
<b>Just doctors &amp; health professional</b>	
<ul style="list-style-type: none"> <li>• Your GP is your primary carer and will have known you for a long time.</li> </ul>	<ul style="list-style-type: none"> <li>• There needs to be a discussion with BMA to allow Jersey doctors to do this.</li> <li>• There needs to be doctors or nurses who are willing to do this.</li> <li>• It shouldn't be in the hands of one person.</li> <li>• GPs don't always know you very well.</li> </ul>
<b>Should there be approval before AD takes place, e.g. courts, tribunals</b>	
<ul style="list-style-type: none"> <li>• A good safeguard to have more people involved and look into the issues more.</li> <li>• Signed off by a court so adding a legal layer to protect medical staff.</li> <li>• Legal side is a safeguard.</li> <li>• Final answer must be a judge (there has be someone beyond GP, POA).</li> </ul>	<ul style="list-style-type: none"> <li>• How quickly can they move if time is a critical factor? Is it a reasonable thing to rush?</li> <li>• Safeguards aren't being carried out.</li> <li>• POA is a concern.</li> <li>• Legal process is very expensive.</li> <li>• 'Ambulance chasers'.</li> </ul>

<ul style="list-style-type: none"> <li>• Charities could be part of the tribunals - they would have a safeguarding role.</li> <li>• Similar to a major surgery.</li> <li>• Panel of Dr's, experienced with AD and palliative care.</li> <li>• Should be a legal review of some kind - if open to non-residents or if someone opposes.</li> <li>• Panel representatives from different specialisms; neurological, surgeon, psychiatric etc. Give an overall assessment.</li> </ul>	<ul style="list-style-type: none"> <li>• Getting a panel together every time.</li> <li>• Would you need to know medical professional's views on AD, as their personal beliefs may affect the decision making (those on a 'panel').</li> </ul>
<p><b>Additional discussion of pros and cons of review after AD has taken place</b></p>	
<ul style="list-style-type: none"> <li>• A self-check. Provides feedback to the government.</li> <li>• Composition of approval ethical panel + post AD review/scrutiny. Must include lay people, medics, lawyers. Not government run. Compassion-centric approach.</li> <li>• This will ensure all procedures are followed and observed.</li> <li>• Every case should be scrutinised even if they did not go through with AD.</li> <li>• Ongoing review, legal requirement, those involved have to be 'reported'/documented.</li> <li>• Need all.</li> <li>• The end of a life is a legal process as well - need to go through medical and judicial steps. Doctors can't cover all of this.</li> <li>• You must have two doctors and the judiciary and best practice.</li> <li>• There needs to be a multidisciplinary team and the judiciary is needed too.</li> <li>• It shouldn't be in the hands of one person.</li> <li>• All are necessary.</li> </ul>	

Court or tribunal involvement – Additional points from the discussion

#### **Approval before the assisted death**

- First & foremost the individual has to ask for assisted dying. They would go to their GP, (regulations for Jersey nurses & doctors needs to be changed to allow them to hear and discuss potential cases). Alternatively, someone could approach their palliative care provider. Could it be part of the question re DNR.
- Patient notifies someone they want to access AD & put request to Board.

- The group is in agreement that there should be a board to approve the decision. You agree the decision should be made by more than once person. 2 medical - (1 physical, 1 psychological), 1 legal, 1 independent.
- Cooling off period of 3 weeks in which time the Board has considered and advised if case is approved.
- Check with patient after min of 3 weeks.
- Even if legalised, you have a panel that doesn't agree it will go nowhere.
- If there is tight governance before that covers both medical and legal, there should be no surprises after.
- Panel members might need to sign up to a list to participate - opt in, and that agree with AD.
- If all the governance etc. is done, the framework is in place, then individual doesn't have to do it.

#### **Review/scrutiny after the assisted death**

- Need a legal advisor involved in board to look over the case prior to decision being made.
- Will the scrutiny report be available to the family after the AD?
- Importance of documenting everything.

#### **Both approval before and review after the assisted death**

- Definitely should be scrutiny after AD takes place to ensure everything is done to standard and in accordance with the law. This will provide good feedback re what may need to be changed down the line.

