



ASSISTED DYING INJERSEY

Phase 2 Consultation Feedback Report

April 2023

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1: Introduction

A public consultation on assisted dying proposals ran for a 12-week period from 17 October 2022 to 14 January 2023. This was the second phase of consultation, building on a Phase 1 consultation which took place between March and April 2022.

The Phase 1 consultation focused on Islanders' views towards assisted dying – their hopes, thoughts, and concerns. The Phase 2 consultation focused on how an assisted dying service could work in Jersey.

This report describes the Phase 2 consultation process and summarises the responses received, which will inform the development of a report and proposition to be considered by the States Assembly.

This report does not respond to the themes raised, seek to qualify them or correct any inaccuracies or misconceptions presented by respondents (whether those inaccuracies and misconceptions apply to the proposals as published, or to practice and evidence related to assisted dying in other jurisdictions). It simply reports what has been said for purposes of information and transparency.

1.1 Background to consultation

Citizens' Jury

In February 2020, following community interest in assisted dying, the then Minister for Health and Social Services, Deputy Richard Renouf, committed to establishing a Citizens' Jury ("the Jury") to consider whether assisted dying should be permitted in Jersey. The Jury took place in Spring 2021 with its recommendations being published in September 2021.¹²

States Assembly 'in principle' decision

The Jury's recommendations formed the basis of a report and proposition presented to the Assembly by the Council of Ministers' (P95/2021)³. In November 2021, the States Assembly debated that report and proposition and agreed, in principle, that assisted dying should be permitted in Jersey but that, prior to the preparation of the law drafting instructions, detailed proposals should be brought back to the Assembly by October 2022.

The October 2022 deadline was extended by the new Minister for Health and Social Services, Deputy Karen Wilson ("the Minister") to allow an extended consultation period, providing the public, stakeholders and elected representatives more time to consider assisted dying proposals.

Phase 1 consultation

In Spring 2022, Islanders were invited to take part in Phase 1 consultation, sharing their hopes, thoughts and concerns about assisted dying. A Phase 1 feedback report *Assisted dying in Jersey: Public Engagement Summary Report* was published on 5 May 2022, noting the key themes that arose⁴. These key themes informed the detailed proposals set out in the Phase 2 consultation.

¹ Further information on Citizens' Jury process: <u>Citizens' Jury on assisted dying in Jersey (gov.je</u>)

² Citizens' Jury Final Report: <u>Final Report from Jersey Assisted Dying Citizens' Jury (gov.je)</u>

³ <u>p.95-2021.pdf (gov.je)</u>

⁴ Public engagement summary report on assisted dying in Jersey (gov.je)

Expert input

In addition to Phase 1 consultation feedback, the Phase 2 consultation proposals were also informed by⁵:

Professional leads working group

A professional leads advisory group, established to advise on matters relating to assisted dying service development and delivery. Members include:

- the Medical Director
- Chief Nurse
- Acting Chief Pharmacist
- Interim Chief Allied Health Professional
- Director of Mental Health and Adult Social Care
- Associate Medical Director for Prevention, Primary and Intermediate Care
- Accident and Emergency Consultant, GMC Responsible Officer
- Chief Inspector of the Jersey Care Commission as an observer

Dialogue with professional bodies

Health care professionals working in Jersey are registered with UK professional registration bodies, including the General Medical Council (GMC), the Nursing and Midwifery Council (NMC), the Health and Care Professions Council (HCPC) and General Pharmaceutical Council (GPhC). There has been both joint and individual discussions with these bodies regarding the potential role of health care professionals in any future assisted dying service.

Experience and expertise in other jurisdictions

The proposals are based on extensive research of assisted dying legislation and practice in other jurisdictions. This includes discussions with professionals who have expertise in, and practical experience of, assisted dying.

⁵ <u>Assisted dying in Jersey (gov.je)</u>

2: The consultation process

The Phase 2 consultation took place between 17 October and 14 January 2023 (a 12-week period).

A detailed consultation report was published on www.gov.je⁶ accompanied by:

- a summary report in English⁷
- a summary report in Easy Read⁸
- an assisted dying proposal leaflet in English⁹
- an assisted dying proposals leaflet in Portuguese¹⁰
- an assisted dying proposals leaflet in British Sign Language (BSL) [video format]¹¹

Printed copies of the consultation report, summary reports and leaflets were available to collect from Customer and Local Services, La Motte Street, or via request on <u>assisteddying@gov.je</u>.

Public engagement sessions also took place providing Islanders an opportunity to share their thoughts and views on the published assisted dying proposals. The format of the public sessions was a presentation of the proposals, followed by questions and discussion (unless otherwise indicated in Table 1). Public events took place in different locations across the Island, with a focus on St Helier venues to reflect population spread. Sessions took place during office lunch hours, after office working hours, as well as during evenings and weekends. See table 1 below, for detailed information.

Public engagement sessions			
Audience	Location	Date	Additional information
All Islanders aged 18+	Town library	Saturday 22 October 10am-12pm	
All Islanders aged 18+	Town library	Wednesday 26 October 12 - 2pm	
All Islanders aged 18+	Communicare, St Brelade	Wednesday 2 November 12-2pm	
All Islanders aged 18+	Town library	Thursday 10 November 6 - 8pm	

Table 1. Public consultation engagement events

⁶ Assisted dying in Jersey consultation (gov.je)

⁷ <u>https://www.gov.je/SiteCollectionDocuments/Health and wellbeing/Assisted Dying Summary of</u> <u>Proposals.pdf</u>

⁸ <u>https://www.gov.je/SiteCollectionDocuments/Health and wellbeing/Assisted Dying Consultation Easy</u> <u>Read.pdf</u>

⁹ Assisted Dying Phase 2 leaflet English.pdf (gov.je)

¹⁰ Assisted Dying Phase 2 Leaflet Portuguese.pdf (gov.je)

¹¹ Assisted Dying Consultation - YouTube

All Islanders aged 18+	St Clement Parish Hall	Wednesday 23 November 10am- 12pm	
Disabled islanders	Town Library	Tuesday 13 December 6 - 8pm	Supported by Enable Jersey, text captions available
dDeaf and hard of hearing Islanders	Town Library	Wednesday 18 January 6 - 8pm	Supported by Enable Jersey, BSL/English interpreter and text captions available
Portuguese- speaking members of the community	Town centre, various locations	Saturday 22 October 12 - 2pm	Supported by Portuguese-speaking community worker
Health and Community Services Department staff	Education centre, General Hospital	Wednesday 11 January 6 - 8pm	
Health and Community Services Department staff	Education centre, General Hospital	Thursday 12 January 6 – 8pm	

The format of the Stakeholder consultation engagement sessions varied although most involved a presentation of the proposals, followed by questions and discussion. See table 2 below, for detailed information.

 Table 2. Stakeholder consultation engagement sessions

Stakeholder	Date	Format
Royal College of Nursing	18 October	Teams online meeting
Care sector representatives	19 October	Teams online meeting
Jersey Hospice	19 October	In person
End of Life Choices Jersey	1 November	In person
General Practitioners (GPs)	3 November	Teams online meeting
States Members	4 November	Teams online meeting
Jersey Dying Well Group (with Prof. Baroness Finlay of Llandaff)	17 November	In person
Citizens' Jury participants	17 November and 22 November	Teams online meeting
Voluntary and community sector groups representing disabled Islanders	24 November	In person
Superintendent Registrar	28 November	Teams online meeting
Humanists UK	1 December	Teams online meeting
Dignity in Dying UK	8 December	In person
My Voice Jersey	13 December	In person
My Death My Decision	14 December	Teams online meeting
Care Not Killing UK	14 December	Teams online meeting
Living and Dying Well	6 January	In person
Faith representatives	11 January	Teams online meeting

2.1 Promoting participation in the consultation

People were encouraged to participate in the consultation via:

- social media posts
- digital screens
- full and half-page advertisements in the Jersey Evening Post and digital webpage advertisements
- Bailiwick Express advertisements
- advertisements on Radio 103
- promotional banners on <u>www.gov.je</u>
- emails to stakeholder groups

See <u>appendix 1</u> for further detail.

2.2 Ways to participate

Islanders were invited to respond to the consultation in a number of ways:

- in writing (via email or post)
- in person at engagement events
- via an online survey (recommended for those who had read the full consultation report)
- commenting on Government of Jersey ("GoJ") social media posts.

3: Overview of responses

3.1 Grouping response by audience

For the purpose of processing, collating and summarising, the responses were grouped by key audience:

Stakeholder organisations

Includes campaigning organisations who either support or oppose assisted dying; organisations who represent Islanders impacted by the assisted dying proposals; organisations who may be impacted by the assisted dying proposals; professional bodies who may be impacted by the introduction of assisted dying legislation in Jersey.

[All written and survey responses from stakeholder organisations are included in a separate PDF document that can be accessed at gov.je/assisteddying '<u>Appendix A – assisted dying</u> <u>consultation phase 2 organisation responses</u>]

Organisation responses were received from:

- 1. All-Party Parliamentary Group on Choice at the End of Life (APPG)
- 2. Anscombe Bioethics Centre
- 3. Association for Palliative Medicine of Great Britain and Ireland
- 4. CARE (Christian Action Research & Education)*
- 5. Care Not Killing and Our Duty of Care
- 6. Catholic Union of Great Britain
- 7. Channel Islands Humanists
- 8. Christian Medical Fellowship (CMF)
- 9. Compassion & Choices (USA)
- 10. DIGNITAS
- 11. Dignity in Dying
- 12. End of life choices Jersey
- 13. European Institute of Bioethics (Brussels, Belgium)
- 14. General Medical Council (GMC)
- 15. Go Gentle Australia
- 16. Humanists Against Assisted Suicide and Euthanasia (HAASE)
- 17. Jersey Dying Well
- 18. Jersey Evangelical Alliance
- 19. Lives Worth Living A Campaign of SPUC Pro-life
- 20. Living and Dying Well
- 21. Medical Ethics Alliance
- 22. My Death, My Decision
- 23. National Secular Society
- 24. Quennevais Evangelical Church
- 25. Royal College of Psychiatrists
- 26. The Christian Institute to the Assisted Dying
- 27. The Nursing and Midwifery Council (NMC)
- 28. Tōtara Hospice (Auckland, NZ)

^{*} CARE submitted a response on 13 January 2023, but this was not received by the consultation team. The CARE response was added into the feedback report on 4.5.23 and can be viewed in full at <u>Appendix A</u>

Stakeholder individuals

Includes individuals formally responding to the consultation in a professional capacity, for example, health and social care practitioners, academic researchers and those with a legal background.

[Where the individual has given permission to publish, written responses from stakeholder individuals are included in a separate PDF document that can be accessed at gov.je/assisteddying <u>'Appendix B – assisted dying consultation phase 2 stakeholder individual responses</u>]

Public (resident and non-resident)

This includes responses from Jersey residents and non-residents. Some respondents who provided written submissions chose to disclose their location, others did not. Of those responding to the online survey, 535 individual responses were completed on-island, 316 in the UK and 42 from other locations.

Also included in this group are health and social care professionals who responded to the consultation in a personal rather than professional capacity but, in doing so, made passing reference to their professional background.

Source	Number of respondents (total people)
Online survey	Total: 902 Location: • Jersey – 537 • UK – 320 • Other jurisdictions – 45
Written submission	Total: 307 Audience: • Stakeholder organisation – 22 • Stakeholder Individual – 31 • Public- 254 (228 email and 26 postal)
Social media comments (official GoJ posts only)	104
Public engagement sessions	Approx. 80 people
Total	1393

3.2 Numbers of respondents

Table 3 – overview of consultation responses.

Note:

Some individuals and organisations may be counted twice – for example, if attending a public engagement session and responding to the survey.

Some people printed the survey questions and submitted by post or email. These were manually inputted into the online survey.

A small number of submissions (emails and letters) were received shortly after the 14 January deadline date but were nevertheless included.

4: Processing and collating consultation responses

In collating and processing the consultation responses, the aim is to identify the main points made by respondents, giving weight in particular to those supported by arguments and evidence and those from respondents with relevant experience and expertise.

The consultation feedback includes:

- **quantitative feedback** from the online survey e.g., the numbers and proportions of people who responded to the survey questions
- **qualitative feedback** from the 'free text' section of the survey, from written responses and from the public engagement sessions.

It is important to note that people who responded to the consultation choose to do so because of their interest in assisted dying. It must not be assumed that their individual or collective views are representative of wider public opinion.

"A consultation is not an opinion poll; it is a tool to allow those who want to express an opinion to have their say. Consultations are not carried out among representative samples of those in a target audience, nor are the responses able to fully explain the views of those responding on every relevant matter contained within the proposals. A consultation should not, therefore, be taken as a comprehensive statement of public, business or stakeholder opinion – it simply harvests a wide range of views and opinions among interested parties on given proposals. As compared with the results of a representative survey of opinion on the same subject, it will tend to overrepresent the opinions of those who feel most strongly about the subject, since they will have the strongest incentive to respond."¹²

Professor Robert Blackburn, Professor of constitutional law at King's College London

Note: the terms 'supportive' and 'opposed' have been used in this feedback report to differentiate between respondents who stated they were in favour of assisted dying, and those who stated they were not in favour assisted dying. It is recognised that these are broad terms which do not adequately reflect the variations in peoples' views but are used for ease of understanding.

4.1 Analysis of online survey

The online survey was intended to be completed by people who had read the full consultation report. This was clearly set out in the introductory text – '*In order to complete this survey, you should first read the Assisted Dying in Jersey Consultation Report, which sets out the proposals for an assisted dying service in Jersey*'.

Quantitative questions

The online survey included 30 multiple-choice questions on the proposals, which allow for consistent analysis of:

¹² <u>00 CASE STUDIES (parliament.uk)</u>, page 166

- total number of respondents to each question, and how many responses were received for each of the multiple-choice options
- multiple choice options as a percentage of total responses to each question

Questions 2 and 3 of the survey asked respondents if they held a strong view on assisted dying [see <u>appendix 3</u> for the full list of survey questions]. This allowed for further analysis of responses by views on assisted dying, categorised as whether the respondent:

- held a strong view as to whether assisted dying should, or should not, be permitted
- did not hold a strong view on assisted dying
- chose not to disclose whether they held a view on assisted dying.

Qualitative questions

All 30 questions allowed for 'free text' responses – i.e., respondents could explain in their own words the reason for their response.

A thematic analysis approach was used to analyse the responses, this entailed:

- Step 1: reading all the free text responses and identifying emerging themes
- Step 2: assigning each free text response to the most representative theme, allowing the most commonly repeated or key themes to be identified.

Where a respondent disagreed with a proposed number, and suggested an alternative number, that alternative number was captured as part of the analysis (for example, they disagreed a process should take X number of days, stating in their free text comments that it should take Y number of days).

Quotes used in <u>Section 6</u> of this report reflect the range of responses received to each question.

Note: Some of the survey responses received by post were on the headed paper of a campaigning organisation opposed to assisted dying and included 'pre-filled' answers to the survey questions. The pre-filled answers were repeated by a number of online survey respondents.

Whilst it is clear that a campaigning organisation was instrumental in shaping these responses, they were completed by individuals with unique IP addresses [i.e. they were completed by various respondents in different locations], so have been processed as separate responses.

Responses were also checked by IP address to establish if people were submitting multiple survey responses in order to 'skew' the data.

In total, multiple survey responses were received from 31 different IP addresses, however in most of those 31 cases, there was no more than two surveys sent from each of IP addresses, which suggests a shared household computer being used by more than one member of the household.

The maximum number of survey responses received from a single IP address was six. In this case, each of those six responses have been reviewed and the variations in response suggest that the survey responses were sent by six different people (as opposed to six responses sent by one person) so it is presumed that the IP address is connected to a shared computer, for example, a library computer.

4.2 Analysis of written submissions

People were invited to send written submissions (by post or email). These written submissions were categorised by audience as outlined in <u>Section 3.1.</u>

Public

Submissions from the public were divided into two groups: those supportive of assisted dying and those opposed to assisted dying. It was very clear from all the written responses received whether the respondent was supportive or opposed to assisted dying.

Again, a thematic analysis approach was applied [see Section 4.1] All public responses were analysed against the most common themes that emerged from the online survey responses. Detailed response could be assigned several themes.

Note: 67 emails opposed to assisted dying from members of the public were received between 31 December and 3 January 2023, the majority supplied a UK address. These emails contained common themes, had a similar structure and included repeated phrases which suggests a coordinated campaign initiative. However, as each email was sent from separate email addresses and/or signed by different individuals, they have been counted as separate consultation responses.

Stakeholder organisations and stakeholder individuals

Submissions from stakeholder organisations and stakeholder individuals were read and individually considered. These responses were not analysed by theme, instead stakeholder responses are briefly summarised with quotes from individual and organisation stakeholder responses being included in <u>section 5</u> and <u>section 6</u> of this report.

4.3 Analysis of social media

The primary purpose of the GoJ social media posts during the consultation period was to create awareness of the consultation, encourage people to attend engagement events, read the consultation document and complete the online survey.

Social data analytics were collected for each post to understand impact. They were categorised by:

- reach: the number of people who saw each post at least once
- **impressions:** the estimated total number of times each post was seen. This is different to *reach* as it may include multiple views of a post by the same person
- engagement: the number of reactions, comments, shares or clicks on each post.

In addition, some people posted comments in response to the GoJ social media posts. These comments were captured and sorted by theme. The number of responses per theme was then recorded. The comments were redacted to remove names of the social media accounts and ensure anonymity. See <u>appendix 2</u> for further detail.

4.4 Analysis of public engagement events

The format of these events was presentation of the proposals, followed by questions and discussion. Notes were taken during the event, with themes being captured. A list of the key themes is detailed in <u>appendix 4</u>.

All attendees were also invited to complete the online survey or provide a written response.

4.5 Analysis of stakeholder engagement events

The format of these sessions varied although most involved a presentation of the proposals, followed by questions and discussion. The purpose of these events was to provide an opportunity to discuss the proposals in depth with stakeholders, to help inform their formal written submission to the consultation.

5: Summary of responses – General feedback on assisted dying

5.1 General feedback - Support for / opposition to assisted dying

The Phase 2 consultation did not explicitly request views on whether assisted dying should, or should not, be permitted. This was explored a part of Phase 1 consultation which asked Islanders to share their thoughts, hopes and concerns around assisted dying. ¹³

Nevertheless, a significant number of responses (both written and in-person) focused on the question of <u>whether</u> assisted dying should be permitted, as opposed to <u>how</u> an assisted dying service could work in Jersey.

Indeed, all individual written responses (as opposed to online survey responses or in-person comments) provided feedback that was either clearly in support of, or in opposition to, assisted dying.

The key themes on attitudes towards assisted dying are summarised in this section.

5.1.1. Key themes in support of assisted dying

Key themes observed in written responses from the public and stakeholders who support assisted dying:

- a. suffering and quality of life
- b. personal choice / autonomy
- c. dignity and peace of mind
- d. access and equality
- e. palliative care
- f. public support

The themes are listed in order of frequency (i.e., 'suffering and quality of life' was the most frequently raised theme, 'public support' the least frequently raised theme).

a. Suffering and quality of life

Assisted dying as a means of alleviating suffering was the most frequently raised theme, noted in nearly three quarters of all written responses in support of assisted dying. Many respondents shared their experiences of loved ones at the end life, witnessing pain and suffering and a 'bad death', even where their loved ones had good access to palliative care and support services.

Others noted that a decline in quality of life was a reason some requested access to assisted dying, and often this decline was as a result of suffering because of a medical condition.

¹³ <u>Public engagement summary report on assisted dying in Jersey (gov.je)</u>

Written responses

<u>Public</u>

"My Dad died of cancer 4 years ago at the Jersey Hospice, they were amazing but the pain relief given did not work towards the end and we saw my Dad distressed and in much pain, this no way to die, his death was not peaceful." **Ref: AD1**

"My family had a dreadful experience in 2021 witnessing my wife's awful struggling and suffering... She was in hospice care for two weeks The administration of morphine did not give sufficient relief for her suffering. This was especially distressing to witness during the last five days of her life...I will never ever forget what I saw." **Ref AD7**

Stakeholder individuals

"In six years and the many cases in which I have participated, I have yet to meet a patient who wants to die. They would gladly relinquish the opportunity for more suffering-free time with their loved ones, but that's a choice they don't have." **Assisted dying Practitioner, California**

"Importantly, the general practice of aid in dying [assisted dying], or the particular laws surrounding its implementation, make no judgments about what kinds of life are worth living. The only inherent values in the practice of medical aid in dying are ones concerning compassion for suffering, and perhaps most importantly, respect for autonomy. Neither the practice nor the laws force anyone to seek aid in dying and to suggest that people with disabilities are especially vulnerable to social nudging is to perpetuate the myth that people with disabilities cannot make decisions of their own and need to be protected from themselves." **Professor and Chair of Philosophy, Utica University in New York**

Stakeholder organisations

"A core argument in support of assisted dying is the reduction of pain, misery, and suffering." **Channel Islands Humanists**

"No one wishes to die. But, people wish to not continue suffering. If their suffering could be alleviated, if their medical condition could be resolved, they would continue living. In fact, assisted dying is about alleviating suffering and for this to provide a legal and safe framework which an individual can choose to make use of." **DIGNITAS**

"Dad didn't choose death. Dad chose life over and over again. He chose it when he knew he would have his sides ripped out. He chose it when he knew he would have chemotherapy that would make him sick for another six months. He chose life, he chose life, he chose life. And when life was no longer a choice, he decided to die on his own terms. – Katie Harley, whose father Phil, 70, metastatic bowel cancer, elected to have an assisted death in Victoria in 2019." **Go Gentle Australia**

b. Personal choice/autonomy

The right for a person to have choice over the end of the life and control over the manner and timing of their death, was the second most frequently cited theme in support of assisted dying – noted in one third of the submissions. This response was often linked with theme of suffering – i.e. a person should have control at the end of their life in order to prevent suffering, should they wish to. This included some respondents with religious beliefs (i.e., they told us about their beliefs in their responses).

