Jersey Assisted Dying Citizens' Jury Recommendations – Initial Report

June 2021

01. Introduction

The Jersey Assisted Dying Citizens' Jury was established in Spring 2021. Citizens' juries are used all over the world to look at complex issues and make recommendations to decision makers. It is a method of deliberation, where a small group of people, broadly representative of the demographics of a given area, come together to carefully consider an issue.

The Jersey Assisted Dying Citizens' Jury consisted of 23 Jersey residents. The Jury was selected through a process of sortition to demographically reflect the Island's population. Jury members were tasked with answering the question:

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

The Jury was established following an e-petition in 2018 calling for the States Assembly to amend Jersey law to allow for assisted dying. 1,861 people signed that petition. This was followed in 2019 by an online public survey, a GP and doctors' survey and a public meeting, all of which indicated some level of support for assisted dying in Jersey.

The Minister for Health and Social Services determined that a Citizens' Jury should be established to consider the issue of assisted dying. He did so with a view to ensuring that the States Assembly, and other key stakeholders, would have an in-depth understanding of the community's response to the associated medical, ethical, legal and regulatory issues prior to any States' debate on this topic.

Involve were commissioned to design and run the Jury sessions including all of the participant liaison.¹ Involve is an independent public participation charity.

The Jury consisted of 10 sessions totalling 24 hours of meetings. Jurors heard from a range of witnesses from around the world and the process was independently facilitated and overseen by an independent advisory group.

The purpose of this initial report is to share the recommendations from the Jersey Assisted Dying Citizens' Jury, including:

- an explanation of the Jury voting process,
- the results of the voting process, and
- key messages from Jurors to the States Assembly.

A final report will be published in late summer 2021 providing:

- an explanation of the methodology of the Jury process,
- information related to the demographics of the Jurors,
- a summary of the evidence heard, and

¹ <u>https://www.involve.org.uk/</u>

• detailed notes from the Jurors' discussions throughout the process explaining how they reached these recommendations.

The final report will also include all the voting results and additional detailed comments shared by Jurors in each of the votes. There will be a separate section which explains the views of Jurors who held different perspectives to the majority of other Jurors, demonstrating the breadths of the Jurors' views. In the meantime, more information on the Jury process can be found on the Government of Jersey website.²

² <u>https://www.gov.je/Caring/AssistedDying/Pages/CitizensJuryOnAssistedDying.aspx</u> ³ Jury members have been invited to share any additional statements which will feed into the Final Report.

02. Explanation of the voting process

The Jury had a three staged voting process, with different votes taking place following different sessions.

- 1. The initial vote followed session 8
- 2. The second vote followed session 10
- 3. The final vote was a week after the second vote

Jurors spent time deliberating with each other in between each vote. Several key votes were used to find out the Jury's preferences in order to ensure views of all Jurors were captured and represented.

2.1. Initial vote

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

As the majority of jurors answered 'yes, I agree', sessions 9 and 10 focused on the circumstances under which assisted dying should be permitted. If the majority of jurors had answered 'no', sessions 9 and 10 would have focused on the reasons why assisted dying should not be permitted.

2.2. Second vote

The second vote focused on 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 jurors to indicate their preference, rather than answering 'yes' or 'no'). The second vote was based on voting principles used for other citizens' juries & citizens' assembly processes.

2.3. Final vote

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

As part of the whole voting process jurors were provided opportunities to:

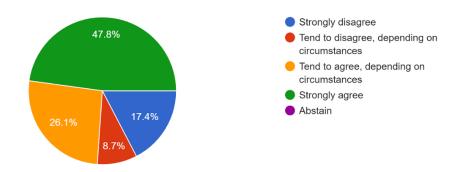
- issue key messages to States members (as set out in this report), and
- make additional comments on matters included in the voting process (to be set out in the final report)

This allowed for the breadth of views of individual jury members to be captured throughout the process, including, where individual jurors did not vote with the majority. The diversity of views will be set out in detail in the full report.

03. Results of the voting process

3.1. Initial vote: whether assisted dying should be permitted

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



In principle, the majority of the Jury voted in favour of assisted dying being permitted in Jersey, with 48% strongly agreeing and 26% tending to agree.

3.2. Second vote: the circumstances under which assisted dying should be permitted

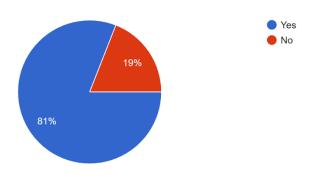
The second vote focused on the possible circumstances under which Jurors felt assisted dying should be permitted in Jersey. Each question from the voting form is detailed below alongside the voting results.

Results are split into the three sections, which reflect the structure of the final Jury sessions: eligibility criteria; mode; regulations & safeguards.

3.2.1. Eligibility Criteria

Residency Criteria

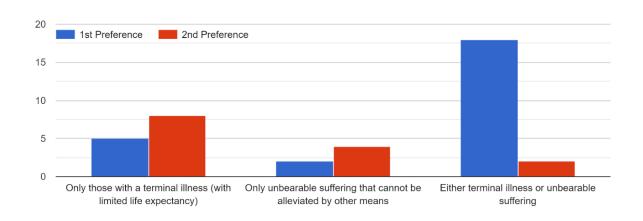
Should assisted dying only be for Jersey residents?