#### **Other general points from the discussion**

- Family should have a say but not make the decision.
- Individual needs control over who they want to be involved.
- What is best for the individual may not be what the family thinks / wants.
- Family knows person better than anyone else.
- Families suffer because of these scenarios.
- Choice for individual if they want family representation.
- Patients must meet with palliative care team so they know what their other options are before making a decision.
- Concern palliative care is for cancer patients only.
- Palliative care is needed in hospitals not just the hospice. The process needs to be brought in quicker than it is currently.

## Who can assist/administer the assisted death?

Pros	Cons
<b>Only doctors</b>	
<ul style="list-style-type: none"> <li>• Some people may not have family.</li> <li>• People you have a relationship with for example the medical professional.</li> <li>• Definitely professional MEDICAL staff; Dr's, Nurses and other formal medical staff.</li> </ul>	<ul style="list-style-type: none"> <li>• [No notes].</li> </ul>
<b>Doctors and nurses</b>	
<ul style="list-style-type: none"> <li>• Someone medically qualified to make sure it is done correctly.</li> <li>• Nurse practitioner level only. Some find they are more experienced at administering injections than doctors so better experience.</li> <li>• Some people may not want their family to know.</li> <li>• People you have a relationship with for example the medical professional.</li> <li>• Definitely professional MEDICAL staff; Dr's, Nurses and other formal medical staff</li> </ul>	<ul style="list-style-type: none"> <li>• Concern about junior nurses being involved.</li> <li>• Would need a law change.</li> </ul>
<b>Others e.g. not a qualified medical professional</b>	
<ul style="list-style-type: none"> <li>• IDEA. Person administering is pre-approved by a panel then they do not need to be a Dr/nurse. Ensure process is followed + can spot any change of mind or coercion.</li> <li>• Provide a location where people can go to take the lethal dose so administered properly in presence of someone well trained to follow process.</li> <li>• People who you want at your death can be present free from fear of prosecution.</li> <li>• A lay person, you could nominate yourself.</li> <li>• Appropriate mental health professional present to make sure you are in your right frame of mind, said your peace - But be</li> </ul>	<ul style="list-style-type: none"> <li>• Would need a law change.</li> <li>• Lay person can't do euthanasia.</li> <li>• Safeguarding - pills go missing (PAS), careful it can't be stored!</li> <li>• Someone could take medication themselves.</li> </ul>

careful as there is a lot of variation in the mental health profession.	
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### Who can assist/administer the assisted death? – Additional points from the discussion

#### Doctors/doctors & nurses

- EVERYBODY involved should be documented as having been involved.
- As long as medical staff are comfortable being involved and have an opt out option.
- Would need medical staff present to ensure patient IS the person administering.
- Doctors and senior nurses or specially trained nurses.

#### Others e.g. not a qualified medical professional

- Crucial underlying concern. The need to have someone present to rule out foul play and last-minute change of mind.
- Need to consider who can help someone administer the lethal dose.
- What does involved mean, what is assistance?
- Can there be a process where assisters are approved by the board? so designated people can be identified and exempted from prosecution.
- NO, should NOT be anyone who is NOT a medical professional.
- BUT what about if a patient wanted their partner to assist? Or someone else, at request of the patient?
- OR would want someone else assisting; faith based?

#### Other general points from the discussion

- Should not be one person - we would be happy if there were two.
- Group undecided on if family have the right to know your plans to die or not.
- this feel like the slippery slope - could be open to misuse.
- The individual involved has to feel empowered and in control throughout - they are the most important in the whole process.
- The person should be able to nominate who it is - whether doctor, layperson, family member.

#### Cooling off period

Pros	Cons
<b>Not necessary</b>	
<ul style="list-style-type: none"> <li>• [No notes].</li> </ul>	<ul style="list-style-type: none"> <li>• [No notes].</li> </ul>