Responses from individual stakeholders and stakeholder organisations also highlighted the importance of people having the right to personal autonomy and self-determination at the end of life.

Written responses

<u>Public</u>

"I think to legalise assisted dying in Jersey would offer many people the peace of mind to know that they could have the control over ending suffering from a terminal illness. It might be that they choose never to do this, but why let them live with the terror of not having the choice?" **Ref:AD5**

"Most of us don't want our loved-ones to see us suffering greatly at life's end, as we want to leave them with happier memories of us. If we knew when our life would end we could arrange for our loved-ones to be there & a chaplain to pray. We're going to be with Jesus so why hang on to "life at any price." **Ref:AD4**

Stakeholder individuals

"Patients approaching the end who want to exercise their autonomy and gain some control over their own dying process, assisted death offers them empowerment at a time that many feel powerless and disenfranchised." **Assisted dying Practitioner, California**

"Our research has demonstrated that assisted dying can also give; a sense of competence, relatedness, and autonomy. Critically, these basic human needs are valued as much during the dying process as they are in life." **Senior Lecturer in Psychology, London South Bank University**

Stakeholder organisations

"We believe that having a choice at the end of your life is essential. People have the right to bodily autonomy, and no one should be made to suffer unnecessarily." **Channel Islands Humanists**

c. Dignity and peace of mind

Approximately one fifth of the individual written responses received in support of assisted dying, referenced the importance of dignity, with notions of personal choice and dignity being strongly connected. Again, responses focused on the view that dignity was a matter of self-determination. Fear of loss of dignity, and the wish for a 'good death', are perceived as legitimate reasons to choose an assisted death.

Some focused on the peace of mind that assisted dying can bring; regardless of whether a person chooses to have an assisted death, having the option available could provide sense of control which, in of itself provides a palliative effect– i.e., "knowing I <u>could</u> have an assisted death helps me to face the end of my life."

Discussions at the in-person events linked dignity to the concept of 'life at any price'. Participants were reflecting on whether, as a society, advances in medicine have resulted in us being too focused on being kept alive (including during our last illnesses) as opposed focusing on quality of life and quality of death - i.e., as a society do we need to balance dignity and quality of life / death, against the pursuit of longevity?

Written responses

<u>Public</u>

"Mum didn't want that for herself, and she definitely didn't want that for us as her family either. She wanted to die with dignity, just as she had lived most of her life with dignity, and she didn't want to be a burden to us. But she wasn't allowed to do or be those things." **Ref AD8**

"Dying with dignity and free of distressing symptoms (physical, psychological and social) is the main goal, in my view. An assisted death with appropriate safeguards will be an important addition to the current facilities available (nursing and palliative care, social support etc) to help more achieve a "good death". **Ref AD9**

Stakeholder individuals

"Symptoms of acute and chronic anxiety and depression, caused by feelings of fear of the unknown, lack of control and loss of dignity could be alleviated if the choice of an assisted death were available." **Retired Palliative Care Nurse**

"Palliative effect of peace of mind: Feedback from Victorian applicants and their relatives have reported on the palliative effect of knowing that they have access to the VAD substance if they choose to use it. Families and loved ones are often comforted by witnessing the applicant's wishes being fulfilled and their autonomy respected, regardless of whether the applicant uses the lethal substance." Attorney-General of South Australia

Stakeholder organisations

"Indeed, in 35% of cases [in Oregon, USA], individuals prescribed aid-in-dying medication did not ultimately use it. Rather it served as peace of mind that it would be available were their suffering to become intolerable – a form of so called "emotional insurance". National Secular Society

"These laws benefit more than the small number of people who decide to use them. Awareness of the law has a palliative effect, relieving worry about end-of-life suffering. In the jurisdictions that have already authorized medical aid in dying, for example, people report significant relief from worry about future physical and emotional pain just from knowing the option is there should they need it, regardless of whether or not they decide to pursue it." **Compassion & Choices, USA**

d. Access and equality

Responses noted the significant inequality that currently exits, as Jersey residents who have financial means, and who are physically capable of travelling, can already have an assisted death at Dignitas in Switzerland.

Some responses stated that lack of access to assisted dying results in some people electing to take their life by suicide. Responses also expressed fears around prosecution for those

whose loved ones may ask for help to end their life – either in Jersey, or by supporting them to travel to Switzerland.

Written responses

<u>Public</u>

"People should not have to travel to another country to end their life, not only is this unreasonable it is unjust and creates inequality as only some people are able to afford this or are physically able to travel. Similarly, people should not have to put their loved ones at risk for prosecution for helping them die." **Ref:AD5**

Stakeholder individuals

"As reported in the Parliament of South Australia's Joint Committee on End of Life Choices, the State Coroner David Whittle advised that people who are chronically or terminally ill and experiencing an 'irreversible decline in physical health' have elected to commit suicide rather than endure what palliative care has to offer. The Coroner had identified a number of deaths by suicide, seemingly in response to people suffering 'a deteriorating quality of life' from a disease likely to result in death." Attorney-General of South Australia

Stakeholder organisations

"Marjorie Wallace CBE, chief executive of mental health charity SANE, has said traditional suicide prevention measures "are not an appropriate response" for those who are nearing the end of life and wish to ease the dying process, because their motivation is "to shorten death, not shorten life" Without the assistance of a medical professional, these individuals lack the means and expertise to end their lives in a peaceful and dignified manner. Furthermore, the lack of an explicit legal framework exposes those who might seek to assist such patients, even when motivated entirely by compassion, to prosecution." National Secular Society

"Our outdated law on assisted dying discriminates between those who can and cannot afford an assisted death in Switzerland; criminalises grieving relatives who support their loved ones to exercise control over their deaths; and forces a small but significant number of dying people to end their lives before they are ready in lonely and sometimes violent ways." Karin Smyth MP and Kit Malthouse MP, co-chairs of UK All-Party Parliamentary Group on Choice at the End of Life

e. Palliative care

Approximately one fifth of responses in support of assisted dying referenced palliative care in a number of contexts. Some, drawing on their own experiences, were clear that even the best palliative cannot alleviate everyone's suffering at the end of life, or the suffering experienced by people who have physical, non-terminal conditions. Other responses expressed the view that *assisted dying* and *palliative care* are not two diametrically opposed concepts, as sometimes presented, but can and should exist together. A small number of responses on this theme stated that:

• whilst palliative care was 'for the majority' at end of life, assisted dying should always be for 'the minority' whose suffering cannot be alleviated

• assisted dying is not, nor ever should be a replacement to palliative care, nor should it divert funding away from palliative care or other end of life services.

Written responses

<u>Public</u>

"There also needs to be an honest acknowledgment ...that palliative care simply can't deal with some of the most severe pain levels that come with certain diseases and latter-stage cancers." Ref AD8

Stakeholder individuals

"Palliative care cannot alleviate all suffering near the end of life. It cannot give back patient autonomy and dignity, but some (apparently) physical symptoms cannot always be alleviated either. The Office of Health Economics recent research found that 17 people a day will die in pain even with the very best palliative care." **Retired Palliative Care Nurse**

"In Belgium and the Netherlands, research suggests the introduction of VAD has not stunted the development of palliative care, and that government funding grew at a consistent rate with countries such as the UK that have not legalised VAD.¹⁴ The same year that VAD was implemented in Victoria, the Victorian State Government announced more than \$62 million in additional funding to palliative care services."¹⁵ Attorney-General of South Australia

"Many Canadians have poor access to Palliative Care, as do many in the UK, but funding/support for clinical palliative care has increased dramatically in much of the country since MaiD [assisted dying] became legal [see full submission in <u>Appendix B –</u> <u>assisted dying consultation phase 2 stakeholder individual responses</u>" for detail] ...There is no data suggesting that the practice of MAID in Canada is driven to any degree by poor access to Palliative Care, socioeconomic deprivation or isolation." **Head and Professor, Division of Palliative Care, University of Ottawa, Canada**

Stakeholder organisations

"Having been directly involved as a leadership team, I can say, with the backing of my team, that for these patients this is the right thing to do [becoming a hosting assisted death service following the introduction of legislation in New Zealand in 2021] and is not at all at odds with our palliative care values, approach and principles. We have been privileged to be with them, support them, help them have their wishes met." [Chief Executive] Tōtara Hospice, New Zealand

"Palliative care and assisted dying are not mutually exclusive: The APPG supports greater investment in palliative care alongside the development of a safeguarded assisted dying law. Overseas evidence demonstrates that even with access to the highest quality of palliative care services, some people still suffer and wish to have control over the timing and manner of their death. There is evidence that palliative care can flourish alongside the introduction of assisted dying legislation." Karin Smyth MP and Kit Malthouse MP, co-chairs of UK All-Party Parliamentary Group on Choice at the End of Life

¹⁴ 'State of palliative care development in European countries with and without legally regulated physicianassisted dying', *Health Care* 2014 (Ministerial Advisory Panel on Voluntary Assisted Dying Final Report page 39).

¹⁵ Additional palliative care funding for Victoria announced | Aged Care Guide

"It is not a choice between palliative care OR assisted dying. The two can, and do, coexist. Evidence from Victoria and WA [western Australia] shows around 80-85% of people who choose VAD [Voluntary Assisted Dying] are also receiving excellent palliative care. VAD is simply another option. Moreover, the existence of VAD laws does not result in a decline in palliative care. In fact, the opposite is true." **Go Gentle Australia**

f. Public support

A small number of responses noted the consistent ongoing public support for assisted dying, both in Jersey, the UK and beyond.

Written responses

<u>Public</u>

"The majority of people in Jersey are in favour of offering people a choice, as a democratic country surely we should be listening to what the majority support." **Ref AD5**

Stakeholder organisations

"Island Global Research polling found 90% of islanders support a law to allow terminally ill, mentally competent adults to avail themselves of assisted dying and only 3% believe that Jersey should wait for Westminster to act first.¹⁶" **National Secular Society** "Numerous public opinion polling from a variety of sources, both nationally and at the state level, demonstrates that the American public consistently supports medical aid in dying, with majority support among nearly every demographic group... Gallup's 2020 Values 70 and Beliefs poll shows that a majority of respondents have consistently favored [medical aid in dying] since Gallup first asked about it in 1996." **Compassion and Choices, USA**

5.1.2 Key themes in **opposition** to assisted dying

Key themes raised by individual respondents opposed to assisted dying were:

- a. Pressure to end life and protection of vulnerable people
- b. Slippery slope
- c. Palliative care
- d. Sanctity of life
- e. Safeguards (coercion)
- f. Role of doctors
- g. Public understanding / awareness

¹⁶ Island Global Research - News - The End of Life Survey Results

The themes are set out in order of frequency (i.e., 'pressure to end life' was the most frequently raised theme, 'public understanding / awareness' the least frequently raised theme).

a. Pressure to end life and the protection of vulnerable people

The most frequently cited theme by those opposed to assisted dying (over half of responses in opposition) was a concern that, if assisted dying is introduced in Jersey, certain individuals or groups of people may feel the pressure to have an assisted death to avoid being a burden to family members or to wider society. This notion was developed further by some responses which voiced concerns that the introduction of assisted dying may shift societal views on death, older adults, disability and even the inherent value of human life.

[**note:** concerns about individuals being coerced into having an assisted death is covered in <u>Section 5.1.2.e</u> of this report '*safeguards (coercion)*']

In contrast to responses received in support of assisted dying [ref 5.1.1.d 'access and equality'], responses in opposition to assisted dying cited concern that the introduction of assisted dying may result in increased rates of suicide in the wider population.

Written responses

Public

"Such a Law would encourage people to view the life of chronically sick, incapacitated, chronically depressed and very elderly people as being of less value than that of healthy 'normal' people. This would be a fundamentally degenerate and dangerous humanitarian attitude.

Such a Law would most probably greatly increase the danger of coercion of sick and 'burdensome' people to end their lives, and such coercion would not be easily visible to medics attending to the case. It would promote in dependent people feelings of guilt of being a burden." **REF AD10**

"Changing the law to allow euthanasia or assisted suicide will inevitably put pressure on vulnerable people to end their lives for fear of being a financial, emotional or care burden upon others. This would especially affect people who are disabled, elderly, sick or depressed." **Ref AD11**

Stakeholder individuals

"Changing the law in this way inevitably casts judgement on the value of human life and how vulnerable people would perceive themselves and how they would be perceived by others... As someone who works hard to prevent suicide, the work of psychiatrist colleagues would be foreseeably undermined in Jersey" **NHS Community Psychiatrist**

"The proposed law will affect vulnerable people who in over 50% of cases will feel a burden to others. What is put forward as a 'right to die' will in a significant number of vulnerable people result in them believing that they have a 'duty to die' due to being a burden on carers and relatives." **Retired GP, Jersey**

Stakeholder organisations

"Introducing euthanasia and assisted suicide will inevitably affect how, for example, elderly and disabled people view their own worth, and how they are viewed by others. It would plant the idea in the minds of some of the most vulnerable in our society that they are worth less than others." The Christian Institute

"Inevitable pressures of the cost of treatment and lack of resources, this may well lead to people seeking death by assisted suicide or euthanasia owing to external pressures." Care Not Killing and Our Duty of Care Joint response

b. Slippery slope

Nearly half of the public written responses opposed to assisted dying expressed concern that the eligibility criteria and any safeguards set out in law would 'erode' over time. Responses provided examples of other jurisdictions where assisted dying eligibility criteria had widened over time, either through political decisions or as a result of Court challenge on the grounds of human rights.

Other responses expressed concern that the number of people requesting or receiving an assisted death in some other jurisdictions had risen over time, particularly in Canada and the Netherlands.

Written responses

Public

"Sadly there are many countries and states around the world which have set off down this slope, and there is much evidence from looking at what has happened in those places that it is indeed slippery. The laws allowing such practices have been quickly broadened in countries like Belgium and Canada, so that now children and the mentally ill have come within the scope of these permissive laws." **Ref AD12**

Stakeholder individuals

"The law in Belgium moved from killing adults in 2002 to killing children in 2014 under their euthanasia laws. It is such a 'slippery slope'." **NHS Community Psychiatrist**

Stakeholder organisations

"The government's proposal insists that assisted dying is a service provided to people in certain limited circumstances that will be set out in law, but in other jurisdictions assisted deaths have risen dramatically since being introduced: Canada's assisted deaths have risen more than 10 times in 6 years." **Jersey Evangelical Alliance**

"New evidence from Canada indicates the tendency to expand to those who suffer not from physical diseases or conditions but from depression borne of poverty, homelessness, or other social conditions. In the context of increasing numbers of people defining themselves as suffering from various medical conditions, we think the numbers will climb in any area where ASE [assisted suicide and euthanasia] is legalized." **Humanists Against Assisted Suicide and Euthanasia**

c. Palliative Care

Just under half of responses received in opposition to assisted dying referenced palliative care. Some responses conveyed the view that assisted dying would not be needed if everyone had access to the best palliative care; a theme developed by some respondents who believe resources and political focus should be directed on improving Jersey's current end of life care, as opposed to introducing assisted dying.

Other responses expressed concern that the introduction of assisted dying would actively divert resources away from palliative and end of life care services which could result in a lack of access and a 'false choice' – i.e. "I am choosing assisted dying, because I can't receive the care I need to alleviate my suffering."

Written responses

Public

"[We have] our excellent Jersey Hospice, providing compassionate help to those with terminal conditions to pass away without pain and with dignity. The dying process is managed by excellent palliative care. The pain and suffering and other effects we suffer at the end of our lives are thus assisted within the secure framework of the current law." **Ref AD13**

"I do believe that an investment in our palliative care services would be a better use of our finances and resources, and enable us to provide care in a loving and humane way for those with medical conditions who would otherwise opt for Assisted Dying." **Ref AD14**

Stakeholder individuals

"It is unnecessary. Most suffering can be relieved with good palliative care and family/community support. In my experience sustained desire to die is very rare (I can only think of 4-5 patients in a 17 year career thus far)." **Consultant geriatrician, UK**

"It would be extremely detrimental to palliative care services to introduce assisted dying as this would detract from the need to improve care across the board for all patients. It would also be dangerous for patients as it would be seen as an 'easy alternative' for those who don't have access to the level of care and support they need." **Consultant in Palliative Medicine, UK**

Stakeholder organisations

"The Jersey proposal would establish assisted suicide as a free entitlement, but should assisted dying become a legal right when palliative care is not a right? ... The proposed assisted dying service will be available free of charge unlike GPs and medical investigations. Many palliative care services will continue to be charity-funded." **Jersey Evangelical Alliance**

"The Jersey Dying Well Group desire to see the continued development of palliative and end-of-life care to become the best that is achievable in Jersey and opposes the introduction of the proposed law on Assisted Suicide and Euthanasia." Jersey Dying Well Group

d. Sanctity of life

A third of responses opposed to assisted dying referenced sanctity of life. These were submitted predominantly from people who made explicit reference to their religious beliefs, although a small number of people, who stated they held no religious views, also commented on an inherent value of human life.

Responses on this theme noted the sacred or precious nature of life; a belief that life should not be shortened at any cost; or a belief that society and / or individuals have no right to decide to end their own life or the life of another.

Some written responses from stakeholder organisations emphasised that a 'right to life' was enshrined in the European Convention of Human Rights and, discussion during in-person meetings, noted that the Convention did not enshrine a 'right to death'.

Written responses

Public

"Civilised society has always held human life to be sacred, something to be preserved at all costs. All its institutions function with the inherent aim of preserving and enhancing the quality of life its citizens experience.... To allow someone to end their own or another's life undermines its sanctity, sending the message that life is not sacrosanct but can be ended for the "right" reasons." **Ref AD15**

Stakeholder organisations

"The prohibition of killing other people is a foundation of societal life, due to the highly regarded view of the worth of human life. Everyone has a right to life under Article 2 of The Human Rights Act 1998." **Jersey Dying Well Group**

"The value of a human life is not based on perceptions of someone's autonomy, contribution or capacity. Once we start ranking the value of people's lives in this way, we breach a fundamental principle which protects everyone: that all lives are of equal value." **The Christian Institute**

e. Safeguards (coercion)

Just under a third of responses expressed a view that both Jersey's proposals and assisted dying regimes in other jurisdictions had insufficient safeguards to protect vulnerable people and prevent coercion – i.e. individuals are pressured into a decision to have an assisted death. Some held the view that the systems in other jurisdictions had been developed with insufficient safeguards in place, others stated concerns that safeguards in the Jersey proposals may fail or may not be applied correctly, and coercion would not be detected, as evidenced in other jurisdictions.

A small number of people who attend public engagement sessions expressed an internal conflict between agreeing the 'principle' of assisted dying but being concerned over the 'reality' of implementing assisted dying, and the ability to design a system with sufficient safeguards to protect vulnerable people.

Written responses

<u>Public</u>

"The safeguards that are proposed are largely illusory and will not prevent many people being killed in circumstances which the current proponents of the new law do not intend." **Ref AD13**

"People tell you they will be safeguards put in place but none have been fourth coming. For example, Doctors are very rarely able to diagnose a patient with depression or loneliness or social economic challenges without a prior relationship with in-depth consultation. If the patient wishes to keep these things hidden, they will do so as a result, perhaps of coercion or feeling they're burden on the family." **Ref AD16**

"I do believe that it will be impossible to come up with a robust, secure, set of safeguards that will prevent any abuse." **Ref AD14**

"I also strongly believe that those safeguards that are introduced, are in danger of becoming diffused over time especially as financial, manpower and other constraints increase, which is extremely likely." **Ref AD17**

Stakeholder individuals

"I also do not believe that there is any safeguarding process Jersey could introduce that can guarantee that no unintended deaths happen. It will be impossible to avoid abuse, human error and coercion occurring and with no independent regulatory service in place in Jersey, even more difficult to identify malpractice." **Community nurse, Jersey**

"THERE ARE NO SUFFICIENT SAFEGUARDS FOR euthanasia or assisted suicide. The proposed law will affect vulnerable people who in over 50% of cases will feel a burden to others." **Retired GP, Jersey**

Stakeholder organisations

"Our view is that the safeguards proposed are far from adequate and that no system of euthanasia can ever be truly safe for vulnerable people." **Care Not Killing and Our Duty of Care Joint response**

"Elder Abuse is hidden and very common, particularly financial abuse. The proposed so called 'safeguards' will not protect the elderly from coercion and manipulation by unscrupulous relatives who for selfish motives will manipulate the vulnerable person for financial gain and even their own convenience." **Jersey Dying Well Group**

f. Role of doctors

Both medical professionals and members of the public held the view that the introduction of assisted dying may impact on the central role of doctors to treat, cure or prevent death (whilst respondents supportive of assisted dying stated that assisted dying could align with a doctor's role of preventing suffering).

For some, legislation that allows medical professionals to actively end a patient's life represents a fundamental shift in medical practice, with potential to lead to distrust of

medical professionals (for example, a fear that patients would not disclose their suffering in case a doctor 'recommended' assisted dying).