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

Health Criteria

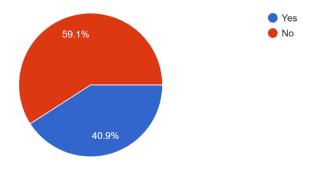
Part 1: Who should be eligible for assisted dying related to health?



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

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.

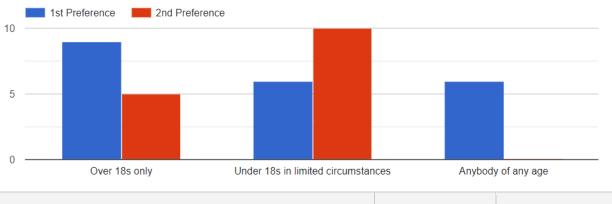
Part 2: If you chose unbearable suffering, should this include suffering caused by a mental condition?



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

Age Criteria

Who should be eligible for assisted dying relating to age?

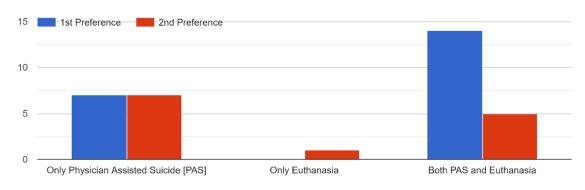


Options	1st Preferences	Percentage
Over 18s only	9	42.9
Under 18s in limited circumstances	6	28.6
Anybody of any age	6	28.6

Based on first preferences only, the Jury's preferred option was for "Over 18s only". However, this option does not achieve an overall majority and taking into account second preferences results in a near tie between "Over 18s only" and "Anybody of any age". This question therefore requires further consultation.

3.2.2. Mode

What mode should be permitted?



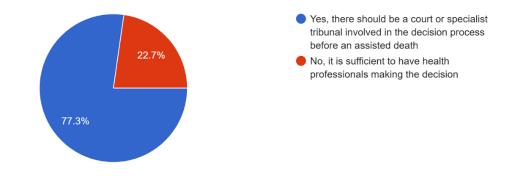
Options	1st Preferences	Percentage
Only Physician Assisted Suicide [PAS]	7	35.0
Only Euthanasia	0	0.0
Both PAS and Euthanasia	13	65.0

The majority of Jurors supported the option for both Physician Assisted Suicide and Euthanasia as the mode of assisted dying that should be permitted.

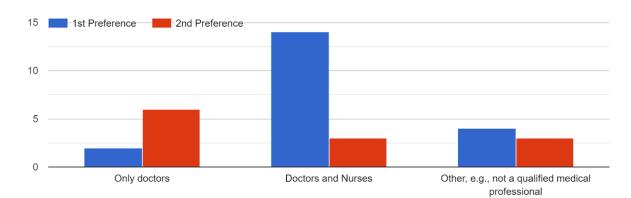
3.2.3. Regulations & Safeguards

Court or tribunal involvement

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



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



Assisting/administering assisted dying

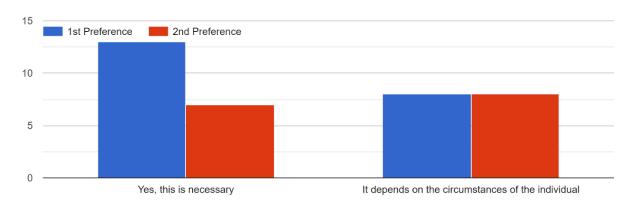
Who can assist/administer assisted dying?

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

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

Cooling off period

Should there be a requirement for a cooling off period?

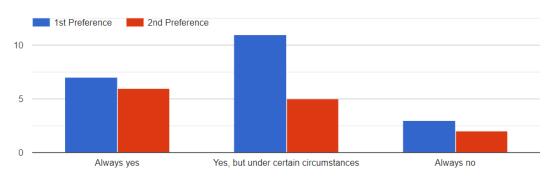


Options	1st Preferences	Percentage
Yes, this is necessary	12	60.0
No, this is not necessary	0	0.0
It depends on the circumstances of the individual	8	40.0

The 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.

Advanced decision-making

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



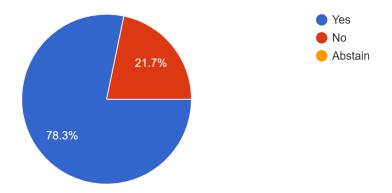
Options	1st Preferences	Percentage
Always yes	7	33.3
Yes, but under certain circumstances	11	52.4
Always no	3	14.3

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

3.3. Final vote

The Jurors were then asked to complete a final vote to respond to the overall Jury question. The vote result is outlined below and again additional comments were captured in this voting form explaining more about the reasons why Jurors voted a certain way. These will be included in the final report.

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



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

04. Key messages from Jurors to the States Assembly

As part of the second vote, Jurors were asked for any final or key message they would like to send to the States Assembly along with their votes. Below are the key messages the Jurors shared. These have been loosely grouped into themes:

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 Jurys 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.

Personal choice

- Persons 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 lead 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 AD it is the patients 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're no other 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 physicians 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 in 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.

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.³
- 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 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 ever aspect during a difficult time such as what an individual may face. Jersey is a place where many come to

³ Jury members have been invited to share any additional statements which will feed into the Final Report.

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.⁴

Protecting vulnerable people

• Protect the vulnerable

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 listed to evidence form both sides of the debate on assisted dying. It has been an interesting & 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.

⁴ Jury members have been invited to share any additional statements which will feed into the Final Report.