<b>Necessary</b>	
<ul style="list-style-type: none"> <li>• 2 possible scenarios. Scenario 1: 2 step request process with time interval of say 2 weeks where request is reaffirmed. Scenario 2: lack of time - need a ruling that caters for that.</li> <li>• Yes - there should be.</li> <li>• Empowerment you are in control - you can call it off if you want to.</li> <li>• Death is scary, unknown is scary. It may not be as bad as you fear. This [cooling off period] means you can change your mind. Then, the option is there if it is so unbearable and it brings calmness, less painful way out.</li> <li>• It needs to be recorded as well.</li> <li>• Option to change mind, don't feel forced within a timeframe.</li> <li>• It needs to be a thought through act.</li> <li>• If they change their mind, request, then change mind, then request again, the 2nd request starts as day zero again.</li> </ul>	<ul style="list-style-type: none"> <li>• Coercion may still be an issue, even with cooling off period. Do they really have the freedom to change their mind?</li> <li>• You will always be fronted with abuse, but it doesn't mean you shouldn't offer what was originally intended.</li> </ul>
<b>Depends on the circumstances</b>	
<ul style="list-style-type: none"> <li>• Length of cooling off period depends on how serious the situation is. A request could be made to the board to shorten the period if extenuating circumstances.</li> <li>• Allows those where death is imminent or in constant pain to not prolong the process with a cooling off period.</li> <li>• Always retain right to say no up until the last moment.</li> <li>• Yes, a cooling off period is necessary - but can be waived if someone has a short period to live.</li> </ul>	

## Cooling off period – Additional points from the discussion

### Cooling off period necessary

- Group agrees there should be some cooling off period.
- If this AD is offered to UK citizens then what are the legal implications and other panels needing to be involved to support the internal Jersey process of Approval?
- Two week period or 10% of their expected life period.
- Consistency in actually wanting it.
- In order to meet eligibility you have a minimum cooling off period, but can change your mind at ANY point.
- But has a clause or waiver option to not have a cooling off period.
- Cooling off period should extendable if need more time, and more than once.

### Cooling off period depends on circumstances

- Who would be involved in the cooling period? And what would they have to consider? Life is always changing.

### Other general points from the discussion

- Life is precious.
- Death is death - don't be frightened of it.
- There is a lack of spirituality - a passing over when it is your time.
- There are also spiritual laws - the consequences of shortening a life. We are mind, body and soul.
- Doctors in Jersey have too much power.
- There must be support and legal things to protect loved ones and the families so they can be there at the end.
- It must be done in a humane way, the right way.
- Will there be mental support to the patient, counselling, or some kind of support?

## Advanced decision making

Pros	Cons
<b>Always no</b>	
<ul style="list-style-type: none"> <li>• No potential for 'others' who have interest in your death having a say.</li> </ul>	<ul style="list-style-type: none"> <li>• People who are near death and cannot longer be on life support will starve and can die a more painful death.</li> <li>• Not have the ability to make the decision.</li> <li>• Person with dementia should not be eligible for AD.</li> </ul>

	<ul style="list-style-type: none"> <li>• Want to log concern about person with dementia given AD Not pro. Risk - unable to remember and possible coercion from family. Dodgy grey areas. Person can be very different at beginning is than at advanced stage.</li> <li>• Concern about safeguarding.</li> <li>• Emotional wellbeing is a factor.</li> <li>• What if people changed their mind but didn't log it.</li> <li>• Little old lady having lethal injection is awful! That memory will stay with me forever. [Case in the Netherlands of woman with dementia]</li> <li>• Mental capacity is tricky.</li> </ul>
<b>Always yes</b>	
<ul style="list-style-type: none"> <li>• Ability to make the decision</li> <li>• More potential to alleviate suffering.</li> <li>• People able to die at a point in a state in which they want to be remembered. Going with dignity.</li> </ul>	<ul style="list-style-type: none"> <li>• May change decision but not be able to communicate it.</li> <li>• Open to abuse.</li> <li>• Potential for other beneficiaries to have a say in your death.</li> </ul>
<b>Yes, but under certain circumstances</b>	
<ul style="list-style-type: none"> <li>• Invaluable option for someone who has complications after a procedure with known high risks.</li> <li>• Person can at any point change their directive.</li> <li>• YES, but under certain circumstances; such as dementia, when physical ailments start to take a hold, or if fall in to permanent coma status.</li> </ul>	<ul style="list-style-type: none"> <li>• Could someone challenge it?</li> </ul>

Advanced decision making – Additional points from the discussion

**Yes, advanced decision making should be permitted, but under certain circumstances**

- Road accident on life support, and medical professions and family agree.

- I think it's a good idea - we need to be careful about this. This is a tricky one! I'm a bit undecided.
- Encourage people to develop living wills for future decisions - part of living will would have to determine when the Euthanasia takes place.
- Need for legal involvement?
- Like a living will or DNR.
- In conjunction with your medical professional, stated in full mental capacity.
- OR no-one SHOULD be able to challenge, legally binding?
- Needs a supporting 'governance' framework, and decision is witnessed, possibly not a family member... maybe two witnesses? Living will?