At some in-person sessions, with the public and HCS staff, it was suggested that there was a perception that assisted dying legislation could be misused by some professionals (for example, encouraging a person to have an assisted dying to alleviate pressures on services)

Some responses stated that assisted dying should not be viewed as part of a health service but treated separately and set apart from the Island's healthcare system [see more in Section 5.2.e]

Written responses

Public

"The relationship between medical doctors and their patients must be profoundly and irreversibly changed... How can a patient any longer be sure of the motive of his or her doctor?" **Ref AD18**

"This will fundamentally change the relationship between doctor and patient and will fundamentally alter the role of doctors who have been trained to treat and care for the lives of their patients, rather than directly terminating them." **Ref AD19**

Stakeholder individuals

"As a retired General Practitioner I think this this would fatally damage the relationship of trust between doctor and patient." **Retired GP**

"[Assisted dying]_threatens the relationship of trust and care that exists between patients and healthcare professionals whose duty is to 'do no harm'." **Palliative Care Consultant UK**

"Vulnerable people need to feel confident that the medical and nursing profession is there to save their life." **Hospice Nurse, UK**

Stakeholder organisations

"The imbalance between patient and doctor (84) means that the line between encouragement to suicide and an open discussion about options is entirely blurred and cannot be safeguarded against." **Living and Dying Well**

g. Public understanding/ awareness

Some responses (members of the public, and individual and organisation stakeholders) stated that whilst opinion polls in Jersey, the UK and internationally consistently show majority support for assisted dying, they believe that many people do not have a full understand what is meant by assisted dying, confusing it with other end of life practices, for example hospice care or palliative sedation.

Others noted that the public may not have a sufficient awareness of the proposals under consultation or what happens during an assisted death. For some, this perception of misunderstanding was linked to the language used around 'assisted dying' as opposed to 'assisted suicide' or 'voluntary euthanasia' [see more in Section 5.2.2]

Responses from members of the public expressed concern that awareness of assisted dying, and any negative connotations associated with it, could have a negative impact on the reputation of the island, including the ability to recruit health and care professionals.

Written submissions

<u>Public</u>

"First and foremost I doubt that the majority of people (members of the last States Assembly) who voted in principle to change the law properly understand the topic or the consequences of a law change, to the point that I would question if they even know the difference between assisted suicide and euthanasia." **Ref AD20**

Stakeholder individuals

"Assisted dying' is a misleading term that the general public does not fully understand – many people think this means hospice-type care or the withdrawal of life prolonging treatment – not the administration of lethal drugs to end their life intentionally. Even the vocal minority shouting for this legislation are quite ill-informed about what it means in practice." **Community nurse, Jersey**

Stakeholder organisations

"A July 2021 survey in the UK found that more than half of respondents thought the term 'assisted dying' meant "providing hospice-type care to people who are dying" or "giving people who are dying the right to stop life-prolonging treatment. Only 42% realised that it refers to giving lethal drugs to a patient to end their life intentionally" **Care Not Killing and Our Duty of Care Joint response**

5.2 General feedback – introducing assisted dying in Jersey

This section summarises feedback on specific matters related to the introduction of assisted dying in Jersey, over and above direct feedback on the specific consultation proposals, as set out in <u>Section 6</u>. These include:

- experience of other jurisdictions
- language and terminology
- costs of an assisted dying service
- delivering an assisted dying service
- medical vs non-medical model of assisted dying
- political process of introducing assisted dying.

5.2.1. Experience of other jurisdictions

Many responses referenced assisted dying practice in other jurisdictions citing 'successes' to learn from or 'failures' to provide caution to as *how* or *whether* assisted dying should be introduced.

'Successes' included the fact that multiple jurisdictions already provide for assisted dying and had in place effective safeguards (ie. if "others can achieve it, so can we"). Campaigning groups noted that over 200 million people around the world already have access to assisted dying and stated that in the interest of equality and the autonomy of individuals, this should be extended to Jersey residents.

Written responses

Stakeholder individuals

"The way our law has been written and implemented, safeguards exist on all sides. Only patients who can demonstrate their capacity to make sound medical decisions can access aid in dying. This helps prevent coercion, and in the 25 years that aid in dying has been legal in jurisdictions in the United States, <u>there has never been a single substantiated</u> <u>claim of coercion</u>." Assisted dying Practitioner, California

Stakeholder organisations

"Overseas evidence demonstrates that legislation which balances individual autonomy and the protection of vulnerable people is possible and preferable to the status quo... The evidence we gathered from parliamentarians and frontline clinicians from these jurisdictions [US, Australia and New Zealand], confirms that such an approach successfully balances the importance of promoting individual autonomy at the end of life while protecting those who may be vulnerable." Karin Smyth MP and Kit Malthouse MP, co-chairs of UK All-Party Parliamentary Group on Choice at the End of Life

'Failures' included references to jurisdictions where:

- assisted dying had been introduced without sufficient safeguards or where safeguards had been eroded over time or were not properly applied – leading to concerns over the misuse or abuse assisted dying practice, or
- the eligibility criteria had widened over time for example, extending to those with mental illness or to children aged under 18.

Written responses

Stakeholder individuals

"There have been many concerning reports from countries that have already legalised assisted dying which detail harrowing tales of pressure on vulnerable patients to end their lives to prevent them being a 'burden' on their families and society. The Oregon Health Authority's annual report from 2020 showed that <u>53% of people opting for assisted</u> suicide mentioned the fear of being a burden on family, friends or caregivers as a factor in their decision." **Consultant in Palliative Medicine, UK**

Stakeholder organisations

"New evidence from Canada indicates the tendency to expand to those who suffer not from physical diseases or conditions but from depression borne of poverty, homelessness, or other social conditions. In the context of increasing numbers of people defining themselves as suffering from various medical conditions, we think the numbers will climb in any area where ASE [assisted suicide and euthanasia] is legalized." **Humanists Against Assisted Suicide and Euthanasia (HAASE**)

"In other jurisdictions, over time, every safeguard has been attacked as being discriminatory and anti-choice. Those in favour of assisted suicide in Jersey have already voiced a desire to erode or eliminate any safeguards. Groups are already trying to extend

the 6-month prognosis limit and in Scotland a petition has been submitted to include mental health problems. Any safeguard is easily challenged in court." **Jersey Evangelical Alliance**

5.2.2. Language and terminology

The consultation report set out a broad definition for assisted dying – Assisted dying is where a person with a terminal illness, or experiencing unbearable physical suffering, chooses to end their life with the help of a medical professional¹⁷. In line with some other jurisdictions (for example, Australia), it also used the following terms:

- **'self-administered'** to denote when a person takes the assisted dying substance to end their life, and
- **'practitioner administered'** to denote when a doctor or nurse gives the person the assisted dying substance, usually by intravenous injection, to end their life.

This is in contrast to the original proposition (P95/2021) which referenced:

- **'physician-assisted suicide'** whereby a registered medical professional may prescribe lethal drugs at the request of a person, who meets defined eligibility criteria, to enable that person to self-administer the drugs to end their own life
- 'voluntary euthanasia' where a person who meets the defined eligibility criteria has their life ended, at their voluntary request, by a registered medical practitioner¹⁸

A number of in-person responses, from those who supported assisted dying, favoured the term 'assisted dying' as a broad concept, stating it was clear, appropriate and consistent with terminology used in other jurisdictions. They expressed a preference for the term 'assisted dying' over acronyms used in Canada ('MAID' – Medical Assistance in Dying') or Australia ('VAD' – Voluntary Assisted Dying') or 'euphemisms' as used in the USA ('Death with Dignity Act').

A large number of submissions from those who are opposed to assisted dying (both public written responses and campaigning organisations) stated that the term 'assisted dying' was either unclear or an attempt at 'whitewash'. 'Assisted suicide' or 'Physician-assisted suicide' and 'euthanasia' or 'voluntary euthanasia' being given as preferred terms.

Written responses

Stakeholder organisations

"The term [assisted dying] is used by its proponents as a gentler sounding alternative to assisted suicide and euthanasia, but it has no meaning in law." Lives Worth Living – A Campaign of SPUC [Society for the Protection of Unborn Children] Pro-life

"Using the language of 'assisted dying' gives the public the impression that what is being proposed is broadly equivalent to palliative care – that it is about helping people in their dying moments. This is simply inaccurate and distorts the reality that the proposed law would permit medical professionals to kill their patients. That is a radical departure from doctors' duty of care." **The Christian Institute**

¹⁷ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, page 10

¹⁸ paragraph 95-2021.pdf (gov.je), page 2

"The Jersey Government's definition of "assisted dying" is misleading and repeats the euphemistic campaign messaging of those seeking a change in the law. The Government of Jersey is proposing both assisted suicide and euthanasia." **Care Not Killing and Our Duty of Care Joint response**

The consultation report included the following statement 'Assisted dying is not the same as *suicide.*' Some respondents strongly agreed that it is important to differentiate assisted dying from suicide. Others contended that it is wrong to say that assisted dying is not a form of suicide.

Written responses

Stakeholder individuals

"Another point I wish to make is the importance of language and not referring to VAD [Voluntary Assisted Dying] as suicide or assisted killing. South Australia's Assistant Commissioner of Police... reported that from 1 January until 22 November 2019, ten people had taken their lives as a result of terminal illness, equating to approximately 11 per cent of all suicides during that period... The age of those persons ranged from 63 to 88 years, and most deaths in such circumstances are undignified, violent, and sometimes botched... It is however an offence to assist someone in their suicide or suicide attempt. Consequently, the 'vast majority' of suicides in South Australia are committed when the person is alone and 'without their family to comfort them'." Attorney-General of South Australia

Stakeholder organisations

"The assertion made on page 2 of the Summary of Proposals that "Assisted dying is not the same as suicide" is not born out by the evidence." Lives Worth Living – A Campaign of SPUC [Society for the Protection of Unborn Children] Pro-life

"The consultation document states: "Assisted dying is not the same as suicide" (paragraph 11). This is unhelpful and misleading." **The Christian Institute**

NOTE

Paragraph 11 of the consultation report stated: 'Assisted dying is not suicide <u>or assisted</u> <u>suicide</u>'. This was an error, it should only have read as 'Assisted dying is not suicide.' ¹⁹

5.2.3. Costs of an assisted dying service

A small number of public and individual stakeholder written consultation submissions questioned the cost of establishing and maintaining an assisted dying service and noted that

¹⁹ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, page 11

the States Assembly would need to understand the costs involved in order to make an informed decision.

Some expressed concern that the costs of assisted dying service would divert funding away from existing end of life and palliative care provision, stating this to be the case in some other jurisdictions. However, a number of responses [see Section 5.1.1.e.] contradict this view, citing evidence that the introduction of assisted dying legislation has increased funding and / or enhanced palliative care provision.

Written responses

Public

"It would take the emphasis off compassionate palliative care, because it would be cheaper to kill people." **Ref AD21**

The existence of assisted dying will lead to a reduction in investment in palliative care of the elderly, disabled and terminally ill. This is happening in Canada." **Ref AD22**

Note: The consultation report states that it is envisaged that assisted dying legislation would not be brought into force until '*the Assembly is satisfied that all Islanders can access good palliative and end-of-life services*' and notes that additional funding has been secured for palliative and end of life services via the 'Palliative and End of Life Care Strategy for Adults in Jersey 2022-2025'.²⁰

A potential lack of clarity over what may constitute 'good palliative care' was a concern for some stakeholder organisations. Other submissions questioned the prioritisation of resources more broadly, noting deficits in funding for existing healthcare services, giving examples of other vital services not currently available on-island (for example, single shot radiotherapy).

Written responses

Stakeholder organisations

"The definition of what constitutes 'good palliative care and end of life services' will always be changing as medical knowledge advances. It will also depend on individual, not generic, circumstances. There is a concern that this proviso could postpone the law's introduction indefinitely, on the basis that care could always be better. A more workable approach is to ensure that any applicant has been offered the best services then available. The funding of those services is of course for the government to decide upon." **My Death, My Decision**

"We suggest it is not appropriate for the State to provide a free death service when other services that would save life or improve the quality-of-life left are not being provided... Specialist palliative care is provided in the hospice, but currently there are beds closed

²⁰ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, page 11

(only six are open at the time of writing this document) due to staff shortages. Specialist home care provision has fallen as there are now only two nurses in the team and input to the hospital has been scaled back... the proposal is for state-funded bereavement support for the relatives of those who have had assisted dying. This is inequitable across the population" Living and Dying Well

At in person public engagement sessions and HCS staff sessions, concerns were expressed about what some perceive to be disproportionally high set-up and running costs for an assisted dying service which will benefit a relatively small number of people. [It is estimated that between 2 and 38 Islanders per year would have an assisted death.]

Responses highlighted the experience of other jurisdictions including Canada and Oregon which indicated a net saving in healthcare costs, due to the high costs of end-of-life care for some patients. For some, this was viewed as positive and pragmatic, others feared this could lead to systemic pressures to encourage assisted dying for patients over other more expensive end of life care options.

Written responses

Public

"In other jurisdictions there is danger of this approach becoming a cost-effective alternative to providing properly for high support needs." **Ref AD23**

Stakeholder organisations

"With nearly 25 years of data since the first implementation of Oregon's medical aid-indying law in 1997, we no longer have to hypothesize about what will happen if this medical practice is authorized. The evidence is clear: medical aid in dying protects patients, affords dying people autonomy and compassion during the most difficult time, improves end-of-life care, and costs jurisdictions almost nothing to implement." **Compassion & Choices, USA**

5.2.4 Delivering an assisted dying service

a. Standards and governance concerns

Responses from members of the public, stakeholder organisations and some individual onisland health care professionals expressed concerns over the practicalities of delivering an on-island assisted dying service. Some focusing on recent reports related to HCS's governance structures, lack of standards and lack of provision of essential services.

Written responses

Stakeholder individuals

"Currently the hospital and secondary care is providing a very poor service to the Island. Specifically there is poor governance from the leadership team and a lack of provision in services for the diagnosis of terminal illness. For example there is no Rapid Diagnostic Clinic for patients with suspected cancer. There are main specialities who do not currently have Consultant support or are run by locum Consultants (e.g. Haematology and Rheumatology). There is no Care of the Elderly Specialty service. GPs have limited access or no access to tests which would enable quicker diagnosis of cancer (for example FIT tests / difficulty in access radiological tests (>12 months wait for CT colonography (which is used to again try and diagnose certain cancers)." **Practising GP, Jersey**

"There is a poor governance structure within Health and the Primary Health Care Team. There are conflicts which could inappropriately lead to professional criticism on an individual on whether they decide to be involved in a service or not. For example, the current Primary Care Medical Director who is responsible for commissioning services is also the Responsible Officer for GPs (the RO is the GMC link to Jersey who decides on GP's Fitness to Practice)." **Practising GP, Jersey**

Stakeholder organisations

"The recent report by Professor Hugo Mascie-Taylor (Review of Health and Community Services (HCS) Clinical Governance Arrangements within Secondary Care report) made 61 important recommendations that must be urgently addressed. The issues in governance highlighted it the report raise questions as to how current structures would have the capacity to oversee a Jersey Assisted Dying Service without serious jeopardy to oversight of services whose mission is to save life and improve quality of life." Living and Dying Well

b. Staffing concerns

Responses from stakeholder organisations and stakeholder individuals focused on a potential lack of staff to run an assisted dying service, and the impact that assisted dying may have on future recruitment – assisted dying was presented both as a draw and as deterrent to coming to Jersey to work.

In addition, concerns were raised that staff involved with assisted dying – either as assisted dying practitioners or as providers of secondary opinions – could be diverted from other much needed services.

Written responses

Stakeholder individuals

"The introduction of assisted dying would place Healthcare Assistants, Nursing Associates and Registered Nurses at the epicentre not only of patient decision-making, but as administrators of medication used to prematurely end the life of a human being. This would cause considerable moral distress for current healthcare professionals and render the nursing profession an unattractive career option for future generations of men, women and young people." Lecturer in nursing, midwifery & health education, UK

Stakeholder organisations

"There is an acute shortage of manpower [in Jersey]. General Practice has a 15% vacancy factor at present; nurse vacancies remain unfilled at all clinical grades – especially band 6 and 7- and in care homes and in the hospice; there is an acute shortage

of allied health professionals with many occupational therapists resigning posts in the past two years; there are shortages in social care for patients in their own homes with no fast track to financial social services support to allow them to be cared for at home." Living and Dying Well

"Our members in Jersey have expressed specific concerns regarding the six principles of safeguarding, noting that the medical community in Jersey is small with only 12 psychiatrists. Regarding palliative care, members in Jersey have also raised the point that there is only one hospice in Jersey, and that there are no specialist dementia care homes. To staff an assisted dying service in jersey, clinicians would likely need to be taken from other services. This impact would need to be assessed prior to implementation, including implications for staffing." **Royal College of Psychiatrists**

Some HCS staff raised concerns about the impact on working relationships– i.e. how well would colleagues work together if they held fundamentally different views on assisted dying, would a staff member who conscientiously objected to assisted dying want to work with an assisted dying Practitioner? Others expressed concern that doctors, who are under significant pressure, may not perform their duties as an Assisted dying Practitioner to the highest standard. Some also noted that we do not have a clear picture as to how many on-island medical staff would be willing to participate in an assisted dying service, and if off-island locums were required, whether this would affect the quality, cost, and viability of the service.

5.2.5. Medical vs. non-medical model of assisted dying

Written responses and views expressed at public engagement events and HCS staff sessions highlighted divisions as how assisted dying is perceived. Many saw assisted dying as natural extension of the healthcare service (we provide for end-of-life care, and assisted dying is an end of life choice) and, as such, stated that assisted dying should be integrated into care provision. Those who ascribed to this 'medical model' of assisted dying, tended to support the assisted dying process outlined in the consultation report, which provided for a doctor-led assessment and approval process.

Others – both supporters and opponents of assisted dying – saw assisted dying as being about personal choice and entirely unrelated to health care / treatment. This 'non-medical' view of assisted dying bears similarities to the model provided in Switzerland.

Some proponents of the 'non-medical' view (predominately supporters of assisted dying) state that assisted is about personal choice– not about medical intervention or expertise. Others (predominately opponents of assisted dying) advocate the 'non-medical' approach as it upholds the right for medical professionals to conscientiously object and does not disrupt or interfere in the relationship between medical professionals and patients.

Written responses

Stakeholder individuals

"There would be overall **better quality life** for patients if assisted dying could be incorporated as one aspect of palliative and terminal care. A good quality of the life that's left is after all the overarching goal of good palliative care." **Retired Palliative Care Nurse**
"If assisted suicide and euthanasia is made legal in Jersey (I sincerely hope it is not) then a Tribunal should review EVERY request – this should be a legal process not a medical one." **Consultant in Anaesthesia & Intensive Care Medicine**

"The relationship with doctors would be changed irrevocably. At the moment doctors seek to preserve life and do all they can to enhance the quality of life, right to the end." **Ref AD25**

"The ethical underpinning of this legislation is to empower patients with incurable painful conditions to escape lives not worth living. The patient, then, should be the sole determinant of this. No court or tribunal could ever be in as good a position as the patient to make this decision." Director of The Centre for Philosophy of Epidemiology, Medicine and Public Health, University of Johannesburg

Stakeholder organisations

"Making use of any form of assisted dying... is a personal choice in the frame of every individual's right to self-determination; no matter whether (or not) such individual is in fact or assumed to be a member of a certain group defined by medical diagnosis or life expectancy." **DIGNITAS**

5.2.6. Political process associated with consideration of assisted dying proposals

Some individuals and stakeholder organisations challenged the proposed process associated with the development and approval of assisted dying proposals. Concerns included:

- the P95/2021 'in principle' decision was made by a previous States Assembly and should not stand for a future Assembly.
- the public had not been given sufficient opportunity to influence the debate.

Written responses

Stakeholder organisations

"There should then be a repeat of the vote on the principle of the legislation and, if this is carried, the States Assembly should take responsibility for the shape of the legislation. This should not unthinkingly echo the results of the votes of the 'Citizens' Jury'." **Professor of Bioethics, St Mary's University & Director, Anscombe Bioethics Centre**

"The Government of Jersey's 121-page consultation report states that: "the purpose of this consultation is not to consider whether assisted dying should be permitted in Jersey – as the Assembly have already determined, in principle, that it should be permitted – but instead to understand peoples' response to how an assisted dying service should work." (p7) This approach neglects the constitutional principle (cf Dicey) that no parliament can bind its successor; Jersey elected a new States Assembly in June 2022, following the earlier vote in November 2021." Care Not Killing and Our Duty of Care Joint response

Avoiding an 'incoherent' law

One joint submission referenced findings from research undertaken in Australia. It highlighted the importance of ensuring that assisted dying proposals – and the associated safeguards – are considered by the Assembly in the round, rather than focussing on individual legislative elements separately. The research found that a holistic approach is required to avoid inconsistent' legislation:

"A final observation about the law-making process, based on what we have seen in the six Australian law reform processes, is the need to avoid the ad hoc addition of safeguards which are awkwardly tacked on to already sound law. This leads to the assisted dying law being incoherent or inconsistent in important ways... we argue that any proposed changes to the Bill must be carefully scrutinised in light of the Bill as a whole:

When thinking about the politics of reform, it can be tempting to only consider each safeguard or process individually. Each may have merit and advance a particular policy goal. It may also be difficult politically to argue that a specific safeguard is not needed, particularly if it appears to achieve at least some useful purpose. However, when the safeguards are aggregated, the VAD [Voluntary Assisted Dying] system as a whole can become very complex and unwieldly, and slowly take the legislation away from its policy goals. This "policy drift by a thousand cuts" – the incremental loss of policy focus through accumulation of individual safeguards without reference to the whole – is a key issue for other states to consider when evaluating their proposed VAD reforms. It is suggested that each part of the law be evaluated both on its own, and also for its impact on the functioning of the overall system. This is needed to enable VAD laws to meet their policy goals, in particular, the two key goals at the core of the design of the VAD Act: safeguarding the vulnerable while respecting the autonomy of eligible persons who wish to access to VAD'." Joint submission – Professor of End-of-Life Law and Regulation Professor of Law Australian Centre for Health Law Research

Timeframe for introduction of assisted dying

A number of people who attended public engagement sessions (both supporters and opponents of assisted dying) expressed the need to ensure that assisted dying proposals are fully considered, with due care and caution, and not rushed. Conversely, a small number of people – all of who were strongly in favour of assisted dying – expressed the view that Jersey is taking too long to develop assisted dying legislation, which is having a negative impact on people who are currently suffering and being denied access to an assisted death.