#### **Advanced decision making should always be permitted**

- DNR adds a layer of complexity to this issue. Needs to be added to the priority list of what happens.

#### **Other general points from the discussion**

- There need to be better medical records.
- Need some way to register like a donor card.
- Need computer records so there are safeguards.
- Capacity assessment has safeguards included.
- If we had a chip in us it would help.
- Medical records are poor here - will you pull out the right piece of paper?
- There are checks for paperwork.
- Capacity assessments do get scrutinised.

## APPENDIX F - SECOND VOTE COMMENTS

These are the comments Jury members added to their second vote forms sharing their individual perspectives on the questions.

### Eligibility criteria

#### Residency

##### UK residents

- With the possibility of UK residents eligible at a later date.
- Look to include UK in near future.
- Jersey has needed the UK during the pandemic and relies on the NHS. Maybe also UK for UK residents.
- I believe it should start as only for residents but if successful it could be opened to UK residents.
- If possible and without complications; UK residents also. I'd be up for the rest of the world too, but I fear that's too much too soon.
- Also, UK NHS patients.
- We should open it to the UK and potentially for the family of individuals that live on the Island.
- We should open it to the UK and potentially for the family of individuals that live on the Island.

##### Residency dependent

- Must be Entitled resident.
- After a minimum residency period.
- I believe anyone who has qualified for healthcare by virtue of the current requirements (6 months residency) should be eligible.
- You must have lived/worked and paid tax for 12 months minimum.
- I would suggest that this service could be offered in line with how other health services are accessed (i.e. minimum length of time needed to live on island to be eligible).

##### Other people after a certain time

- Gradually roll it out to others.
- If possible and without complications; UK residents also. I'd be up for the rest of the world too, but I fear that's too much too soon.
- Yes, to begin with [only Jersey residents]. Maybe scope to make it available to others in the future.

##### Only Jersey Residents

- No further comment, it would not be possible for non-Jersey residents to avail this service due to the length of time that would be required to stay in the island.
- Needs to be Hersey resident to avoid 'tourism'.
- I don't want Jersey to become a destination for assisted dying as opposed to an example of how it can work in a community. I don't feel our health system could afford to support people requesting this service from outside the island.
- We wouldn't want our residents applications to be delayed due to a surge of applications from elsewhere
- It shouldn't be for anyone.

### **Views against assisted dying**

- I do not wish to abstain and want it noted that I am against assisted dying.

### **Health criteria**

#### **Terminal illness**

- Only terminal illness.
- I believe it should be irreversible and incurable.
- I believe terminal illness should apply to all (children's and adults), unbearable suffering should apply to adults from 18 years or over.
- Anyone who has an unusable illness or unbearable suffering (physically or mentally) should be eligible for assisted dying.
- I think terminal illness or unbearable suffering descriptions need to be clearly defined and both should have the caveat of "that cannot be alleviated by other means".

#### **Case by case**

- Should be decided on case by case basis.

#### **Mental conditions**

- A mental condition CAN manifest itself as a physical pain BUT thorough medical examination etc should be undertaken.
- I'm not entirely opposed to mental health sufferers being eligible, but fellow participants made good points about letting other countries trial this out first as it could be a lot for the Government to handle effectively and with the proper care the issue would need.
- Anyone who has an unusable illness or unbearable suffering (physically or mentally) should be eligible for assisted dying.
- I am strongly against AD and mental health should never be considered if in the unlikely event this law is passed in Jersey.

#### **Strict rules**

- Suggest conditions are more restrictive at first, as these will evolve over time.

## Views against assisted dying

- I do not wish to abstain but want it noted that I am against assisted dying.

## Age criteria

### Terminal illness

- But with tighter safeguards for children. Maybe only if terminally ill with a shorter life expectancy. But maybe from age 16+, given they are then old enough to be parents themselves.
- I believe terminal illness should apply to all (children's and adults), unbearable suffering should apply to adults from 18 years or over.

### Unbearable suffering

- Unpopular opinion amongst my peers, but I do believe that one is never too young to know true suffering. To put it down to age as the only qualifier is too cruel. Only in exceptional circumstances would this be permitted as I do somewhat agree that sometimes children wouldn't know better. And, of course, always with the parent's/family's permission.
- I believe terminal illness should apply to all (children's and adults), unbearable suffering should apply to adults from 18 years or over.
- Why should we treat people differently just because of their age? A 15-year-old with unbearable suffering should be viewed as the same as someone who has lived a long happy life, but is now in unbearable suffering

### Change over time

- Should be restrictive at first. Could be eased over time.

### Medical and Parent/Guardian permission

- A girl can give birth to a child under the legal age (and a boy be a father) but that does not mean she/he is of an adult mind so caution must be undertaken should ever such a situation arise. In other cases of a minor the decision must be of the medical professional (more than one) and the parent/legal guardian.
- Unpopular opinion amongst my peers, but I do believe that one is never too young to know true suffering. To put it down to age as the only qualifier is too cruel. Only in exceptional circumstances would this be permitted as I do somewhat agree that sometimes children wouldn't know better. And, of course, always with the parent's/family's permission.
- Permission from parents should be obtained under the age of 16.

### Age limit

- I feel that if an age limit is set it should be lower.
- As the adolescent brain is still developing until our early 20's and as we already have an age of majority in place legally it seems to make sense to continue with that line in the sand.
- Never ever children.

### Challenging criteria to discuss

- I found this area very difficult to consider. I do not want to see any child suffer pain, however when we talk about choice, I understand that the choice should be given to those who are determined to be capacious to make this decision. It is my understanding that the Capacity and Self Determination Jersey Law specifies the age that an individual can be deemed as having capacity (its either 16 or 18) and this should be reflected in this AD legislation. If a child is deemed not to be recognised as having capacity due to the nature of their age, this would mean the decision would lie in someone else's hands/best interest decision, and I do not feel that this is appropriate or supports the pro-choice argument.

### **Views against assisted dying**

- I do not wish to abstain and want it noted that I am against assisted dying.

## **Mode of assisted death**

### **Medical professional**

- At least two unrelated physicians.
- PAS seems to be a bit difficult to regulate, but within the presence of a trained advisor/administrator of the drug would be best to ensure that there's no foul play and that the patient's care and interests are always catered to.
- A medical practitioner should always be present.

### **Individual**

- Person should be able to take drug themself.
- depends if the patient is able to administer the drug or not. Personally I don't really see the problem with either.
- I would have suggested that the final process of taking the medication to end one's life should lie with the individual themselves, as taking the action is the individual making their final choice and acting upon it. However, we must also recognise that some individuals may not be able to physically take a mediation or even conscious to do so, so how can we support these individuals to do so. Perhaps in this case, PAS should be the first option, and if that is not achievable then the option of euthanasia can be reviewed as a multidisciplinary decision/tribunal process. We also considered what happens in those scenarios where the medication taken by PAS doesn't actually end an individual's life. If the individual is unable to take further medication independently, then how is their choice respected? Only Euthanasia would support this.

### **Circumstantial**

- With PAS the default and euthanasia only for those not capable of PAS (maybe due to physical ailment or in conjunction with an advanced directive.
- Depends if the patient is able to administer the drug or not. Personally, I don't really see the problem with either.
- Euthanasia should be used where Physician Assisted Suicide is not possible, due to circumstances beyond our control. I.e the Patient is in a vegetative state.

- I would have suggested that the final process of taking the medication to end one's life should lie with the individual themselves, as taking the action is the individual making their final choice and acting upon it. However, we must also recognise that some individuals may not be able to physically take a medication or even conscious to do so, so how can we support these individuals to do so. Perhaps in this case, PAS should be the first option, and if that is not achievable then the option of euthanasia can be reviewed as a multidisciplinary decision/tribunal process. We also considered what happens in those scenarios where the medication taken by PAS doesn't actually end an individual's life. If the individual is unable to take further medication independently, then how is their choice respected? Only Euthanasia would support this.
- Euthanasia by advanced directive.

### **Views against assisted dying**

- I do not wish to abstain and want it noted I am against assisted dying.
- Against all methods my reasons will be in my statement.