6: Summary of responses – Feedback on the detailed proposals

This section summarises feedback on the detailed proposals set out in the consultation report, across five key areas:

- 1. eligibility criteria
- 2. Jersey Assisted Dying Service
- 3. assisted dying process: request and approval
- 4. assisted dying process: planning and delivery of an assisted death
- 5. regulation and oversight.

The feedback has been grouped into responses received from:

- members of the public
- stakeholder individuals, and
- stakeholder organisations.

Responses to the online survey are included in this section. Questions 1 to 3 of the survey asked people:

- if they consented to their comments being made public If they said no, their comments are not quoted in this report but their views have been factored in
- whether they held strong views on assisted dying Their responses have been used, where relevant, to sort survey responses into four categories:
 - respondents with a strong view that assisted dying should be permitted ("supporters")
 - respondents with a strong view that assisted dying should <u>not</u> be permitted ("opponents")
 - o respondents with no strong view
 - o those chose not to disclose their views ("unsure / unknown")

6.1 Eligibility criteria

The proposed eligibility criteria for assisted dying in Jersey were set out on pages 13 to 18 of the consultation report²¹. The online survey asked specific questions on the eligibility criteria that related to:

- life expectancy for neurodegenerative conditions
- residency, and
- age.

The online survey did not ask specific questions about parts of the eligibility criteria that had already been addressed by the States Assembly in P95/2021. For example, the survey did not ask whether people must have a *voluntary, clear, settled and informed wish to end their own life* or *capacity to make the decision to end their own life*²², as the Assembly had already considered this matter.

²¹ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, pages 13-18

²² paragraphs 95-2021.pdf (gov.je), page 2

6.1.1. Health criteria eligibility

a. 12-month life expectancy for those with a neurodegenerative condition

This feedback refers to section of the proposals which set out that a person with a neurodegenerative condition may be eligible for assisted dying if they have a life expectancy of 12-months or less (as opposed to 6-months or less for those with any other terminal physical medical definition).²³

Q.4 Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?



The overall response to this question did not show a clear preference for the inclusion of 12month life expectancy for those with a neurodegenerative condition.

Those in support of assisted dying, favoured the inclusion of the 12-month criteria (91% of those supportive of assisted dying, responded 'yes' to this question) and those opposed to assisted dying did not support it ('92% of those opposed to assisted dying responded 'no'). 53% of those with no strong view on assisted responded, 'yes' and 55% of those who chose not to disclose their views responded 'no'.

²³ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraph 16

639 respondents gave a reason for their response, with supporters of assisted dying being more likely to provide a reason for their response. The most commonly cited reason for supporting the 12-month criteria was the relief of pain or suffering for a person with a neurodegenerative condition.

Other reasons cited included a person's right to autonomy over decisions about the end of their life, and the anticipated reduced quality of life. Reasons cited were consistent with the key arguments in support of assisted dying received in general responses to the consultation – suffering, quality of life, personal choice/autonomy [see Section 5.1.1.]

"I feel any person suffering from any degenerative condition should be given the option to die with dignity and without suffering." **Survey respondent supportive of assisted dying answering 'yes' at Q.4**

The most common reason given by those opposed to assisted dying, who responded 'no' to this question, was the ability / inability of doctors to accurately predict life expectancy [see 'Life expectancy' below]. The second most common reason mirrors the key arguments in opposition to assisted dying – i.e., the need to focus on palliative care, concerns over coercion and fear of an expansion of the eligibility criteria over time. [see more Section 5.1.2]

"Medical conditions can change, sometimes rapidly and sometimes for the better. Assisted dying as it is called would put at risk any hope of late improvement in a condition." **Survey respondent opposed to assisted dying answering 'no' at Q.4**

Stakeholder feedback (individuals & organisations)

Stakeholder responses largely echoed the survey responses from members of the public. The majority supportive of assisted dying responded 'yes' to Q.4, citing the prevention of suffering and the importance personal choice/autonomy. However, a number of stakeholders supportive of assisted dying also commented on:

- the inaccuracy of a time-based diagnosis, or
- expressed a preference for no life expectancy criteria to be included [see Section <u>6.1.1.b below</u>].

Those opposed to assisted dying most frequently referenced the inaccuracy of prognosis as the main reason for responding 'No' to question 4.

b. Terminal illness and life expectancy

There was some consensus amongst supporters and opponents as to the difficulties associated with predicting life expectancy, particularly for those with neurological conditions or non-malignant disease such as cardiac or respiratory failure.

Some stakeholder written submissions stated that a timeframe for a terminal diagnosis (whether that be 6 months or 12 months) provided an important safeguard, as it worked to only permit assisted dying for those at the end stage of life, even if end of life could not be exactly predicted.

"The framing of the prognosis requirement ("reasonably expected") concedes the well-known fact that prognostication, especially many months from death, is far from an exact science: a

2017 UCL study found that over half (54%) of those predicted to die within a specified time period lived longer than expected." **Care Not Killing and Our Duty of Care Joint response**

"The definition of what is a 'terminal illness' in terms of prognosis is very difficult and imprecise as predictions of life expectancy can be inaccurate. This could be days, weeks, months, or years.

Misdiagnosis commonly occurs. 88% of head & neck cancer prognoses are wrong, nearly half of predictions in heart failure are wrong, and 5% of terminal diagnoses are wrong." Jersey Dying Well Group

Others suggested there should be no statutory timeframe, either because of difficulties associated with determining life expectancy or, on the basis that, if someone has a terminal condition and is suffering, does it matter whether they will die in 5, 6 or 10 months' time?

"In Scotland, Liam McArthur MSP's proposals for an assisted dying law defines terminal illness in line with the Social Security (Scotland) Act 2018, which relies on clinical judgement and does not include an estimate of prognosis. Dignity in Dying understands that there is no existing definition of terminal illness in Jersey law." **Dignity in Dying**

"The eligibility criteria should be changed in doing away with the criterion of any life expectancy limit. No one, not even the most expert medical professional, is able to predict the future and to know whether a patient is still alive in 6 or 12 months or any other number of months or days. ... In result, the criterion of a certain limited life expectancy is a hypothetical, and it leads to arbitrariness and inequality: one medical professional may hold the opinion that the patient is going to die in 6 months, but another may estimate this to be 6 months plus one day." **DIGNITAS**

c. Mental illness and psychiatric conditions

A number of stakeholder responses noted that whilst the proposed eligibility criteria only provides for people with a physical illness or disease, it needs to be acknowledged that those people will often have dual diagnosis of a mental health condition, such as depression. Some expressed concern as to how this would be addressed in the assisted dying eligibility assessment.

"We note that mental disorder, mental disability or mental incapacity are not included within the proposals' eligibility criteria. Should there ever be any re-evaluation of this aspect of the proposals, we would expect to participate comprehensively in this process. We wish to point out, however, that physical conditions commonly co-exist and interact with mental health conditions. Psychiatrists are often the primary treating clinicians for people with dementia, brain injuries of various forms, and functional neurological illness." **Royal College of Psychiatrists**

Some opponents expressed concern that those with a dual diagnosis may not be able to differentiate suffering that arises from their mental health condition (and a wish to end their life) from suffering that arises from their physical medical health condition (which makes them eligible for an assisted death), or that some mental health disorders result in physical symptoms and suffering.

"Although the present proposals exclude mental health disorders, this will not be the case in practice as these co-exist with physical illnesses. A person with severe Anorexia Nervosa will eventually have physical symptoms due to their condition and could request assisted dying on that basis." Jersey Dying Well Group

Several responses from stakeholders who support assisted dying stated that excluding mental illness as a qualifying criterion was inequitable; a view that was also expressed at several of the public engagement sessions.

"Paragraphs 17 & 21 insist that the condition suffered from be physical, not mental. This is not a distinction that modern medical science clearly supports: mental illness is recognised as being 'brain-based' and the understanding of this keeps evolving: let's not get left behind! We would say that **any** condition which is currently incurable, and is the cause of unbearable suffering, should qualify for relief, irrespective of whether it is being classed as physical or mental." **End of Life Choices Jersey**

"I support widening the criteria to include those who consider that life has become unbearable through suffering from whatever illness they have as long as they were competent to make that decision." **Ref AD24**

d. Unbearable suffering

A number of written responses from stakeholders focused on the inclusion of unbearable suffering in the eligibility criteria: *'an incurable physical medical condition that is giving rise to* <u>unbearable suffering</u> that cannot be alleviated in a manner the person deems tolerable.'

Some responses accepted the subjective and variable nature of suffering, understanding that it is the person who is suffering who must determine whether their suffering is bearable. Whereas other respondents stated that the eligibility criteria should not be based on a subjective notion, or rather that assessments of eligibility should not be based on subjective criteria.

"If the notion of "unbearable suffering" is self-determined by the person, then any degree of expectation of suffering cannot be judged merely by a clinician or other health professional, as suffering is not inherently linked to a condition but to an individual's subjective experience of a given condition, influenced by many social, psychological, emotional, and existential factors including the attitude of those providing care." Living and Dying Well

"The unbearable nature of the suffering is largely subjective and depends on the patient's personality, ideas and values." **Care Not Killing and Our Duty of Care Joint response**

Several submissions disagreed with the provision in the eligibility criteria that effectively allows a person to decline treatment of that they find intolerable²⁴

"This provision opens a grey area in the law where someone with an incurable physical condition could request assisted suicide on the basis that undergoing treatment that would delay death would cause unbearable suffering. For example, someone with complications of poorly controlled diabetes could decline to continue to use insulin, thereby becoming eligible for assisted suicide." Living and Dying Well

²⁴ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraph 18

e. Precision of definitions

Several stakeholders (including those supportive of assisted dying, opposed or hold a neutral position) commented on the need for absolute clarity when defining eligibility criteria. Feedback included:

Current suffering for those with a terminal condition

Responses received from two stakeholder organisations commented on the wording in paragraph 13 of the consultation report – *'has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months*²⁵ Noting that it was ambiguous and did not appear to explicitly allow for those with a terminal illness who are <u>currently</u> suffering:

"No mention is made of a third category (quite possibly a majority of applicants) who have **both** a terminal illness **and** current suffering. Which Route are they on? Do they have the choice? If so, it would be madness for them to choose Route 2, with all its extra burdens. In practice, most applicants would be putting pressure on their perhaps reluctant doctors to give them a terminal prognosis, so as to get onto Route 1." **End of Life Choices Jersey**

"We consider the proposals confusing in relation to those who are terminally ill. Paragraphs 16.a and b of the report suggest that only those who meet the prognosis timeframes (six or twelve months) and for whom the condition is expected to give rise to unbearable suffering, can follow the shorter Route 1 – not if they are currently so suffering... This could easily be addressed in the suggested wording in paragraphs 16.a and b of the report, by altering it to read '... is causing or is expected to cause unbearable suffering...'" My Death, My Decision

Others questioned where it was viable to include reference to a future expectation of suffering:

"How is it possible to determine whether suffering can or cannot be alleviated if a decision for an assisted death has been made not based on current suffering, but the possibility of future suffering? ...The expectation of suffering is as unpredictable as the time-prognosis of a terminal illness." Living and Dying Well

Causal link between eligible health condition and life expectancy

One response noted that the wording of the consultation report did not make it sufficiently clear that life expectancy must directly relate to the eligible health condition to qualify for assisted dying:

"The States Assembly should amend the language of criterion (e) [as set out in the consultation report p.13] to require a causal link between the medical condition that makes a person eligible for assisted death and their life expectancy. A suitable formulation might be: "has been diagnosed with a terminal physical medical condition... and <u>which is reasonably</u>

²⁵ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraph 13

<u>expected to cause the person's</u> death within six months." Lecturer in Health Law, UCL Faculty of Laws

<u>Circumstances under which those with a neurodegenerative condition may access</u> assisted dying

One response noted that the consultation report was unclear as to whether those with a neurodegenerative condition may qualify for an assisted death only if they have a life expectancy of 12-months or less, or if they have a life expectancy of more than 12-months but are currently experiencing unbearable suffering.

"It is unclear whether individuals with neurodegenerative diseases may only access assisted death under criterion (e)(ii) (terminal physical medical condition) or whether they may also access assisted death under criterion(f) (non-terminal unbearable suffering)." Lecturer in Health Law, UCL Faculty of Laws

6.1.2. Residency status eligibility

The consultation proposed that assisted dying should only be available to Jersey residents and defined Jersey resident as 'a person who has been ordinarily resident in Jersey for at least 12 months before requesting an assisted death.'²⁶



Q5. Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

²⁶ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, page 16

Answer Choices	Responses		
Yes		47.78%	431
No		31.49%	284
Don't know		20.73%	187
Please tell us the reasons for your response 616			•
Answered: 902 Skipped: 0	Response Total:		902

i. 12 months ordinarily resident

Excluding 'don't know' responses, the majority of respondents agreed that assisted dying should only be available to people who have been Jersey resident for 12 or more months. Support for the 12-month residency criteria included both supporters and opponents of assisted dying (48% of those strongly supportive of assisted dying and 47% of those strongly opposed answered 'yes').

616 respondents gave a reason for their response. The most commonly cited reason for supporting the proposal was the prevention of 'death tourism'. Other reasons included managing service demand from non-residents and any associated increased pressure on health services.

Respondents opposed to the 12-month residency criteria focused on social compassion – they believe that all people should be able to end their suffering regardless of their residency status. Some argued that people born in Jersey should be allowed to access the service regardless of whether they live off-island [see Section 6.1.2.b below].

Several responses who disagreed with the proposal held the view that a 12-month residency period was too short.

"Jersey might become a centre for assisted death or 'death tourism." **Survey respondent opposed to assisted dying answering 'yes' at Q.5**

"How does where someone lives impact their capacity for societal compassion? If they are eligible for health services in Jersey that's all that matters." **Survey respondent supportive of assisted dying answering 'no' at Q.5**

ii. Those born in Jersey but not currently resident

In addition to the online survey comments, feedback was also received in written submissions citing that the residency eligibility should extend to those born in Jersey, or with permanent 'entitled' status.²⁷

"People who are residentially qualified must have the right to return 'home' should they become terminally ill." **Ref AD27**

"I think greater consideration should be given to allowing former residents to return to Jersey for assisted dying, if they so choose. If they are resident overseas and terminally ill, it would

²⁷ <u>Residential and employment statuses and what they mean (gov.je)</u>

greatly ease pressure on them and their Jersey relatives if they could end their days here." **Survey respondent supportive of assisted dying answering 'no' at Q.5**

"Those born here may want to come home to die and there is no obvious reason why they should not, were they able to provide evidence that they fulfil all the other criteria and have a valid Jersey birth certificate." Survey respondent opposed to assisted dying answering 'no' at Q.5

"A person born in Jersey should retain their rights under Jersey law. They should not be deemed death tourists if they choose to die in their native island." **Survey respondent supportive of assisted dying answering 'no' at Q.5**

One stakeholder submission detailed the experience of the residency requirement in Australia, noting the legislation in Queensland sets out an exemption clause:

"The residence requirement has produced some difficulties in Australian jurisdictions. One response to this is to have a default residence requirement but allow for discretion in particular cases to avoid injustice....

Queensland 'residency exemption...'

(a) the person has a substantial connection to Queensland; and...

(b) there are compassionate grounds for granting the exemption "

Joint submission - Professor of End-of-Life Law and Regulation Professor of Law Australian Centre for Health Law Research Australian Centre for Health Law Research

6.1.3. Minimum age limit for eligibility

The consultation proposed that a person must be 18 years old or over to be eligible for Assisted Dying.



Do you agree that assisted dying should only be permitted for people aged 18 or over?

i. Over 18s only

Survey responses indicate a mixed view towards the '18+' eligibility criteria, with marginally more saying yes to the 18+ criteria than saying no. When responses are considered by views towards assisted dying, supporters were more likely to agree with the proposed age limit (41%), whereas opponents showed a broadly equal proportion of agreement (34%) and uncertainty around the age limit (35% answering 'don't know').

The most commonly cited reason for agreeing with the 18+ criteria related to the notion that only people aged 18 and over have the maturity and legal capacity to consent to assisted dying.

Those who did not agree with the 18+ criteria, broadly cited two key reasons:

- people of any age can experience pain and suffering and most young people (15-16 years old) are capable to consent and make informed decision [see below 'b. 'mature minors' / Gillick competence']. Some respondents stated that assisted dying should be offered to children and young people as long as there was parental consent.
- a fundamental lack of support for assisted dying for any person of any age.

ii. 'mature minors' / Gillick competence

At public engagement sessions a number of participants (albeit a minority) noted that whilst allowing assisted dying for 18+ only was a straightforward option, it would exclude young people and older children with the competency and maturity to make informed decisions about their medical treatment and wish for an assisted death, citing potential use of Gillick competence to determine on a child-by-child basis whether they have the ability to consent to having an assisted death.

In-person discussions also focused on the likely complexity of decision making for those aged under 18 in relation to parental consent.

"As the Jersey voting age is 16, if a person is old enough to help decide how Jersey is governed then they are old enough to make an informed decision to select assisted dying." **Survey respondent supportive of assisted dying answering 'no' at Q.6**

"If it's about consent and autonomy and at say age 14 you can consent to life changing surgeries, contraception, abortion etc there is no reason to restrict on age. Indeed, it would b e ageist." **Survey respondent opposed to assisted dying answering 'no' at Q.6**

This view was echoed by a number of stakeholder individuals and organisations who were supportive of assisted dying:

"The assisted dying laws of Belgium and Netherlands adhere to this and allow for under-18 to access assisted dying under specific circumstances. Jersey should take this as an example. A 17-year-old young Jersey Islander may well have capacity to understand the consequences of a diagnosis of a severe illness, may it be terminal cancer or neurodegenerative ailment or any other, and what assisted dying implies. Furthermore, if a 17-year-old is permitted to set up and/or have respected an advance directive to refuse treatment, which will hasten death if applied (passive euthanasia), it does not make sense to bar such young person from assisted dying which leads to the same result." **DIGNITAS**

"Minors should be permitted access to assisted death under the Jersey Assisted Dying Law. ...We shield minors—we may scrutinise and override their medical decisions (or, in this case, deny the opportunity for such decisions)—because our concern is for the long-term consequences of such decisions, or because we worry that the values minors use to take decisions are unstable. But in the case of minors with capacity who would be eligible for assisted death but for an age criterion:

a) there may be less long term to speak of (in the case of terminal or life-limiting illness) compared to minors expected to live a full life;

b) the fatal consequences of assisted death may be less bad than the prolonged experience of unbearable suffering (until death or adulthood); and

c) the individuals concerned may have developed, through the experience of serious medical conditions and treatment, a sophisticated, mature perspective." **Lecturer in Health Law, UCL Faculty of Laws**

Note: The target audience for this consultation was Islanders aged 18+. Views of children where not explicitly sought on the advice of the Children's Commissioner.

6.2 Jersey Assisted Dying Service

The consultation proposed how an assisted dying service could work in practice and the types of staff who would be involved, with the online survey asking specific questions about:

- paying for the assisted dying service, and
- conscientious objection.

Proposals for an assisted dying service were set out in Section 4 of the consultation report.²⁸

6.2.1 Providing an assisted dying service

a. Health and Community Services Department

The consultation report (page 19) proposed that an assisted dying service would be managed and delivered by GoJ Health and Community Services Department ("HCS").

As set out in <u>Section 5.2.5</u> – 'Medical vs non-medical model of assisted dying' and <u>Section</u> <u>5.2.4</u> – 'Delivering an assisted dying service' some respondents queried whether an assisted dying service should be delivered as part of mainstream government-led health service provision, with others raising concerns about HCS's capacity and capability to deliver the service.

In addition, a small number of consultation responses (written and in-person) expressed a view that if an assisted dying service is delivered by HCS, there should be clear separation from other health and care services:

"The Jersey Assisted Dying Service should be completely outside the health care system for all its activities, with premises away from the hospital. Such premises could provide a place where the person takes lethal drugs (similar to Dignitas) and any bereavement service should be located in such premises." Living and Dying Well

b. Free of charge

The consultation proposed that the Jersey Assisted Dying Service would be available free of charge to any eligible person, regardless of whether the assisted death takes place in an HCS facility or another location.

²⁸ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, pages 19-31

Q.7 Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria?





Overall, the most common response to this question was 'yes, it should be free'. Supporters overwhelming agreed it should be free (79% of supporters), those with no strong view on assisted dying also agreed that the service should be free (53%). Assisted dying opponents did not support the proposal (with only 9% agreeing it should be free and 42% responding 'don't know'),

The most commonly cited reason for agreement was to ensure equity of access and respect of human rights. Other reasons included dignity of the patient and the notion that free assisted dying would reduce spend on long-term care and treatment.

Those who did not agree with a free service, broadly fell into two groups:

- Group one argued that, given primary care is not free in Jersey, assisted dying should also be paid for by the patient. A small proportion of respondents elaborated on this theme, stating that access should be means tested and / or a charge would act as a helpful deterrent.
- Group two were fundamentally opposed to assisted dying and disagreed with all the proposals in their entirety.

A small number of respondents stated that improving palliative care and existing healthcare services should be a higher priority than provision of a free assisted dying service.

Written responses

Public and stakeholder organisations

A number of respondents (written responses) also stated that assisted dying should not be free, providing similar reasons to those noted in the survey responses above. A number suggested that making assisted dying free could send a message to vulnerable Islanders that assisted dying was being prioritised over other care, treatment or support needs.