## **Regulations & Safeguards**

### **Court or tribunal involvement**

#### **Court or panel involvement**

- A panel should be with the person from the beginning to the end, making sure they are not being pressured to end their life. Making sure that all is above board.
- Big pro- again, ensures that the procedure is done with absolute care and certainty. Big con- time constraints for the patient. This would have to be a circumstantial.
- Once a court gets involved a precedent is then set and it starts to go down the messy route of legal battles which brings the process into a grey area.
- A Board would take the pressure off of Individual doctors and nurses, whilst being able to undergo scrutiny.
- If this was ever to be passed it should only ever be under a court process.

#### **Review after the assisted death**

- Why should a Court be involved as it once again takes away the decision of the person seeking AD which is the opposite of what they want. A process after the event should happen to determine all efforts were undertaken and that the AD was done legally.

#### **Mix of authorisations**

- Mix of medical, legal and lay person.
- A medical profession can initially determine eligibility is met, have the case agreed with one other doctors, then referred to a panel who can review the case and support or otherwise the request.
- There Should be four people at least. 2 Doctors, 1 Lawyer and one independent.

- A panel of people including medical staff, legal representation and one other appointed panellist/board participant.
- I feel we would need both medical and judicial elements but further to that probably a multi-disciplinary team covering medical, mental, legal, social to have a more complete overview of a case.
- Any Tribunal should be formed with a medical professional, specialist in field of health that has qualified the individual for AD (or at least a testimony), social worker, legal representative as well as input from charitable/support organisations linked with the individual's diagnosis (such as Macmillan for Cancer patients). Family testimonies can be heard, but should not influence the decision without the individual concerns consent.
- The decision should stay with the individual if their mental capacity allows, where it does not allow a court should be involved and a panel of doctors, so the best interests of the patient are assessed.

### **Medical professional**

- Person's Doctor must be involved in the process.

### **Views against assisted dying**

- I do not wish to abstain but want it noted that I am against assisted dying.

### **Cooling off period**

#### **Length of time**

- Must be at least a 2 week cooling off period.
- A cooling off period of 14-21 days unless there is reason to believe that death is imminent.
- There should be a cooling off period of at least 1 months unless someone is not expected to live that long in which case it could be waived.
- A shorter cooling off period should be introduced for anyone with a significantly shortened life expectancy. But a cooling off period should be required.

#### **The cooling off decision process**

- The cooling off period could be amended by the specialist tribunal.
- At least 2 decisions for AD should be made by the patient. The second to confirm or nullify the previous decision.
- If a person says they want AD then within the cooling off period they change their mind then back again the 'clock' starts again.

#### **Change mind at any time**

- At all times right up until the last minute the person can say I don't want to go through with it.
- The patient should be able to change their mind at any time. But to ensure true understanding a period of reflection should be included. Given a person's life expectancy could be limited maybe the shorter of 2 weeks or 10% of life expectancy.
- Patient to retain right to cancel at any time.

### **Obligatory cooling off period?**

- I think a cooling off period should always be required. If for any reason someone's prognosis is less than the cooling off period then although it sounds harsh they will not survive the process of applying for AD anyway, however the safeguard of an unwavering cooling off period will safe guard all going through the process.
- Cooling off period should always be there, extendable at the request of the individual but should not be mandatory for terminal cases where the life expectancy is very limited.

### **Case by case**

- Each individual case must be looked at differently.

### **Views against assisted dying**

- I do not wish to abstain but want it noted that I am against assisted dying.

### **Who can administer assisted dying?**

#### **Medical professionals**

- People who are specially trained to assist is an option. Nurses have a more caring approach and form better bonds with patients, not to say doctors don't, but nurses spend more time with patients.
- While I think loved ones should be allowed to be present. It should be a medical professional who carries out the procedure.
- Assuming a perfect world then lay people should be able to administer, however I feel there should be some medical personnel on hand in case of adverse reactions or complications.
- Someone with no nursing or doctors' qualifications should be nowhere near lethal drugs.
- I think the more you specify it has to be a professional to assist/administer AD the more pressure builds on the individual to complete the action, i.e. the individual can only have the final administration when a doctor/nurse is available which may influence when they do it and not be in their own time.
- Medical staff should always be present to ensure that any lethal drugs are administered to the correct individual.
- 'Other' could be someone appointed by the board who would deal with this case. if medical professionals then a sturdy support package must be in place for them.

#### **Individual**

- Dr may not administer. Individual involvement. Euthanasia.

#### **Patient choice**

- Person chosen by the patient.

#### **Independence**

- There should be an independent observer to ensure proper process and safety.

### **Views against assisted dying**

- I do not wish to abstain but want it noted that I am against assisted dying.

## Advanced decision-making

### Living will

- A 'living will' or directive, maybe witnessed by two independent people, could ensure the patient's wishes can be carried out, if they later meet the Assisted Dying thresholds. The Witnesses must have no financial interest in the persons financial affairs.
- A Living Will or such legal document should be used/obtained.
- In cases of dementia as the person in question would no longer be the same individual. The patient's interest is always first and foremost and they would always be allowed to update this at any given time.
- If somebody has made an advanced decision and it is done within guidelines then this must be upheld as it is their wish.
- This should be in the form of a living decision and be renewed regularly (i.e. every 3 years).
- Available if patient becomes nonresponsive for instance after high risk surgery.
- It should be part of future planning and discussed with a GP.

### Physical capacity

- Losing physical capacity should not preclude people from having the option of AD, however my concern around losing mental capacity is whether the patient would understand, potentially have changed their mind and not communicated it or not been able to communicate it. With the possibility of a person having dementia later in life.

### Tribunal for final decision

- I think like a donor card for organs, an advanced decision could be offered in some circumstances. However, I still feel that a tribunal in these situations need to make the final decision to grant AD on the basis that their diagnosis or suffering "cannot be alleviated by other means". Advanced decisions should also have a mandatory periodic review to confirm their legitimacy and they are in fact up to date.

### Views against assisted dying

- I do not wish to abstain but want it noted that I am against assisted dying.

## APPENDIX G - FINAL VOTE COMMENTS

These are the comments Jury members added to their final vote forms sharing their individual perspectives on the question.

### The Jury process

- A good and proper process to arrive at this people's decision.
- I do not think this voting system has been fair, so I shall be writing to members of the government when the time is right.
- I hope the Health Minister takes into account ALL our thoughts and reasoning into account and make the correct decision.
- I hope the States of Jersey agree with this Jury's recommendations.

### Vulnerable groups

- The vulnerable would still be at risk.
- The vulnerable will be at risk.

### Patients' rights

- I don't agree that it should only be available to over 18s. More consideration should be given on age.
- I would've liked to see more than just Jersey residents and the emphasis on the fact the person/patient can opt out at any time. However, I believe this is a huge step forward.
- Euthanasia should only be by an advanced directive of the person wishing it to be so, For example in the event of their becoming non responsive after high risk surgery.

This advanced directive should have safeguards placed on it to avoid abuse.

This process has been a journey of fact and discovery for myself and I am sure for all other jurors.

I thank all concerned at Involve for the opportunity to take part in this debate and final vote and I pray that the final vote of the jury will be acted on by our government in understanding and answering the question:

Should Assisted dying be permitted in Jersey?

Thank you.

### Views against assisted dying

- "I don't feel jersey should allow assisted dying on island. I feel that palliative care should be enhanced and that jersey should look to change its legislation to allow abs support islanders to travel to Dignitas or elsewhere without repercussions.

Perhaps even a relationship with places such as Dignitas could be developed therefore providing islanders with more comfort in this matter. Covid has had a huge part to play in potentially a person's decisions in terms of wishing assisted dying upon themselves due to restrictions of travel it has left a small group of islanders feeling abandoned in a sense as they can't travel to other places. COVID 19 has been such a rarity for most if not all - potentially a once in a lifetime situation where a pandemic occurs to this magnitude. I don't feel this is the

correct time to implement a decision such as assisted dying during a pandemic where people's feeling are mixed and for the first time ever perhaps for some people restrictions on travel have occurred resulting in them not being able to go away due to the pandemic meaning that the people who do want this decision to be passed want it because they feel the strain and want it as an option because of restrictions rather than looking at the bigger picture.

If we can enhance palliative even further we could provide islanders with a sense of security and comfort in that they won't make the decision for assisted dying and use funds to implement more island treatments for cancers/ gynaecological issues etc.

Looking at figures that we have been provided we have a very very very small community of people who have looked into assisted dying - 4 in total in Jersey, 2 of which have sadly passed away.