"To make assisted suicide/euthanasia freely available to those people who meet the criteria would, arguably, communicate to the most vulnerable members in society that they were of little or no value and that they constituted a financial burden on society." **Ref AD28**

"Making assisted suicide available free of charge would act as an incentive for those in financial difficulties who would prefer to end their lives simply to avoid incurring medical expenses. This is especially dangerous for vulnerable individuals who fear becoming a burden to their families." Lives Worth Living – A Campaign of SPUC [Society for the Protection of Unborn Children] Pro-life

c. Assisted dying Practitioner training and qualifications

The consultation proposals set out the requirements for professionals who may choose to opt in to participating in an assisted dying service. As a minimum requirement they would need to:

- be registered with the Jersey Care Commission ("JCC") to work in Jersey, and more than 12 months post full professional body registration (e.g. GMC- General Medical Council)
- have opted-in to work as Assisted dying Practitioner
- have completed assisted dying training; and
- be able to demonstrate the skills outlined in the Assisted dying Practitioner competencies framework²⁹.

The survey did not include a specific question on training and qualifications, however feedback was received from both individual and organisation stakeholders, both in written submissions and in-person sessions, including the HCS staff engagement sessions. Feedback focused on 3 key areas:

- level of experience for Assisted Dying Practitioners
- training
- supervision, whistleblowing and support.

Level of experience

Many stakeholders with a health background stated that the assisted dying practitioner role would not be suitable for newly qualified doctors. Some felt that 5 years minimum experience was a suitable threshold, others cited the Australian model where the minimum requirement

²⁹<u>Assisted Dying Consultation Report.pdf (gov.je)</u>, pages 27-28

is consultant level or 10 years post-qualification. The submission from the Nursing and Midwifery Council (NMC) questioned limiting the role of carrying out assessments to doctors only, suggesting nurses may also be suitable for such a role.

"[The proposals] requires the doctor to only have been fully registered for 12 months. These doctors will be very junior and while they may fulfil the competency framework of a limited training programme, their broader experience of clinical practice, disease progression, human relationships and family dynamics will be far too immature to ensure they can take on the roles envisaged. Clinicians should be at least 10 years post-registration. It will be important that a clinician with expertise in the specific condition." Living and Dying Well

"Medical practitioners need only be one year post qualification. I would be keen to see this extended to perhaps 5 years to enable a level of practical working experience and hopefully wise maturity." **Practising GP, Jersey**

"Currently the consultation proposals limit assessment to medical doctors. Should the Government of Jersey wish to extend this we see no regulatory reason why suitably qualified and experienced nurses should not be able to participate in the assisted dying assessment as well as the delivery process. Our standards equip professionals with a wide range of professional knowledge and clinical skills, including assessing needs and planning care, and many nurses practise in highly complex and specialized roles." Nursing and Midwifery Council

<u>Training</u>

The consultation report described the proposed training requirement.³⁰ Some attendees at in-person stakeholder meetings and HCS staff sessions expressed a wish for more detail on the training content and format. Some stated that, in addition to training related to the duties of assisted dying practitioners and associated legal requirements, there should be a specific focus on areas of key concern – i.e., the detection of coercion and assessing the decision-making capacity of a person requesting an assisted death.

"Our members have previously reported that there is a general uncertainty around using [capacity tests] that can translate to patients needing to be seen by psychiatrists and other mental health professionals unnecessarily. Consideration must be given to any additional training required to ensure clinicians are prepared to assess capacity more widely and in these particular scenarios." **Royal College of Psychiatrists**

Supervision, whistleblowing and support

Some respondents expressed a wish for more detail on the supervision arrangements for assisted dying practitioners and those working in the service (e.g. Care Navigators). This was raised in relation to concerns about burnout and complacency - the risk that practitioners who become overly accustomed to assisted death may not retain a critical eye (ie. they do not retain the position that an assisted death should be the last, or least preferred, end of life option).

³⁰ Assisted Dying Consultation Report.pdf (gov.je), page 27

At least one medical practitioner questioned the ability of colleagues to raise concerns about other practitioners practice, emphasising the importance of a robust whistleblowing process.

Proposals to enable access to wellbeing and psychological support service for assisted dying practitioners, were welcomed, with respondents noting that this was essential ensure service quality and the welfare of practitioners.

6.2.2. Conscientious Objection

In debating P95/2021 the Assembly agreed, in principle, that 'the law should provide for a conscientious objection clause so that any nurse, medical practitioner or other professional is not under a legal duty to participate in assisted dying'.³¹

The consultation report set out the scope of the proposed conscientious objection clause.³²

a. Right to conscientious objection

Supporters and opponents of assisted dying almost universally agreed that a person has a right to conscientious object to assisted dying and that excising of that right should not impact on a person's employment. Professional registration bodies noted that the conscientious objection clause within any assisted dying legislation could and should work together with their existing guidance for professionals.

"We support the proposal that the new law will provide for a conscientious objection clause so that professionals are not under a legal duty to participate in assisted dying... Our Code makes provision for conscientious objection), and we have also published conscientious objection guidance." **Nursing and Midwifery Council**

"The GMC supports the right for doctors to practice in line with their beliefs and supports the proposal to introduce a statutory right to conscientiously object to participate in an assisted death.

Our guidance on 'Personal beliefs and medical practice' sets out that doctors can opt out of providing a procedure which they have a conscientious objection to, as long as this doesn't result in direct or indirect discrimination against individual patients or groups of patients and doesn't obstruct patients from accessing services." **General Medical Council**

Some respondents stated that right to conscientious objection should extend to organisations, as well as individuals.

"It is important that any conscience clause in Jersey extends to organisations and not just individuals. An organisation must have the right to declare openly that it refuses to have assisted suicide or euthanasia conducted on its premises without jeopardising its funding... Additionally, the law should state clearly that no recognised health body or organisation which operates in the field of health or social care can consider a doctor's refusal to participate in procedures around assisted suicide when making any determination about the employment, promotion, appointment, or career of that doctor." **Living and Dying Well**

³¹ p.95-2021.pdf (gov.je)

³² Assisted Dying Consultation Report.pdf (gov.je), pages 23-26

b. Conscientious objection and direct participation

The proposals make a distinction between direct and indirect participation in assisted dying and posed questions on the scope of direct participation in assisted dying.

Some written stakeholder submissions stated that whilst the consultation proposals provide examples of 'direct' and 'indirect' participation, the scope of conscientious objection was not adequately defined.

Some stakeholders during in-person sessions noted a perceived inequality based on professional standing – for example, pharmacists would have the right to conscientiously object as their involvement would constitute direct participation (i.e. preparing and dispensing the assisted dying substance), whereas, patient transport vehicle drivers would not have the right to refuse to transport a person to an assisted dying assessment appointment as this would not constitute direct participation.

"We agree that a nurse could not refuse on the basis of conscientious objection to carry out tasks which are within the normal range of their work, and which are not directly related to the assessment or delivery of an assisted death" **Nursing and Midwifery Council**

"There is no ability to refuse to deliver 'medical supplies' to be used for the purpose of 'the delivery of an assisted death'. Thus the law would coerce people into delivering lethal drugs knowing these were to be used to assist suicide. However, delivering lethal drugs for the purpose of facilitating suicide is archetypal of assisting suicide." **Professor of Bioethics, St Mary's University & Director, Anscombe Bioethics Centre**

c. Supporting assessments

The consultation proposed that, if a professional is required to undertake a supporting assessment, this would constitute 'direct involvement' and fall within a conscientious objection clause. A supporting assessment is where the doctor assessing a person's eligibility for an assisted death requires another specialist to undertake an assessment of a matter which is outside of their expertise for example, the assessing doctor asking a psychiatrist or psychologist to determine decision-making capacity for a person with a

psychiatric diagnosis.

Q.8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?





A significant majority of survey respondents agreed that professionals should have the right to refuse to undertake a supporting assessment. This included almost all respondents strongly opposed to assisted dying (98%) and the majority of respondent who support assisted dying (61%).

575 respondents gave a reason for their response. The most common being that doctors should have the right to object if assisted dying presents a conflict of conscience (religious, ethical or moral), with a large number of respondents referencing to the right of a professional to have personal autonomy and freedom of choice.

Respondents who disagreed that professionals should have a right to refuse to undertake a supporting assessment, cited the need to respect the patient's choice. Some suggested that the right to conscientiously object should be limited to supporting a person to die (the assisted dying "delivery stage") not the assessment stage. Others stated that personal morals and beliefs do not belong within a professional context.

"It is ethically wrong to force someone no matter what expertise they may have in the medical field to partake in the taking of another's life if they do not wish to be involved." **Survey respondent opposed to assisted dying answering 'yes' at Q.8**

"If the person refusing is because they don't agree with assisted dying then the assessment needs to be done by someone else." **Survey respondent supportive of assisted dying answering 'don't know' at Q.8**

Stakeholder feedback (individuals & organisations)

Stakeholder feedback mirrored the wider survey responses i.e., the majority agreed that health and care professionals should have the right to refuse to participate in supporting assessments.

d. Premises owners

The consultation proposals set out that a premise owner / operator would have the right to refuse to allow for an assisted death on their premises (for example, a care home provider could choose not to permit a resident to have an assisted death in the resident's room in the care home).

Q.9 Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)



Yes - they should have the right to refuse

No - they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises

Answer Choices	Responses		
Yes - they should have the right to refuse		58.76%	530
No - they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises		36.03%	325
Don't know		5.21%	47
Please tell us the reasons for your response 532			•
Answered: 902 Skipped: 0	Response Total:		902

Overall survey respondents agreed that premise owners / operators should have the right to refuse an assisted death on their premises but there was significant difference between those who support assisted dying (23% responding 'yes') and those opposed to assisted dying (97% responding 'yes').

532 respondents to the survey gave a reason for their response. The most common themes being:

- owner / operator should have freedom of choice, they may to assisted dying on the grounds of conscience or have other concerns, such as impact on staff recruitment
- protecting the mental health and wellbeing of staff and other residents
- assisted dying should take place in bespoke premises

The majority of respondents who disagreed, stated that a person should be allowed to die in an environment that is familiar and comfortable to them, and that personal views of service providers should not overshadow a person's right to choose. Others suggested that care providers have a duty to support a good end to life, including an assisted death.

"How can anyone be forced to have a life taken knowingly on their premises. I would not have been happy if my mum, who was in a care home, was in the same place where assisted dying was going on." **Survey respondent opposed to assisted dying answering 'yes' at Q.9**

"Yes, of course they should have a right to refuse. Freedom of conscience, like freedom of speech and freedom of religion, is a fundamental building block of a liberal (in the classic sense) and free society." **Survey respondent opposed to assisted dying answering 'yes' at Q.9**

"This question is a lot more difficult to answer. Conscientious objection ~ the owner of such care facility may have strong religious views. The patient may only have gone into this home to obtain an assisted death. However one could argue that if the individual has been resident for a term *say 12 months) they have the right to call that room their natural home. I find it difficult to come to a reasoned conclusion on this point." Survey respondent opposed to assisted dying answering 'don't know' at Q.9

"I would hope that when the premises are the place a person considers their home nobody would refuse their request for assisted dying and a clause wouldn't be necessary." **Survey respondent supportive of assisted dying answering 'no' at Q.9** "A care home is set up as a business and as such operations must comply with the law. This includes assisted dying. It's not for owners or operators to use their personal beliefs to drive policy. See the case in a UK B&B, which it was argued was the home of the owners and they had the right to refuse two homosexual men a double room because of their, the owners, Christian values. The owners lost the case because they had opened up their home as a business." Survey respondent supportive of assisted dying answering 'no' at Q.9

Stakeholder feedback (individuals & organisations)

The stakeholder feedback echoed the range of survey responses -i.e. balancing a premises owner's right to act according to their beliefs vs. a person's right to die in a place they consider to be their home.

"We are aware of at least one Catholic care provider on the island of Jersey, and there may be others. It is vital that the values and ethos of such places are protected by a specific conscientious objection clause for premises. This right should not only be for care homes where there is a religious background, but for any premise owner/operator that wishes not to allow assisted suicide." **Catholic Union of Great Britain**

"Assisted dying should always be possible at one's home, one's place of living. A care home may well be the new home, the new place of residency of a person, because due to health reasons they cannot live in their flat or house anymore. It would be undignified and a possible health risk to impose on such person to leave their (new) home, their (new) place residency in the care home just because they wish to make use of assisted dying." **DIGNITAS**

6.2.3 Discussion of assisted dying with patients

a. No prohibition on raising the subject of assisted dying

The consultation proposed that the law should not prohibit health and care professionals from talking to their client / patient about assisted dying, even where the client / patient did not raise the subject in the first instance. It stated that guidance and training will be provided, setting out when such conversations are appropriate³³.

³³ Assisted Dying Consultation Report.pdf (gov.je), paragraphs. 80-89



Q15. Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Marginally more respondents agreed than that the law should not prohibit professionals from raising the subject of assisted dying (48%) than disagreed (44%). The level of agreement varied significantly between those supportive (81% responding 'Yes – I agree') and those opposed to assisted dying (79% responding 'No – I do not agree').

It must be noted however, that the question posed was a double negative, which some respondents stated was likely to result in misinterpretation (although analysis of the comments indicate that the question was understood by the majority of respondents).

558 respondents to the survey gave a reason for their response. The most common reason given by those who agreed with the proposal, was the right of a person to be informed; the need for equal access to information, plus transparency as to end of life options. A small number of respondents stated that professionals have a duty of care to raise options a patient may want to access to end their suffering.

The most commonly cited reason for not agreeing related to concerns about any coercion, persuasion or undue influence that may arise if a patient believes the professional is inferring that assisted dying is their best option. Some stated that professionals who raise the subject would be acting contrary to their duty of care, and in conflict with the Hippocratic Oath.

"Doctors must be able to advise their patients as they deem appropriate and in the patient's best interests. Such a restriction on GPs would impede a patient's freedom of choice and

seriously undermine the rights to be given to Islanders under the legislation." **Survey** respondent supportive of assisted dying answering 'yes' at Q.15

"Medical professionals should not initiate consideration of assisted dying as an option. Medical professionals should always first seek to improve the health and well-being of their patients. Where that may not be possible, they should not do anything that harms their patients, or leads those patients to harm themselves. This should be the core principle of medical care." **Survey respondent opposed to assisted dying answering 'no' at Q.15**

"I think a GP should be qualified enough to choose when it is appropriate to offer it as an option. I think it is only relevant to mandate it should there be an overwhelming amount of GP's which would hold back due to personal beliefs." **Survey respondent supportive of assisted dying answering 'don't know' at Q.15**

Stakeholder feedback (individuals & organisations)

There was a significant amount of feedback related to this proposal in written stakeholder submissions. Professional registration bodies emphasised the importance of clear guidance for professionals on the issue, over provisions in the law. Stakeholder organisations opposed to assisted dying highlighted the potential impact on the doctor-patient relationship, and the possibility that a doctor raising assisted dying as an option could be interpreted as a 'recommendation' to the patient. Stakeholder organisations supportive of assisted dying stressed the importance of open and frank discussions with professionals about end-of-life options.

"We support the development of guidance for all health and care professionals to manage conversations around assisted dying and end-of-life options particularly as nurses may be approached first by someone raising the issue of assisted dying. We expect individuals on our register to provide holistic and person-centred care. They must maintain a professional relationship with people in their care and keep the communication paths open so that they can continue to express their personal feelings, ideas, needs, concerns and expectations. We expect registered professionals to document all conversations and share any insights with colleagues as set out in our Code (paragraphs 8.6 and 16.4)". Nursing and Midwifery Council

"We agree that the legislation should be silent on this issue, but that this is an area that could be covered in guidance instead. A blanket prohibition would mean that doctors would be prevented from exercising judgement and there may be situations where a patient has not actually raised the subject of assisted dying - but where the discussion is such that the clinician judges they would benefit from them openly bringing it up. Addressing this area in guidance (rather than legislation), would allow for greater flexibility and personalised decision making... it is also quicker and easier to review and amend guidance (if necessary) than it is to change legislation, as evidence bases develop and good practice evolves." **General Medical Council**

"The imbalance between patient and doctor means that the line between encouragement to suicide and an open discussion about options is entirely blurred and cannot be safeguarded against. In the doctor patient relationship, there is an inherent hierarchy and advice about a course treatment is often requested by the patient. A doctor raising assisted dying as a "treatment option" is perceived as suggesting that the patient should consider ending their life, with a subliminal message that what lies ahead is so terrible that the patient would be better off dead. Assisted dying should be entirely separate from healthcare to protect the doctor-patient relationship, leaving the patient the free choice to seek Jersey Assisted Dying Service, and removing the risk of subliminal coercion by the doctor." Living and Dying Well

If a doctor raises the issue of euthanasia or assisted suicide, it may well be perceived by a vulnerable patient to be a suggestion or recommendation. Combined with the inevitable pressures of the cost of treatment and lack of resources, this may well lead to people seeking death by assisted suicide or euthanasia owing to external pressures. **Care Not Killing**

"Raising the subject' does not amount to persuasion. It should be seen as a duty to make the patient aware of all their options." **End of Life Choices**

"We believe that decisions about healthcare are best made in the open, with honest, frank discussions with medical professionals, friends, and family. In order for someone to make an autonomous decision, they need all the information and options available to them. Healthcare professionals should be permitted to broach the subject with their patients as part of a wider discussion about their care options, including palliative and hospice care. We believe this could help to reduce health inequalities when it comes to accessing this service, as patients who are more health literate and aware of their rights, in general, are more likely to be aware of their right to assisted death.

Patient trust is incredibly important in the doctor-patient relationship and it's important that assisted dying does not hurt that relationship. There should be guidance for healthcare professionals on how to provide the information in an objective and informative manner. A patient should never feel pressured by a doctor to either have or reject an assisted death. If a patient is strongly against assisted dying then the healthcare professional should not broach the subject again. Similarly, if the patient actively wants to learn more about assisted dying, the doctor should either provide that information or point the patient to a healthcare professional is found to have broken the guidance and unnecessarily continues to suggest assisted dying that they should be removed from the register." **Channel Islands Humanists**

"Facilitating honest and open conversations about end-of-life issues is a fundamental aspect of good care. This is captured in NHS England's Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. The first ambition states: 'Each person is seen as an individual I, and the people important to me, have opportunities to have honest, informed, and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.'

Ensuring people are informed of their options also prevents the emergence of inequalities and unnecessary barriers to access to services. Clinicians in Jersey would be ethically compromised if they were only able to discuss assisted dying with people who had the language and health literacy skills to raise the subject and the knowledge that assisted dying was a legal option. Research has found that restricting conversations about end-of-life options may lead to less optimal patient outcomes. While it has become apparent during assisted dying debates in other jurisdictions that those who oppose law change may seek to prohibit clinicians from raising the subject of assisted dying through so called 'gag clauses', no evidence has been presented to suggest how these would act as a safeguard or why it would be logical for clinicians to be permitted to initiate discussions about some end-of-life options but not others. While we strongly oppose the idea that clinicians should be prohibited from raising the subject of assisted dying, we do recommend guidance be developed on what prompts from a person might be appropriate prompts for clinicians to discuss the various end-of-life options that might be available to the person." **Dignity in Dying**

b. No explicit requirement to raise the subject of assisted dying

In addition to stating that the law would not prohibit health and care professionals from raising the subject of assisted dying, the proposals also set out that law would not place a <u>duty</u> on professionals to tell people about assisted dying.³⁴



Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

The majority of survey respondents agreed that the law should not place an explicit requirement on relevant professionals to tell people about the assisted dying service. This included both those who support and are opposed to assisted dying.

The most commonly cited reason being the right to conscientious objection, followed by the professional's individual choice and judgement.

³⁴ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraph 87

A smaller proportion of respondents said there should not be an explicit requirement placed on professionals to tell people about assisted dying, as this was contrary to their duty of care and the requirement to offer treatment options with a view to preserving life. Others stated that the first point of information such be via pamphlets and posters in healthcare premises.

Respondents that stated there should be an explicit requirement on professionals to tell people about assisted dying overwhelmingly elaborated on the right of a patient to know all available options.

Again, it should be noted that the question/answer options posed a double negative, which may have resulted in misinterpretation (although analysis of the comments indicate that the was case in only a small number of responses).

"I think a patient should be presented with all options available to them, including assisted dying." **Survey** *respondent* **supportive of assisted dying answering 'no' at Q.16**

"You will lose good doctors and nurses. You'll open the door to low morale by undermining the role of medical professionals. Their duty of care will be diminished and their focus to preserve life and strengthen the weak and suffering will be removed. Why would I want to be the nurse that places that first seed idea of PAS and the then see it go to full fruition knowing there was plenty of potential for that patient and knowing there was a quality service that could have been in place" **Survey respondent opposed to assisted dying answering 'yes' at Q.16**

"Absolutely, such a lawful requirement would negate the ability to be a conscientious objector and undermine the professional conscience of the medical professional involved." **Survey respondent opposed to assisted dying answering 'yes' at Q.16**

Stakeholder feedback (individuals & organisations)

Nearly all stakeholder organisations agreed there should be no explicit requirement placed on professionals, regardless of their views on assisted dying, with the exception of one campaigning group.

"To separate out assisted dying in this way will serve only to delay the time it takes for it to be normalised as an end of life option. Further, the exercise of the right to an assisted death should not be dependent on the arbitrariness of how well-informed a person is. This could amount to discrimination." **My Death My Decision**

6.2.4. Public or private register

The consultation proposed that a register of assisted dying practitioners should be established, and asked respondents whether that register should be public.







A majority of survey responses agreed it should be public, but nearly 20% of respondents stated, 'don't know'. Supporters of assisted dying did not express a clear preference (43% agreeing the register should be public, 35% disagreeing, with other responding 'don't know'). Whereas the majority those opposed to assisted dying felt is should be public (69%).

The most commonly cited reason being to ensure transparency, following by patient safety and accountability. Some responses stated that a public register could help safeguard against coercion from professionals.

Respondents who did not support a public register, expressed concern that practitioners could be subject to abuse via social media or at their places of work, which may eventually deter them from offering the service. Other reasons include data protection and respect to privacy.

Some respondents suggested that the register should only be available to other doctors (rather than the wider public) to prevent possible abuse, while others suggested it should be the practitioner's decision as to whether their listing is public or private.