Therefore, I don't feel that this should be permitted in Jersey. Although, it would be wonderful to provide islanders with this option I feel this has been hugely heightened and people's decisions swayed by the pandemic, and it is not the correct time to make a decision such as this. In addition, I don't feel it's costly and holds huge question marks over whom may be eligible to qualify and who is not. Nurses and doctors take an oath to help the living when they qualify although some doctors and nurses would be happy to assist with assisted dying there will likely be a lot who don't. It is a huge unethical ask for them to go against what they have taken an oath about.

No assisted dying- we do not have the capacity as an island we could pool finances into so many other amazing medical facilities / treatments resulting in patients not having to fly away for them- Change the legislation make it much more accommodating to those suffering and their families if they do wish to travel to Dignitas - Enhance palliative care further.

Thank you for this journey.

- My personal statement will be forwarded as to why my answer is no [this will be included in section 6 if the statement is shared].

## Other

- No comment I am very clear on my decision.

## APPENDIX H – KEY MESSAGES TO THE STATES ASSEMBLY: ADDITIONAL DISCUSSION NOTES

Here are the notes from some of the Jury members [not all groups had time to have this discussion] when asked *was there anything else they wanted to share or what would their key message to the States Assembly be.*

### Fairness and inclusivity

- Make sure it is fair not just for the rich
- Everyone participated.

- It has to be the best possible practice and the best for everybody. How do we ensure this? Just because we can do it doesn't mean we should. Will the politicians take as much time and energy making sure the decision/it is right? They must.
- [Think about] those left behind, re. insurance etc.
- Faith being an important factor on applying and administering?

## Monitoring & regulation

- Would there need to be a change though in insurance re. dying being assisted?
- Generally, once life insurance has been in place for a year you can claim following a suicide.
- Or issue re. what is recorded as main cause of death, e.g. underlying condition?
- Consideration around legislation and medical professionals being allowed to or have to (legally) raise assisted dying as an option or ONLY patient can request - Should [be] patient led.
- Like Canada; an independent witness must confirm signing and dating of request by the person seeking assisted death.
- Jersey legislation allows for others to be with you when administering so you are not on your own.
- In Jersey, utmost privacy is essential, 100% confidential and private (like medical records), no FOI.

## Options & choice

- At the end of the day, and throughout the whole process, what we are talking all about is **PERSONAL CHOICE!**
- Location - what would the options be; home, or specific place/space, hospital, hospice etc?
- OR there is no specification, and it is where the person would want to be, as long as it can be supported there?
- Should be opt in for medical professionals for assisted death.

## Process

- What methods have been considered? Tablet, drip and button (liquid) or other?
- Pre-calming drug first?
- ALL cases should be looked at on a case by case basis, not one case setting the standard for other cases that follow

## Jury experience

- The experience of the jury has made me/us think across perspectives and I feel I have a good opportunity to consider. I am happy with my conclusions.
- It has been very important to all everyone to be able to explore their opinion.

## Politics

- We want a mixture of politicians (with different perspectives on assisted dying) discussing this.
- We'd like ministers to look at this with an open mind

- The population is actually large for the size of the island, departments are under pressure, massive concerns in all areas. When there is pressure, red flags can be missed.

## Safeguarding & support

- Make sure the vulnerable are protected.
- Jersey is small and relatively wealthy (if unequally distributed). It's a small population, if we can't get the safeguards right for the 2-3 people that will need assisted dying, then [who can]. It shouldn't be an impossible task to introduce the safeguards needed, being a small relatively wealthy place. Both palliative care and assisted dying are needed. It shouldn't be too much potential for abuse.
- Family support following AD; in the lines of grief counselling? Required, offered during and after...?

## Palliative care

- It has been good to hear different perspectives, it has impacted on my view. A big piece of work that is needed is an audit of palliative care which needs to include patient feedback on services. If there is better palliative care you may not need assisted dying legislation. Talking about death is hard, getting the conversation moving across Jersey would be beneficial.
- Should work in conjunction with existing medical practices, i.e. palliative care. Not one or the other.

## Next steps

- We need an island wide debate and a format where it can be discussed properly, time for discussion across the population and a referendum. We need more than a citizens' jury.
- We can be the best at what we do. We try to be the best with child protection but don't always get it right. To be the best it can be, it has to come from the top, everyone has to think the same way. Everyone has to work in the same direction.
- It needs to be top down, bottom up and discussion island wide. I will be watching what happens next, it will be much more interesting having been through this. I will be scrutinising what will be happening.