"Transparency is vital. It is important that the degree to which individual practitioners are involved in assisting suicide and euthanasia should be open to public scrutiny" **Survey respondent opposed to assisted dying answering 'yes' at Q.10**

"If the law is changed, accountability is crucial to ensure there is no abuse." **Survey respondent opposed to assisted dying answering 'yes' at Q.10**

"People opposing assisted dying have already demonstrated that they don't mind turning to misinformation and harassment. Why expose doctors to this and enable targeting? Oversight should be the same as any other medical standard." **Survey respondent supportive of assisted dying answering 'no' at Q.10**

"As a health care provider, I would be concerned about the negative impact on myself and my peers that are in agreement with assisted dying. Many families or public may be in conflict to the individuals wishes and could target professionals involved." **Survey respondent supportive of assisted dying answering 'no' at Q.10**

"I am unsure, on one hand transparency is always preferable but I would have concerns that members of the registers may be targeted by those with extreme views on the subject." **Survey respondent supportive of assisted dying answering 'don't know' at Q.10**

Stakeholder feedback (individuals & organisations)

Stakeholder feedback echoed the views of survey respondents – i.e. balancing a practitioner's right to privacy with the need for openness and transparency. Some noted that Assisted Dying Practitioners' consent to participate may vary (for example, some practitioners may only support people to have an assisted death if that person has a terminal illness or if that person has exhausted all other treatment options) and expressed concern as to whether such nuances could be reflected in a public register.

"We have a neutral stance... The GMC's approach to publication and disclosure may be of interest to those considering this issue. Information about UK registered doctors is published on the List of Registered Medical Practitioners (LRMP). We publish this information to fulfil our legal obligations and help meet our objectives to:

- protect, promote, and maintain the health, safety, and well-being of the public
- promote and maintain public confidence in the medical profession
- promote and maintain proper professional standards and conduct for members of the profession.

Our Registration & Revalidation publication and disclosure policy explains the limited circumstances, such as where publication of information presents a significant risk of serious harm to the physical or mental wellbeing of a registrant, where we'll consider requests to withhold registration and revalidation information from the LRMP'." General Medical Council

"The medical profession should not be divided between those who accept and those who refuse to participate in assisted dying. Some doctors may be prepared to provide assisted dying, but with additional medical conditions to those provided for by the law. This could be the case, for example, by including a palliative filter, which would make access to the patient's request for death conditional on the prior implementation of palliative care." **European Institute of Bioethics**

6.3 The assisted dying process: request, assessment and approval

This section summarises feedback received on proposals related to the assisted dying process (including the request, assessment and approval of an assisted death) as set out in Section 5 of the consultation report.³⁵

6.3.1. Steps for assisted dying

The consultation survey asked specific questions on the proposed steps for an assisted death and the differing routes of approval for those with terminal illness ('Route 1') and those with unbearable suffering ('Route 2').

a. Proposed steps

The survey asked respondents if the nine steps associated with requesting and approving an assisted death (as set out on page 32 of the consultation report) were necessary.³⁶



Q11. Do you agree that the nine proposed steps are all necessary?

³⁵ Assisted Dying Consultation Report.pdf (gov.je), pages 32-69

³⁶ Assisted Dying Consultation Report.pdf (gov.je),page 32

Yes		58.87%	531
No		16.74%	151
Don't know		24.39%	220
Please tell us the reasons for your response 578			•
Answered: 902 Skipped: 0	Response Total:		902

The overall response suggests agreement that the proposed nine steps are all necessary. The majority of those strongly supportive of assisted dying agreed with the steps (75% of supporters). Of respondents strongly opposed to assisted dying – only 41% agreed with the nine steps and 40% expressed uncertainty.

The majority of responses that agreed stated that the nine steps provided assurance as to the comprehensiveness of the process, although some caveated this view by noting the need to ensure that each individual step does not take too long.

Responses that disagreed with all nine steps being necessary, were divided into three groups: those suggesting more than 9 steps were required; those proposing less than 9 steps; those disagreeing in general terms, as they were opposed to the principle of assisted dying.

"There should be fewer steps, 5 max., to ensure calm dignity in death for the participant. Too many steps will cause backlogs, admin, and stress for participants." **Survey respondent supportive of assisted dying answering 'no' at Q.11**

"Should this go ahead, at least 9 stages are needed and indeed many, many more! There should also be a judicial stage (but again people in the legal sector may not want to be involved) as this would allow more rigorous appraisal of what is going on (i.e.: worried family members/friends can call out what other family members may be attempting, something medical professionals may ignore or not want to deal with'." **Survey respondent opposed to assisted dying answering 'yes' at Q.11**

"We need as many steps as are needed for individuals to be 100% settled in their desire for this. The more steps there are, the greater protection is for those who are unsure, or are being coerced, or feel they are being coerced. Protection for every member of the general population is a key responsibility of government." Survey respondent opposed to assisted dying answering 'don't know' at Q.11

The survey also asked respondents if they any felt further steps or actions were required.



Q12. Do you think there are any further steps / actions that should be included?

Responses to this question do not show a clear preference. The percentages of people answering 'yes', 'no' and 'don't know' are broadly similar, though there are significant variations by view towards assisted dying. Half of those strongly opposed to assisted dying said additional steps were required (50%), as did respondents who preferred not to disclose their views (47%). Respondents strongly in support of assisted dying mostly disagreed with the inclusion of further steps, with only 9% of supporters stating that additional steps should be included.

Only around one third of respondents provided a reason for their response (314). The most common response being the hope that additional steps would deter people from accessing the service. The next most common response was the suggestion of an additional step requiring consultation with family members / carers to either obtain further consent or identify possible coercion, plus a step to ensure that palliative care support has been fully considered before a patient requests an assisted death.

Other suggestions included a specific step for mental health assessment, to determine whether an assisted dying request arises as a result of depression or a state of feeling helplessness. Finally, a small proportion of responses offered specific suggestions:

- 1. addition of a third independent assessment
- 2. tribunal to assess all Route 1 requests
- 3. third party appeals stage during the planning and preparation (step 6)
- 4. independent tribunal outside of Jersey
- 5. coroner investigation step to exclude coercion.

"I disagree with this proposal for assisted suicide / euthanasia. However, the more steps there are, the lower the likelihood of abuse. For example, if after the second request, there were a second assessment and a further independent assessment, that would reduce the possibility of coercion" **Survey respondent opposed to assisted dying answering 'yes' at Q.12**

"If this is to occur, deep analysis into family and financials should be considered. Friends interviewed, as well as consultation of the individual at different times, not just one off." **Survey respondent opposed to assisted dying answering 'yes' at Q.12**

"There should be more mental health support provided for those who express an interest in assisted dying. Illness and disability can leave any of us prone to periods of depression and feeling useless, yet these periods can be transient. With more support it is likely that more people will feel able to continue with their amazing gift of life, even though challenging circumstances - it is all part of being human. This support should also include spiritual and personal support, as well as practical everyday support with the essentials of life." **Survey respondent opposed to assisted dying answering 'yes' at Q.12**

Stakeholder feedback (individuals & organisations)

Stakeholder feedback broadly reiterated the survey responses, organisations supportive of assisted dying mainly agreed that no more steps were required and highlighted that the process should be no longer than necessary in order to balance safeguards with a system that does not prolong suffering. They also supported that proposal that Route 1 approvals did not require approval by a Court or Tribunal.

Organisations opposed to assisted dying were more likely to favour additional steps.

"We understand from both the citizens' jury and international evidence that it is important that the process isn't too long and arduous. People who apply for an assisted death are often in serious pain, suffering, and indignity and it would be cruel to force them to remain in that situation for longer than is necessary to create a safe and fair system." Channel Islands Humanists

"We would be concerned if any further steps such as prospective approval by the court in all cases were to be proposed (as in the Westminster Assisted Dying Bill [HL] which fell in May 2022)." **My Death My Decision**

"Many actions need to be implemented before approving assisted dying:

- ensuring better management of patients' physical and psychological suffering
- ensuring the deployment of volunteers to visit people at the end of life
- increasing awareness of palliative care solutions
- allocating more resources to palliative care."

European Institute of Bioethics (Brussels)

Specific feedback from the GMC endorsed the proposed steps and proposed an additional step of formal consent to proceed by a person *after* the approval of their request:

"We recognise the need for a robust set of steps to ensure that treatment is only offered and provided in cases where it is unequivocal that patients meet the eligibility criteria and have made a clear and settled decision to end their lives. This is vital with decisions of this nature and magnitude. The nine proposed steps include the requirement that two doctors independently assess and determine a patient's eligibility and asks patients to re-affirm their request for an assisted death, all of which should help to create necessary safeguards. We also note that the process is designed to ensure that patients have control throughout (in terms of whether to continue with the request and, if so, at what pace), which we fully endorse...

...We have some comments about the sequencing of decision making and consent as it is set out in the consultation document, since it is not consistent with our guidance. We suggest addressing this by introducing an additional step to the proposed assisted dying process. This additional step would be introduced after step 5 (i.e. after the assessments and after an assisted death has been approved), and would involve the patient formally recording their consent to an assisted death, and the scope of that consent. This would be different to the written declaration recording their decision to proceed with an assisted death – i.e. the second request (at step 4) as it would be a formal record of the option(s) agreed by both the relevant clinician(s) and the patient and would not be conditional on a future approval of a request for an assisted death. Alternatively, we suggest that this stage of providing a written record of consent (and its scope) could be explicitly incorporated at the 'planning' step (step 6)." General Medical Council (GMC)

b. Minimum timeframe – period of reflection

The feedback in this section relates to a proposed minimum timeframe, or period of reflection, from the date of the formal request for an assisted death to the delivery of an assisted death. For those eligible under Route 1 (terminal illness) this is proposed to be 14 days. For those eligible under Route 2 cases (unbearable suffering) this is proposed to be 90 days.



Q13. Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

The overall response does not show a majority support for the proposed minimum timeframe of 14 days as a period of reflection for Route 1 (terminal illness) cases. However, the majority of respondents that were strongly in support of assisted dying agreed with the minimum timeframe (75%), while the majority of those strongly opposed disagreed (75%).

538 respondents to the survey gave a reason to their response. The most common reason given by those that agreed with the minimum timeframe of 14 days, was that the proposed period was adequate to enable the patient to make an informed decision. Other reasons given were that the proposed timeframe was reasonable enough, or short enough, to prevent prolonging pain and suffering.

The responses that did not agree with the proposed timeframe were divided into separate groups:

- greater than 14 days
- less than 14 days, and
- opposed to assisted dying.

In the first group, the majority of responses recommended a longer period of reflection, the average proposed time being 1 to 2 months. Where reasons for disagreeing with the 14 day timeframe were provided, responses focused on the need for a longer period of reflection to ensure the right decision has been made, especially in cases of a psychiatric diagnosis. Some responses elaborated the need for a longer time period to allow patients enough time to access treatment such as palliative care and mental health assessments. A small
proportion of responses in this group preferred a longer period of reflection to ensure that the prognosis is accurate.

The most common reason given in the responses of the second group (less than 14 days) was a wish not to prolong a person's pain and suffering, others noted that those requesting assisted dying will have already spent time considering the option before making a formal request, so 14 days 'delay' was unecessary.

The last group included all responses that were opposed to Assisted Dying and thus did not agree with any reflection period on principle.

"Although I would favour a shorter timeframe so that individuals whose disease progresses rapidly would not have to wait so long if they felt life was unbearable, in reality getting the assessments and required checks done will take about 14 days." **Survey respondent supportive of assisted dying answering 'yes' at Q.13**

"14 days is a very short period of time for reflection. Poor mental health is so common when faced with a palliative prognosis, patients need time to be able to optimise their mental health and consult professionals, family and friends about their choice." **Survey respondent opposed to assisted dying answering 'no' at Q.13**

"Not sure as may depend on exact circumstances, but would imagine a longer period would be preferable. Some people with terminal illness go on to live for years" **Survey respondent opposed to assisted dying answering 'don't know' at Q.13**

"I think anyone with a terminal illness that's considering assisted dying would be doing so because they want to end their suffering and be in control of their own death 14 days is a long time in some terminal diagnosis." **Survey respondent supportive of assisted dying answering 'no' at Q.13**

Stakeholder feedback (individuals & organisations)

Stakeholder feedback reasserted the range of survey responses - some in agreement with the proposed 14 days (albeit it with exceptions for some individuals), others proposing a shorter time or removal of the minimum time period and a third group advocating for a longer time period.

"We believe a minimum 14 day timeframe strikes the right balance. However, we recommend that further consideration be given to shortening this timeframe should a person's death or loss of decision-making capacity be expected to occur within 14 days so that what is intended to be a period of reflection period does not act as a barrier to access." **Dignity In Dying**

"Assisted dying in Jersey should adhere to the approach of Canada, Belgium, the Netherlands, New Zealand, Switzerland and Germany... which have no such minimum timeframe in law. For the very reason stated in the consultation report, which matches DIGNITAS' 24 years' experience of having conducted over 3,400 PSAS [assisted deaths]: by the time a person makes a formal first request, they have already carefully considered their decision" **DIGNITAS** "It is vital that patients have sufficient time and opportunity to reflect on their decision to end their own life, to ensure it is 'clear and settled'... is particularly important given the grave nature of the decision. However, it is not clear that this requires a mandatory minimum timeframe set out in legislation. The risk is that introducing such a timeframe would not allow for the exercise of flexibility and judgement in cases where a patient is suffering acutely, and this is unduly prolonged (for example, because the patient had been reflecting on their decision for a significant period of time before approaching the service). An alternative may be to introduce minimum timeframes in guidance, whilst allowing for any exemptions in exceptional circumstances (with the onus on decision makers to justify any deviations from guidance). The other benefit of covering this type of issue in guidance instead of legislation is that guidance is more amenable to being reviewed and amended (if necessary), as evidence bases develop and good practice evolves." **GMC**

"It does not seem that 14 days is sufficient time to address factors which can change a person's desire to die. In patients with progressive neurological disease, a wish to die is not related to cognitive or behavioural impairment but is strongly related to depression. Most of those people who express a wish to die report being lonely and had symptoms of depression. In the UK, loneliness is associated with long-lasting depressive symptoms and loneliness predicts pain, fatigue and depression. Clinical depression can take at least 6 weeks to treat successfully. 14 days seems insufficient time the for the opportunity to appeal."³⁷ Association for Palliative Medicine of Great Britain and Ireland



Q14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

³⁷ see full consultation response 'Appendix A – assisted dying consultation phase 2 organisation responses' at <u>www.gov.je/assisteddying</u> for references

Yes - I agree		17.96%	162
No - I do not agree		58.54%	528
Don't know		23.50%	212
Please tell us the reasons for your response 606			•
Answered: 902 Skipped: 0	Response Total:		902

The overall response shows clear disagreement with the proposed timeframe of 90 days as a period of reflection for Route 2 (unbearable suffering) cases. The majority of respondents that were strongly in support of assisted dying disagreed with the minimum timeframe (65%), as did respondents that were strongly opposed to assisted dying (55%).

606 respondents to the survey gave a reason to their response. The respondents that disagreed with the minimum timeframe of 90 days can be divided into three groups – the first group suggesting a period of reflection of less than 90 days, the second group preferring a period of reflection of more than 90 days and the third group expressing a general 'in principle' view opposed to assisted dying.

The majority of the responses favoured a shorter timeframe to prevent further pain and suffering for the person requesting an assisted death. Some expressed a view the period of reflection should be in line with Route 1 (terminal illness), otherwise there would be an inequality.

The group of responses that favoured a longer timeframe elaborated that a longer time was needed to enable a longer period for reflection, access to mental health support or palliative care.

Respondents that agreed with the minimum timeframe of 90 days for Route 2 cases, were less likely to provide a reason for their response.

"I feel 3 months is far too long. As someone who suffers with a chronic pain condition that cannot be cured 3 months is far too long to have to carry on if they are suffering unbearable suffering." **Survey respondent supportive of assisted dying answering 'no' at Q.13**

"It can take some while for different regimes to be tried, e.g. pharmacological, psychological, social and spiritual approaches should all be tried, in addition to any relevant alternative treatments." **Survey respondent opposed to assisted dying answering 'no' at Q.13**

"Again not convinced re the timing. Would the patient be offered Palliative care, in this day and age we have means and facilities to improve the quality of life. This could lead to a change of attitude in the patient." **Survey respondent opposed to assisted dying answering 'don't know' at Q.13**

Stakeholder feedback (individuals & organisations)

Again, stakeholder feedback broadly aligned with the range of survey responses, few stakeholder individuals or organisations showed support for the 90-day timeframe. Reasons for disagreement being fundamentally opposed to the principle of assisted dying; believing that 90 days was too long and would result in undue suffering; believing that 90 days was

too short to allow for full reflection and consideration of other options or believing that it was inequitable to have different time periods for Route1 and Route 2.

"A longer period is appropriate for Route 2 cases where the person is not terminally ill – the longer timeframe is likely to be dictated by practicalities if e.g. a specialist opinion or assessment is required. This is the same time period as now required for analogous cases in Canada, where it seems to be working in practice." **My Death My Decision**

"The reflection period is not a simple question of days but must truly allow the patient to choose the best option for him or her; therefore, the question is whether, in 90 days, it is possible to provide them with physical and psychological support so that their choice is not a default choice. Does the time constraint allow real freedom in the decision?" **European Institute of Bioethics (Brussels)**

"The 90-day waiting period could push individuals to apply to the process early in order to make sure that they would not lose mental capacity during the 90-day period. As previously mentioned, evidence from abroad shows that when an individual applies for assisted death, they have already thought about it extensively and the rate internationally of individuals changing their minds is low." **Channel Islands Humanists**

"The 90-day minimum reflection period proposed for Route 2 cases may be unethical. If a person is assessed to be suffering unbearably in a way that cannot be alleviated in a way that they deem tolerable, there is a strong case that they should not be made to wait longer than individuals with terminal illness or the amount of time necessary to complete the process prescribed by law... The States Assembly should align the minimum timeframes for Route 1 and Route 2 cases." Lecturer in Health Law, UCL Faculty of Laws

c. Expiry of approval

As set out in paragraphs 254-256 of the consultation report, it is proposed that there is no expiry date for assisted dying approvals.



Q26. Do you agree that there should be no expiry date for the approval of an assisted death?

The overall response to the question shows a majority of respondents agree that there should be no expiry date for the approval of an assisted death. Respondents strongly in support of assisted dying were most likely to agree (85%), followed by respondents that held no strong view (61%). Respondents strongly opposed to assisted dying somewhat agreed (41%). Respondents who preferred not to disclose their view did not show a clear preference.

366 respondents to the survey gave a reason to their response. The most common theme in responses that answered 'yes' was that an expiry date would make a patient feel pressured to die and cause undue stress. Other reasons provided, include that the person should decide on the time of their death (not relying on an 'expiry date'), variability in disease progression and the option for people to change their mind at any point.

In responses that answered 'no' the most common reason was the possibility for a change of circumstances. Some questioned whether the eligibility criteria would have been met if a person with unbearable suffering chooses not to proceed with the assisted death – i.e. was their suffering truly unbearable? Others noted the possibility of developments in medicines or treatment options. Other reasons provided by those responding 'no' held the view that no expiry date would expose vulnerable people to coercion in the future – i.e. the person no longer wishes to proceed but is coerced into doing so, or their fluctuating mental health may trigger them to proceed during a period of depression.

Respondents that answered 'Don't know' or 'Other' were mostly opposed to assisted dying in principle.

"That is correct, they should not feel pressured into the decision. It is an important and difficult decision to make, putting a time frame on it will cause stress." **Survey respondent supportive of assisted dying answering 'Yes' at Q.26**

"The person, right up to the very last minute, might have a change of heart." **Survey respondent opposed to assisted dying answering 'Yes' at Q.26**

"People's circumstances and minds change and, given the moral and human gravity of the intended action, if the gap between the initial decision and the final decision is too long, matters must be judged afresh. We know that people change their minds from other jurisdictions." **Survey respondent opposed to assisted dying answering 'No' at Q.26**

"If the person does not want to go through with suicide within the time frame for any reason, their hesitancy suggests they should have to re-apply." **Survey respondent opposed to assisted dying answering 'No' at Q.26**

"A passing depressed moment might trigger the approval long after the major problem originating it had been addressed." **Survey respondent opposed to assisted dying answering 'No' at Q.26**

Stakeholder feedback (organisations)

Stakeholder responses varied, most with a neutral position on assisted dying, for example the professional registration bodies (GMC and NMC), chose not to comment on this aspect of the proposals. Stakeholders that did comment reflected the range of views from the public survey – either 'no expiry, so as not to pressure individuals to proceed with assisted death' vs. 'there should be an expiry date to prevent a person 'using' their approval at a future date in response to coercion from family or a mental health episode'.

"We believe that it is vital that an individual never feels rushed or pressured throughout the assisted dying process. If there were to be an expiry date, an individual could feel pressured into having the assisted death before they are ready to do so. Evidence can show that an assisted death, or potential access to an assisted death, can be more of an insurance policy to ensure that an option becomes available if the pain, suffering and indignity became so much they couldn't bear." **Channel Islands Humanists**

"[There should be no expiry date] ...for the reason stated in the consultation report. It matches the over 35 years legal practice of assisted dying / PSAS in Switzerland from which it is known that an "emergency exit door" (or "provisional green light" as it is called in the procedure at DIGNITAS) provides important emotional relief for suffering individuals" **DIGNITAS**

"A request for assisted suicide may not be as clear and settled as it may appear, therefore, it would be unwise and unsafe to provide approval without an expiry date. Patients with a terminal condition who desire suicide or euthanasia often suffer from treatable mental health issues, most commonly depression. When these patients receive appropriate treatment, they usually abandon the wish to commit suicide." Lives Worth Living – A Campaign of SPUC [Society for the Protection of Unborn Children] Pro-life "The consultation document makes multiple references to considering whether a wish to die is fluctuating. Suicidality is transient and without an expiry date being set on an approval, an individual may act upon an unsettled wish to die during a period of particular strain." **Care Not Killing and Our Duty of Care Joint response**

"With regards to the expiry of approval, whilst there may be risk that an expiry date may induce some pressure to end their life, it would provide an opportunity for a person to think carefully about whether or not to go ahead with an assisted death. Moreover, if the eligibility criteria are based around unbearable suffering, an approval that is not acted upon throws doubt upon the "unbearableness" of the suffering." Living and Dying Well

6.3.2. Assessments

In-person feedback from stakeholders and HCS staff involved detailed discussions on the proposed assessment process.³⁸ The consultation survey asked a question about the option for a second opinion assessment.

a. Doctor led vs. multiagency

Discussions at both public and HCS staff meetings examined the 'doctor-led' nature of assessments as detailed in the proposals. The proposals set out that if the Assessing Doctor is not able to determine matters relating to eligibility they must '*seek the opinion of another relevant professional with appropriate skills and training to support the Assessing Doctor to make a determination*.'³⁹ However, some health professionals offered the view that making a determination on eligibility for an assisted death would be better suited to a multi-agency decision-making approach, for example the mandatory inclusion of nurses to advise on support, care and treatment options and social workers to provide opinion on the wider social context of the person and any considerations regarding coercion or an involuntary decision.

As noted in the survey responses to question 12 '*Do you think there are any further steps / actions that should be included?*' a number of respondents felt that both consultation with family members and consultation with a mental health practitioner should be a mandatory part of the assessments [see Section 6.3.1.a].

"We propose that the requirement to engage with family members be added, as a mandated duty upon the Coordinating Doctor, in liaison with the relevant general practitioner." **Christian Medical Fellowship**

b. Structuring and documenting the assessments

Some responses expressed a view that consultation proposals should have provided a more detailed explanation of the work of Assessing Doctors and should provide examples of the documentation they would be required to complete as part of the assessment process. Some commented on data from Australia, suggesting a full eligibility assessment may take

³⁸ Assisted Dying Consultation Report.pdf (gov.je), see paragraphs 98 - 175

³⁹ Assisted Dying Consultation Report.pdf (gov.je), paragraph 105

up to 60 hours to complete. For some, this was a positive – a thorough assessment. For others, this was an excessive burden for both the patient and practitioner.

"It is essential that it is audited from real-time recording of the consultation. This can be undertaken using a body worn camera as worn by police, ambulance personnel and some emergency medicine staff in resuscitation procedures. The widespread use by the police and ambulance personnel has shown that confidentiality is not jeopardised. Such systems protect all parties from subsequent allegations and would allow the quality of the consultation to be audited to ensure that the assessor did not provide leading questions or fail to pick up important non-verbal cues. Specific steps must be laid out through which the diagnosis is verified, mental capacity is assessed by someone appropriately trained, all reversible causes of suffering have been identified and options discussed with the person, and that processes are in place to detect coercion." Living and Dying Well

c. Assessing capacity

A small number of stakeholder individuals and organisations commented on the careful consideration required for assessing capacity with the assisted dying process.

"The need for careful consideration when setting out a legal test on capacity should not be underappreciated. The Mental Capacity Act 2005 came into being after a lengthy period of scrutiny and review and is regularly updated by a mental capacity forum which provides up to date assessment guidelines. It seems doubtful that a robust legal test addressing the same area can be made within 18 months. More detail needs to be provided on the test, who will be drafting it and the level of scrutiny that will be given to it. Significantly, any change within this area of the law will have consequences for mental capacity more generally and alter the law on consenting to harm - an already contested area of the law." Living and Dying Well

"Understanding the nuances of real capacity for those who are cognitively impaired is extremely specialist. It isn't the same as the dumbed down version we have here and we are not asking someone to make a decision about whether they want a ham or a cheese sandwich. If this proposal goes ahead I feel there needs to be rigour to ensure that no one with any level of cognitive impairment dies under this scheme.

Years before a diagnosis of dementia we see changes in intellect, thinking, processing and reasoning and all of this influences decision making. It also makes people more susceptible and vulnerable to having ideas planted in their mind. Again my belief is that we need to make living well with illness a greater priority and in truth, in Jersey this is not the case. I feel it would be sensible to test cognition on everyone being considered." **Practising nurse, Jersey**

d. Independent assessment

The consultation report states that the 'Independent [2nd] Assessment Doctor' must, independently of the Coordinating Doctor form their own opinions on the matters to be determined but, in doing so, <u>they may consult with the Coordinating Doctor</u> (or any other person engaged in the first assessment process) about matters relating to the person, the person's eligibility or the findings of the first assessment process'.⁴⁰ Feedback from some people who attended the HCS staff sessions expressed concern over the 'independence' of

⁴⁰ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraph 167

the second assessment, if they are able to have sight of the first assessment. Others expressed a view that in such a small jurisdiction 'independence' between practitioners may not be possible, particularly given the likely small numbers of doctors willing to opt in to participate as an assisted dying practitioner.

e. Second opinion

The consultation proposals set out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be either the first or second assessment, but not both - i.e., the person is entitled to one second opinion only.⁴¹



Q17. Do you agree that a person should only be entitled to one second opinion?

The overall response to this question did not show a clear preference for the proposed option of only one second opinion, with 38.1% of all respondents selecting 'yes – I agree'. There was broadly an equal proportion of people who either agreed or disagreed across all views towards assisted dying.

482 respondents to the survey gave a reason to their response. The most common theme in the responses which agreed with the proposals, was that the measure was reasonable and there was enough confidence in the current proposed steps, including the second opinion.

⁴¹ Ibid. paragraphs 116-122

Other responses in this group agreed to one second opinion only, while expressing an opposition to assisted dying.

Responses that disagreed, have been divided into three groups, these were:

- 1. more than one second opinion should be permitted
- 2. no second opinion should be permitted
- 3. opposed to assisted dying 'in principle'

The majority of responses who answered 'No – I do not agree' did so because they favoured more than one second opinion, on the basis that it is the patient's right to have as many opinions as they wish. The second most common reason for responding 'No' was a view that medical diagnosis is not always accurate, and more opinions might be needed to reach a consensus and prevent bias.

"Allowing for multiple further opinions would promote 'doctor shopping' from people who would gravitate to more permissive doctors. Having said that, it is equally important that those providing second opinions are experienced and do not unduly lean towards allowing for ASE [assisted suicide/euthanasia] - otherwise the second opinion would still become relatively meaningless." Survey respondent opposed to assisted dying answering 'yes' at Q.17

"I do not think that the second opinion should be limited to one second opinion only. There are some medical conditions which may be so rare and complicated that 2 opinions may be insufficient." **Survey respondent supportive of assisted dying answering 'no' at Q.17**

"For such a momentous decision, people should be able to talk to other professionals about it. For instance, a consultant may say they can do nothing more towards a cure of a condition. The patient should be free to have a second opinion on this point, and also the space to discuss the matter with other medical professionals about the potential options for living with the condition." **Survey respondent opposed to assisted dying answering** 'don't know' at Q.17

Stakeholder feedback (individuals & organisations)

Stakeholder individuals and organisations who do not support the introduction of assisted dying broadly supported the restriction to one second opinion only. Those with a neutral position or in support of assisted dying, were more likely to disagree with the proposal, and propose that the legislation should not put a limit on second opinions.

"It is not clear to us why legislation should limit a patient's right to a single second opinion only. This may be unnecessarily inflexible and it might not be in line with our guidance, which states, at paragraph 16e) of 'Good 15 medical practice', that doctors should 'respect a patient's right to seek a second opinion'. In addition, it is not obviously true that just because a further second opinion is sought, this is evidence that the patient's case (for an assisted death) is not sufficiently clear and unequivocal. This is particularly the case if the Coordinating Doctor, who originally judged the patient not to meet the relevant criteria, is convinced by the second opinion doctor's judgement. In this situation, both doctors would be in agreement that the patient meets the eligibility criteria." **General Medical Council [GMC]**

"We recommend this is dealt with in the same way as current medical practices and no limit is placed in the legislation itself." **Dignity In Dying**

"The phrasing of the question means that answering yes means one supports allowing one second opinion, while answering no means one supports allowing more than one. We feel that allowing any second opinions opens the door (further) to doctor-shopping" **Care Not Killing and Our Duty of Care Joint response**

"If two Independent Doctors say, 'no', then this is definitive and they cannot doctor shop to find the weak link. This is why Jersey has so many DF118 [dihydrocodeine] prescriptions, because if your doctor says, 'no' you can doctor shop for a weak link." **Practising GP, Jersey**

6.3.3. Permissions and consent

a. confirmation of consent to proceed

The consultation proposals set out a 'Confirmation of consent to proceed' - a written declaration which the person makes as part of their second formal request. 'Confirmation of consent to proceed' allows the Administering Practitioner, who will be present at the assisted death, to take an appropriate intervention, such as administering the substance intravenously, in the event the person loses decision-making capacity but does not die during the process of administering the substance - for example, if they have opted to self-administer the substance and have digested some but not all of it.⁴²



Q18. Should the law allow for confirmation of consent to proceed?

⁴² <u>Assisted Dying Consultation Report.pdf (gov.je)</u> paragraphs 141-144

Yes - I agree		56.43%	509
No - I do not agree		30.16%	272
Don't know		13.41%	121
Please tell us the reasons for your response 421			•
Answered: 902 Skipped: 0	Response Total:		902

The overall response shows agreement that the law should allow for 'confirmation of consent to proceed'. Respondents who were strongly in support of assisted dying were most likely to agree with this proposal (97%), while respondents strongly opposed to assisted dying were more likely to disagree (64% responding 'No – I do not agree') Respondents that did not hold a strong view mostly agreed (71%). Respondents that preferred not to disclose their view, mostly agreed (49%) followed by an almost equal proportion of disagreement (29%) and uncertainty (22%).

421 respondents to the survey gave a reason to their response. The most common theme was that the consent would facilitate the completion of the patient's final wish. Another common reason given was that the consent would allow the Administering Practitioner to prevent further suffering of the patient, followed by the view that consent would act as a safeguard for the Administering Practitioner and provide them protection in law.

Of the respondents that disagreed with 'confirmation of consent to proceed', the most common reason was that the measure would enable euthanasia, as the Administering Practitioner would administer the substance, rather than the person self-administering.

Respondents that answered 'don't know' stated that it was very difficult to assess if a person has changed their mind once they have lost decision-making capacity.

"Of course, the person has gone through all the correct proceedings and consented to everything right up to that point. Backing out would be going against their wishes" **Survey respondent supportive of assisted dying answering 'yes' at Q.18**

"If it has gone that far, then a good doctor would have a duty to ensure their patient's treatment' was complete and did not cause greater harm." **Survey respondent opposed to assisted dying answering 'yes' at Q.18**

"This becomes euthanasia and puts the administering practitioner in a different moral position, not acceptable to a health care provider." **Survey respondent opposed to assisted dying answering 'no' at Q.18**

Stakeholder feedback (individuals & organisations)

Stakeholder individuals and organisations who do not support the introduction of assisted dying were less likely to support 'confirmation of consent to proceed'. And those with a neutral position or in support of assisted dying, were more likely to agree with the proposal.

"The provision of consent to proceed is deeply problematic (para 142). A doctor is supposed to uphold best interests – they cannot do this whilst euthanising a person who might have

otherwise lived and has no capacity to respond or withdraw consent. What is a best interest when someone is supposed to be dying but isn't dying – to keep them alive or to actively bring about their death?" Living and Dying Well

"We believe that the confirmation of consent to proceed is an important step for safety in the very small chance that a self-administered substance does not cause the intended death. We believe that cases where the administering practitioner will need to intervene will be incredibly low." **Channel Islands Humanists**

b. Waiver of final consent

The consultation proposals include the provision of a 'waiver of final consent' - a written declaration which the person may choose to make as part of their second formal request (Step 4 of the process), but which does not become valid until their request for an assisted death is approved (Step 5 of the process).

The 'waiver of final consent' ensures that a person, who has been approved as eligible for an assisted death, will not be prevented from having their request fulfilled (in accordance with previously agreed arrangements) if their health condition deteriorates rapidly to the point which they lose their decision-making capacity before the assisted death takes place.'

The feedback refers to the section of the proposals set out in paragraphs 147-156 of the Assisted Dying consultation report.⁴³



Q19. Should the law allow for the option of a waiver of final consent?

⁴³ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraphs 147-156

Yes - the law should allow for a waiver of final consent		47.89%	432
No - the law should not allow for a waiver of final consent		38.47%	347
Don't know		13.64%	123
Please tell us the reasons for your response 413			•
Answered: 902 Skipped: 0	Response Total:		902

The overall response to this question did not show strong preference for the law to allow 'waiver of final consent'. However, when responses are considered by views towards assisted dying, those in support of assisted dying agreed with the concept of a 'waiver of final consent' (83%), while those strongly opposed did not agree (71%). The responses that did not hold a strong view towards assisted dying showed an almost equal proportion of agreement (41%) and disagreement (39%). Finally, responses of people that preferred not to disclose their view showed a slight preference for the law to allow for 'waiver of final consent' (49%) over not allowing for the waiver (31%).

413 respondents to the survey gave a reason to their response. The most common reason for agreement was the need to ensure that the patient's wish is respected until the end, even if they lose capacity. Other responses simply agreed that the waiver of final consent is a reasonable and humane option.

The most common reason for disagreeing that the law should allow for a waiver of final consent was the lack of safeguards if the person had changed their mind. Other themes include concerns over possible coercion / abuse by third parties, that loss of decision making capacity should act as a deterrent to proceed with the service, pressure on professionals and the need to consider other treatments (palliative care) instead of assisted dying. Finally, a distinct group expressed complete opposition to assisted dying and as a result opposition to the proposal.

Respondents that answered 'Don't know' were mostly opposed to assisted dying. Others were uncertain or raised concerns around cases where a person has lost their decision-making capacity but might have changed their mind in the meantime.

"Yes, definitely, this will cover any persons who goes into a cognitive decline and loses their decision making capacity. They must be able to consent to this before they are unable to." **Survey respondent supportive of assisted dying answering 'yes' at Q.19**

"This makes sense and ensures the patient's final wish is carried out." **Survey respondent supportive of assisted dying answering 'yes' at Q.19**

"This does not make any sense at all. If they have lost their capacity to make decisions they cannot give their final consent to euthanasia. This is precisely the danger for people with a diagnosis of dementia." Survey respondent preferred not to disclose their view towards assisted dying answering 'no' at Q.19

"This is open to abuse by carers who may want to be relieved of the burden of caring for the patient." **Survey respondent opposed to assisted dying answering 'no' at Q.19**

"If it gets that far - and the person loses capability due to their illness before that final stage, then it does need to be reassessed as the person may no longer be in pain/distress and

should be helped to die naturally with dignity over time" Survey respondent opposed to assisted dying answering 'don't know' at Q.19

Stakeholder feedback (individuals & organisations)

As with 'confirmation of consent to proceed', stakeholder individuals and organisations who do not support the introduction of assisted dying were less likely to support 'waiver of final consent'. And those with a neutral position or in support of assisted dying, were more likely to agree with the proposal.

"We agree with the proposal that the law should include the option for the person to complete a waiver of final consent. The Code requires registrants to act in the best interest of people at all times. They must make sure they have obtained and recorded informed consent before carrying out any action." Nursing and Midwifery Council [NMC]

"This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change. As such, we would not take a position on the circumstances when it should be possible to carry out an assisted death. However, as long as there is no evidence that the patient may have changed their mind, this proposal would not be inconsistent with our guidance." General Medical Council [GMC]

"It is very dangerous to give doctors and nurses the legal power to end life where there is no explicit consent from the patient. Where doctors or nurses become used to ending their lives of their patients without consent, the boundaries of the law will be blurred." **Care Not Killing and Our Duty of Care Joint response**

"The waiver of final consent still gives rise to the problems that arise from an advanced decision: how can a determination be made that a person has not changed their mind about an assisted death if there is a period of time between a waiver of final consent and the assisted death taking place. No assumption should be made that a person might not want to change their mind, regardless of how short the period of time in between a request and death." Living and Dying Well

"This is an option introduced in Canada and seems appropriate. Otherwise a person could be denied the assisted death they wish due to unforeseen changes in circumstances. This would be arbitrary and disproportionate. It is however important to ensure there is a public understanding of the difference between this option, which would apply only late in the approval process, and an Advance Decision requesting an assisted death at some time in the future should the person lose mental capacity. We are aware of confusion in people's minds about these two quite different scenarios." **My Death My Decision**

"Dignity in Dying believes having decision-making capacity is a key requirement in any assisted dying legislation and that this applies throughout the approval process and at the time that the person dies. Therefore we do not support the waiver of final consent proposal." **Dignity In Dying**

6.3.4. Approval routes

The consultation proposals set out two different approval routes:

- A. Route 1 (terminal illness), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (i.e., two doctor assessments)
- B. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie., two doctor assessments), and then confirmation of that approval by a specialist tribunal

The feedback in this section refers to the proposals set out in pages 58-62 of the Assisted Dying consultation report and relates to whether there should be two separate approval routes as described above.

<u>Section 6.1.1.b</u> of this report summarises feedback received on definitions of 'terminal illness', 'life expectancy' and 'unbearable suffering'.

a. Rationale for separate routes for approval

Paragraph 193 of the consultation report notes: "The key reasons for proposing two different routes are:

- parallels with current practice / decision making, and
- differences between objectivity and subjectivity in decision making.⁴⁴"

No specific consultation survey question was asked on this topic. However, written submissions from a small number of stakeholder individuals queried the rationale for different approval routes.

"The reasons offered for two distinct approval routes are not sufficient to justify different treatment of individuals with terminal illness or unbearable suffering, respectively. Routine tribunal involvement would likely narrow access to assisted death considerably." **Lecturer in Health Law, UCL Faculty of Laws**

"In my opinion, the authors have misunderstood the distinction between objectivity and subjectivity in the proposal. First, they suggest that a doctor's opinion regarding the terminal nature of a disease (when backed up by a second opinion) is "objective". This is not the case. There is of course an objective matter of fact regarding when the patient will die, but the doctors' opinions remain just that: opinions (which are, by their nature, subjective)... It follows that the apparent lack of objectivity in the case of "unbearable suffering" cannot be a reason to demand a court process or tribunal." **Director of The Centre for Philosophy of Epidemiology, Medicine and Public Health, University of Johannesburg**

b. Agreement with proposed approval routes

The consultation survey sought views on the proposals for two separate approval routes.

Survey responses

⁴⁴ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraph 193

Q20. Do you agree with the two different approval routes as proposed?



Yes		23.95%	216
No - all approvals should be by the Coordinating Doctor based on their assessment and that of the Independent Assessing Doctor (i.e. 2 doctor assessments only for all requests)	-	21.40%	193
No - all approvals by the Coordinating Doctor should be confirmed by a Tribunal (i.e. a Tribunal involved in all cases)		25.83%	233
Don't know		12.20%	110
Other (please specify): Show		16.63%	150
Please tell us the reasons for your response 420			Þ
Answered: 902 Skipped: 0	Response Total:		902

Response to this question show no clear preference for any of the options. This lack of clear preference persists when responses are considered by attitude towards assisted dying.

42% of respondents who were strongly in support of assisted dying favoured Coordinating Doctor approval for Route 1 and Tribunal approval for Route 2, with an almost equal number favouring Coordinating Doctor only approval for Route 1 and Route 2. Respondents who were strongly opposed to assisted dying showed a marginal preference for the two proposed routes (31%) and a similar level of support for the option that all should be confirmed by a Tribunal (29%). Respondents who preferred not to disclose their views, showed a marginal preference of all approvals by the Coordinating Doctor to be confirmed by a Tribunal (35%).

420 respondents to the survey gave a reason to their response. The majority of responses that agreed with the two proposed routes of approval stated that the presence of a Tribunal for Route 2 cases was a reasonable additional step for those without a terminal diagnosis, with some stating that due to their complexity Route 2 cases should be subject to additional scrutiny from a Tribunal. The most common reason given in responses in support of all

approvals made by the Coordinating Doctor, was that a Tribunal would make the process longer and increase the patient's suffering.

The majority of responses agreeing that all approvals (Route 1 and Route 2) should be confirmed by a Tribunal, expressed the view that a Tribunal would act as an additional safeguard against cases of coercion or abuse from relatives, carers and physicians.

"Again, this is a further safeguard, especially for those who may feel they have been pushed along this route to death, but who need a bit more support. A tribunal would be independent of the medical views, and a plurality of people. This would presumably give the same benefit as the Jurat system of trials, with several people involved in the final decision." Survey respondent opposed to assisted dying answering 'No - all approvals by the Coordinating Doctor should be confirmed by a Tribunal (i.e. a Tribunal involved in all cases)' at Q.20

"The tribunal is superfluous, adding a needless administrative burden and cost and prolonging suffering. I also have severe concerns over the makeup of this 'tribunal' and the potential negative influence of members. No doubt the church will seek to be involved, something that should not occur under any circumstances." Survey respondent supportive of assisted dying answering 'No - all approvals should be by the Coordinating Doctor based on their assessment and that of the Independent Assessing Doctor' at Q.20

"A tribunal will only cause unnecessary delay and could also cause the person being assessed incredible stress." Survey respondent supportive of assisted dying answering 'No - all approvals should be by the Coordinating Doctor based on their assessment and that of the Independent Assessing Doctor' at Q.20

"All cases should go to a tribunal. For such a serious issue, maximum safeguards should be in place for every scenario." **Survey respondent opposed to assisted dying answering 'No - all approvals by the Coordinating Doctor should be confirmed by a Tribunal (i.e. a Tribunal involved in all cases)' at Q.20**

"Unbearable suffering" is far harder to assess than terminal illness and the possible palliation options may not be so well known." **Survey respondent opposed to assisted dying answering 'yes' at Q.20**

c. Removal of 'Route 2'

A notable number of comments raised both during public engagement sessions and in written submissions from campaigning groups who support of assisted dying, argued for changing the proposed '2 routes' model.

The basis of this challenge was broadly divided into two groups:

- a. those who do not support assisted dying unless the person has a terminal diagnosis (i.e., only Route 1 should be provided for) and
- b. those who hold the view that anyone experiencing suffering, regardless of whether or not they have a terminal illness, should be treated the same (i.e. Route 1 and Route 2 should be the same, and person on Route 2 should not be subject to a longer 90period of reflection and requirement for approval by Tribunal).

"The division of the proposal into two 'Routes' is cruel, discriminatory and irrational." **End of Life Choices Jersey**

"The criterion of (incurable medical condition that is giving rise to) "unbearable suffering that cannot be alleviated" should be done away with. An incurable medical condition is itself sufficient grounds to permit access to assisted dying. This approach resolves the issue of complexity around objectivity and subjectivity as discussed in the consultation report (para 197 ff) and makes establishing a separate route and a tribunal unnecessary." **DIGNITAS**

"We believe that if the Government chooses to continue with the proposed two routes, then clear guidance needs to be created for people who could fall into both categories, or for people who may start down 'Route 2' but then become eligible for 'Route 1'. Later in the consultation, we will argue that the two separate routes are unnecessary and discriminatory." **Channel Islands Humanists**

"Dignity in Dying campaigns across the British Isles to allow terminally ill, mentally competent adults the option of an assisted death. We agree with the consultation document that the proposed Route 2 deaths are 'fundamentally different' from those in Route 1 and that assisting people to die who are not dying 'is not as readily comparable with existing medical practice and decision-making processes." **Dignity In Dying**

"The track 2 proposals should be abandoned completely. Suffering is a complex subjective experience with many interacting domains (physical, social, psychological, grief and loss, anger, loneliness, poor self-worth, spiritual issues, social and financial problems, etc.). This proposal destroys Jersey's recent suicide prevention initiatives, allows Jersey to abandon its developing mental health services and will abandon any meaningful rehabilitation and support services." **Living and Dying Well**

Stakeholder feedback (individuals & organisations)

Stakeholder individuals and organisations who do not support the introduction of assisted dying were more likely to be supportive of tribunal approval in all cases, and those in support of assisted dying were more likely to prefer 'Doctor only' approval. Organisations with neutral position including the GMC and NMC, did to provide comment on preferred approval routes.

d. Tribunal

This section summarises the general feedback received on the proposal that an assisted dying Tribunal is established – as outline in the consultation report, paragraphs 209-233.⁴⁵

The consultation survey asked if a Tribunal should only review decisions on approvals for 'Route 2' (unbearable suffering). It was proposed that the Tribunal always reviews a decision of a Coordinating Doctor to **approve** a Route 2 assisted dying request but does not review a decision of a Coordinating Doctor **not to approve** an assisted dying request (on the basis there can be an appeal to Court).⁴⁶

⁴⁵ <u>Assisted Dying Consultation Report.pdf (gov.je)</u> paragraphs 209-233

⁴⁶ Assisted Dying Consultation Report.pdf (gov.je) paragraphs 214 & 215



Q21. Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

The overall response to the question shows a broadly equal split. This is also the case when responses are considered by views towards assisted dying – both those in support and are opposed to assisted dying showed no clear preference.

Analysis of the comments provided in response to this question suggests that the question may not have been understood and, as such no clear conclusions can be drawn.

Stakeholder feedback (individuals & organisations)

Some stakeholders argued that decisions on assisted dying should be made outside of medical practice – and that the involvement of the courts or a tribunal was necessary.

"The courts can consider personal and social factors in an individual's life beyond that which is recorded in the clinician record (and beyond those which doctors have access to) and are able to ensure that individuals do not fall victim to abuses of the system. This means the court can balance the rights of some against the protection of others. There is great benefit to society in having the court protect in this sphere and in this way." **Living and Dying Well** "Decisions on assisting suicide and administering euthanasia, were it to be legalised, should be made by judges and the procedures carried out by competent operatives outside healthcare." Association for Palliative Medicine of Great Britain and Ireland

Whilst other stakeholders did not agree that the courts or a tribunal should be involved. They held the position it was an unnecessary step and that assisted dying should be on a spectrum of end-of-life care options, and therefore decisions on eligibility for assisted death should be made by healthcare professionals. [see <u>Section 5.2.5</u>]

"We believe that the Tribunal is an unnecessary step when evidence from other jurisdictions shows that the assessment from healthcare professionals is appropriate, safe, and best practice. The Tribunal adds little value or safety but could put unnecessary stress on the incurably, intolerably suffering." **Channel Islands Humanists**

6.3.5. Appeals

The proposals set out that the assisted dying law would provide for an appeals process – see consultation report paragraphs 234 - 253.

The consultation survey posed specific questions on whether the law should provide for appeals to the Royal Court, the grounds for appeal, the proposed timeframe and who should have the right to appeal.

a. Appeals to Royal Court

Q22. Do you agree that the Law should provide for appeals to the Royal Court?



Yes		60.75%	548
No		17.52%	158
Don't know		21.73%	196
Please tell us the reasons for your response 356			•
Answered: 902 Skipped: 0	Response Total:		902

The overall response to this question shows clear support for appeals to the Royal Court. The proportion of those responding 'yes', 'no' and 'don't know' across the ranges of views towards assisted dying were similar.

The majority of responses that agreed the law should provide for appeals, thought it was a reasonable measure but should only be used in special circumstances. The most common reason for agreement to the proposal was a person's right to appeal, upholding their human and legal rights. Some responses elaborated the appeal would act as a safeguard to prevent coercion or settle unfair refusal cases.

Responses that disagreed with Royal Court appeals stated it would add more cost and 'red tape'. Some also stated that it is for a person to decide how they want to end their life and the Royal Court should not be involved. A smaller proportion of responses argued that the appeals process should be medical, not carried out through the courts.

The majority of respondents that answered 'don't know' and provided a further response were opposed to assisted dying in general terms.

"There has to be a formal route for those who feel that undue pressure has been applied to an individual. Timing is critical but should not prevent such an appeal." **Survey respondent opposed to assisted dying answering 'yes' at Q.22**

"There should be the option for further action when a person feels they have been treated unfairly." **Survey respondent supportive of assisted dying answering 'yes' at Q.22**

"No, I think clinicians are best placed to make decisions" **Survey respondent opposed to** assisted dying answering 'no' at Q.22

"Too much time and costs. Put the money into better palliative care." **Survey respondent** opposed to assisted dying answering 'no' at Q.22

"Individual right to your own life not the courts to decide." Survey respondent supportive of assisted dying answering 'no' at Q.22

Stakeholder feedback (organisations)

Stakeholder responses varied, those that hold a neutral position on assisted dying, for example the professional registration bodies, chose not to comment on this aspect of the proposals. Some campaigning groups that are supportive of assisted dying agreed with the right to appeal, whilst others saw it as an unequal or unnecessary step.

"Most jurisdictions do not provide for an appeal process within their assisted dying legislation, so it is not a necessity. The argument of making such provision in Jersey law "to help support public confidence" appears hypothetical in the light of the fact that a polls show a robust majority of the Jersey public in favour of assisted dying." **DIGNITAS** "The rules and protocols applicable to approvals for an assisted death and likely [criminal?] sanctions should be so structured as to obviate the need for further challenge on a prospective basis. Adding a further step is inappropriate in the same way as a Tribunal." **My Death My Decision**

"It is unlikely, but possible, that a person's right to assisted dying be unfairly refused. In that case, they must be able to appeal." **End of Life Choices Jersey**

b. Grounds for appeal

The grounds of appeal are set out in paragraph 244 of the Assisted Dying consultation report.



Q23. Do you agree with proposed grounds for appeal?

The most common response to this question was 'yes', with supporters of assisted dying the most likely to agree with the proposed grounds for appeal (63%), compared to less than a third of respondents opposed to assisted dying agreed (28%).

The majority of respondents that answered 'yes' thought that the grounds for appeal were reasonable, fair and expressed their confidence in the Royal Court to make such judgements. Other respondents stated that the Royal Court would act as an additional safeguard against coercion.

Respondents that disagreed with the proposed grounds of appeal did so for a number of reasons. The most common reason being respondents who stated that medical diagnosis and prognosis should be included as a grounds for appeal; other respondents thought the residency criteria should not be appealed and a smaller proportion of respondents felt that there should be no restrictions for grounds of appeal.

Respondents that answered, 'don't know' and provided a full response were either opposed to assisted dying in principle or uncertain of the appropriate grounds for appeal.

"I believe that the appeals process should not be barred from consideration of matters of diagnosis and prognosis." Survey respondent opposed to assisted dying answering 'no' at Q.23

"There should be no restrictions with grounds for appeal." **Survey respondent opposed to assisted dying answering 'no' at Q.23**

"This seems to cover appropriate safeguarding considerations." **Survey respondent supportive of assisted dying answering 'yes' at Q.23**

Stakeholder feedback (organisations)

Only a small number of stakeholder organisations commented on the grounds of appeal, stating that they should not be restricted.

"There should be no restrictive criteria for appeal. Appeal should be possible on any aspect of the process. All cases should go through the courts." Association for Palliative Medicine of Great Britain and Ireland

"Given that in medical disputes, private citizens and medical professionals (under the auspices of healthcare organisations) may initiate legal proceedings and appeal medical decisions made by doctors, it should follow that appeals may be made on the grounds of prognoses given by doctors, and the level of care that is or isn't being provided to a person requesting an assisted death. These grounds should be included." Living and Dying Well

c. Timeframe for appeals

The consultation report proposed there should be a minimum of 48 hours between approval for an assisted death and the delivery of an assisted death to allow for appeals - as set out in paragraph 236-239 of the consultation report.



Q24. Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

The most common responses were to either agree with the proposed 48-hour timeframe or state it should be a longer timeframe. Respondents strongly in support of assisted dying were more likely to favour the proposed timeframe (57%) and respondents strongly opposed to assisted dying favoured a longer timeframe (60%). Respondents who did not hold a strong view did not show a clear preference for any timeframe. Respondents who preferred not to disclose their views were more likely to support a longer timeframe (49%).

The most common reason given for supporting the proposed 48-hour timeframe, was that 48 hours struck a balance between being short enough to prevent further suffering, but long enough to give the opportunity for others to appeal.

Responses that supported a longer timeframe proposed an average of one to two weeks instead. The most common reasons for a longer timeframe being: more time was needed to ensure families are aware of imminent death; to allow for the possibility that family members may need to travel to Jersey to appeal; to allow more time for further reflection. Other reasons provided include the need for more time to identify and investigate cases of coercion, allow for changes of mind and to allow for weekends or bank holidays.

Respondents who stated a minimum timeframe was not required were either opposed to assisted dying or felt that the time between approval and an assisted death should be a decision for the patient.

Responses that answered 'Don't know' mostly expressed opposition to assisted dying in general terms.

"Yes, this is very clear and allows for any changes in the original decision to be made." **Survey respondent supportive of assisted dying answering 'Yes' at Q.24**

"Relatives could be on holiday during this process and unable to appeal. One to two weeks would be more appropriate to allow for all parties involved to have their say." **Survey** *respondent* supportive of assisted dying answering 'No– I do not agree, there should be a time period longer than 48-hours' at Q.24

"This may not give enough time for an interested party to intervene - how will an interested party find out? Will family be informed? What about weekends / bank holiday / other times when fewer staff / other issues may be missed." **Survey respondent opposed to assisted dying answering 'No– I do not agree, there should be a time period longer than 48-hours' at Q.24**

"Because I feel this is potential extra undue distress for the patient." Survey respondent supportive of assisted dying answering 'No – I do not agree, there should be no minimum time period for appeals' at Q.24

"People need adequate time to confirm the decision in their own minds. And it varies for different people - some need longer than 48 hours." **Survey respondent opposed to assisted dying answering 'No– I do not agree, there should be a time period longer than 48-hours' at Q.24**

Stakeholder feedback (organisations)

Some stakeholder organisations opposed to assisted dying held the view that the minimum timeframe should be longer than 48- hours.

"If the appeals process is to have value, it requires time and transparency. The freedom to exclude family members runs great risks, as seen in the case of Godelieva de Troyer, a Belgian woman with long-term depression who was euthanised by the co-chair of the euthanasia review body, to whose pro-euthanasia organisation she had donated money, with her son only finding out the day after she had died." **Care Not Killing and Our Duty of Care Joint response**

d. Who should have the right to appeal

Paragraph 245 of the Assisted Dying consultation report proposed that the right of appeal should be restricted to the person requesting an assisted death, and a person with a special interest in their care and treatment, for example a family member.



Q25. Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

The overall response to this question indicates agreement that the right to appeal should be restricted to the person (or their agent) or a person of special interest. Respondents strongly in support of assisted dying were most likely to agree (80%), followed by those who did not hold a strong view (71%) and those who did not disclose their views (53%). Respondents strongly opposed to assisted dying showed only a marginal support (45%).

The majority of respondents that answered 'yes' believed the right to appeal should be restricted to the person, close family members, friends and carers and that lobby groups should be excluded from the process; with some stating that providing people with a special interest in the person a right to appeal could help protect vulnerable people from coercion.

Respondents that answered 'no', generally stated the right to appeal should be restricted to the person only, in some cases to prevent coercion. Other respondents were comfortable with the right of a person of special interest to appeal, as long as they have a close relationship with the applicant (family members, friends, physicians). However, a distinct group of respondents, strongly opposed to assisted dying elaborated the right to appeal should extend to any person with an interest in the case to either stop the process or intervene if the applicant has no decision-making capacity.

"I definitely don't think this is the right place for lobby groups, and this restriction is very important for individuals, families, friends, and society as a whole." **Survey respondent opposed to assisted dying answering 'Yes' at Q.25**

"Family members and carers are very important and should have the right to appeal." Survey respondent opposed to assisted dying answering 'Yes' at Q.25 *"This will help to avoid some abuses of power by a third party"* **Survey respondent opposed to assisted dying answering 'Yes' at Q.25**

"Anyone should be able to step in where they have relevant info." **Survey respondent** opposed to assisted dying answering 'No' at Q.25

Stakeholder feedback (organisations)

A small number of stakeholders responded to this question. Some organisations supportive of assisted dying held the view that only the person requesting the assisted death should have the right to appeal.

"We are concerned that the process for appeals could allow others (family members and loved ones) to unnecessarily interfere with the assisted dying process. We believe that while it is positive for death and assisted dying to be spoken about openly and publicly, a right to appeal would conflict with the bodily autonomy and the freedom to choose that underpin the reasoning behind assisted dying. Most jurisdictions do not provide appeals. Only Western Australia does so." **Channel Islands Humanists**

"We do not agree that a third party should be able to appeal a decision to approve a request. ... there is still a risk that people who are deemed to have a special interest in the care of the person, for example family members or clinicians who might at some point have been involved in the person's care, may oppose assisted dying and could use this process in order to make a vexatious appeal to stop or delay an assisted death taking place. We cannot see any way in which the person can be protected from these types of appeals under the current proposal." **Dignity in Dying**

6.4 Planning and delivery of an assisted death

This section summarises feedback received in relation to the planning and delivery of an assisted death, as set out in Section 6 of the Consultation Report.⁴⁷

6.4.1. Planning and preparation for an assisted death

The consultation report sets out the proposed process for agreeing the time, date, location and mode of assisted death, once the person has been approved as eligible (Step 6 of the assisted dying process.) The consultation survey did not ask specific question on planning and preparation for an assisted death, but feedback was received in the public and stakeholder consultation sessions, and in written feedback.

a. Assisted death plan

The proposals set out that the Administering Practitioner will agree an assisted death plan with the person, to confirm their wishes and preferences for an assisted death.⁴⁸ Attendees at the public consultation sessions agreed with this on the proviso that these discussions started earlier in the process (i.e., during the assessment phase as opposed to being left to later in the process). One stakeholder organisation provided additional feedback on the scope of the assisted death plan:

"It is unclear in the current proposals at what stage the date and time should be agreed. We recommend this is included as part of the assisted death plan conversations in Step 6.

We also recommend Step 6 includes a requirement for the Administering Practitioner to be satisfied the person still has decision-making capacity. This is needed given it is proposed there is no expiry date on the approval of requests, therefore it is possible a significant amount of time may have passed between Steps 5 and 6.

We also recommend Step 6 includes discussion of what the person themselves needs to do or not do on the day of the assisted death prior to the Administering Practitioner arriving. For example, if it is anticipated absorption of the assisted dying substance might be impacted by the presence of alcohol, certain foods or the person's existing medications then this should be fully explored and form part of the assisted death plan.

Additionally, Step 6 should include discussion of what the person wishes the Administering Practitioner to do during the assisted death, i.e. whether to remain in the room or nearby in another room. We would expect guidance to be produced which sets out in detail what discussions should be had at Step 6

The consultation document suggests a person's assisted death plan should cover who will be present and what they will need to do. We recommend the assisted death plan makes reference to what, if any, specific support loved ones plan to provide." **Dignity in Dying**

⁴⁷ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, section 6: pages 73-78

⁴⁸ Assisted Dying Consultation Report.pdf (gov.je), paragraphs 262 - 277

b. Location for an assisted death

The proposals set out that locations for an assisted death must be approved by the Administering Practitioner, and may include private residences, care and nursing facilities and hospital facilities (feedback on conscientious objection by premises owners can be found in <u>Section 6.2.2.d</u> this report).

At the in person feedback sessions a number of queries were raised about:

- a. what would happen if the person does not own their property for example, could a landlord have a right to refuse assisted deaths taking place on the premises?
- b. whether the hospital should be used a location for assisted deaths. Some expressed a preference for an external location (i.e. a separate building, not in the General Hospital), whereas others were content that assisted dying took place on specific wards but noted that careful consideration would need to be given to staff and other patients on the ward who may conscientiously object. One stakeholder organisation provided additional written feedback on the role of the hospital as a location for an assisted death:

"Hospitals have always been, and should remain, places of healing and restoration. Allowing them to become possible places for an assisted death undermines and contradicts their purpose. A lack of distinction between places of treatment and places of deliberately ending life would undermine confidence in the hospital system both by the individual patient (when they witness assisted suicides on their ward) and by the population in general." Living and Dying Well

6.4.2. Assisted dying substance

Step 7 of the consultation proposals sets out the proposed process for prescribing and preparing the assisted dying substance. The consultation survey did not ask specific questions about this element of the proposals, but feedback was provided in the public and stakeholder consultation sessions, and also in written feedback.

a. Medications used for an assisted death, dispensing and storing

The proposals set out that the drug regime and protocols for the substances used in assisted dying will be agreed by the Delivery and Assurance Board [as set out in paragraph 35 of the consultation report – the Board's role would be to oversee the establishment of the Assisted Dying Service, and then would have an ongoing role to assure the Minister and the public about patient experience, clinical safety and service quality].⁴⁹

Feedback received in written submissions from some stakeholders, stated that more detail on the exact medications used should be included at this stage of the proposals, in order to make an decision to proceed with law drafting.

"While much is made in the consultation about the holding of substances securely, which is to be supported, little is made of which substances are to be used. In other jurisdictions, the lethal drugs used have never been subject to proper scientific scrutiny. Previously, large doses of barbiturate were used, but a shortage of supply and escalating prices have meant

⁴⁹ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraph 35

different drug combinations are now being tried to induce sedation with toxic levels, precipitating a heart arrhythmia and death by asphyxia. In Oregon, a mixture of four different classes of drug have been used over the last seven years, but have resulted in longer median times to death." **Living and Dying Well**

"There will be significant legal risks to the Jersey Government. Is the Jersey Government willing to authorise lethal 'substances' that have never been approved of by any regulatory authority anywhere in the world? And will the Jersey Government provide unlimited indemnity in the event of a problem with an assisted death?" **Jersey Dying Well**

"The suggestion of pharmacy training is positive, although guidelines for this training need to be published in advance so they can be scrutinised and strengthened by a range of stakeholders. There is currently no indication that this will be the case. Avoiding drug error by the wrong patient being given lethal drugs will be decreased if the drugs can only be supplied to a patient in their own home." **Living and Dying Well**

6.4.3. Administering the substance

a. Mode of assisted death

P95/2021 – Assisted Dying agreed in principle that an assisted dying service in Jersey may provide for both self-administered assisted dying (often referred to as Physician-Assisted Suicide or PAS) and practitioner-administered assisted dying (sometimes referred to as voluntary euthanasia).

The consultation report set out proposed options for the mode of assisted death:

- i. **self-administration oral** or by a percutaneous endoscopic gastrostomy (PEG) or nasogastric tube (NG)
- ii. self-administration IV injection, intravenous delivery, triggered by the person
- iii. **practitioner administration orally**, including by a percutaneous endoscopic gastrostomy (PEG) or nasogastric tube (NG

iv. practitioner administration - IV injection

In the public consultation sessions, some were of the view that a person should have the choice to self-administer or for the practitioner to administer the medication, especially if they may have physical difficulty in self-administering. Others took a view that if assisted dying is about personal choice and autonomy, it is important that the person takes the final step / decision to end their life by self-administering the assisted dying substance. A third viewpoint was that the substance should always be self-administered, except for when the person is unable to self-administer, in which case it should be administered by the Administering Practitioner.

"Allowing two different routes of administration may impact clinicians' willingness to be involved in the assisted dying process. We recommend further clarity is given on if clinicians would be able to opt-in to the service but limit their involvement to cases where the person opts for self-administration" **Dignity in Dying**

b. Support to self-administer

Paragraph 295 of the consultation report states that if the person has chosen to selfadminister the substance a family member or loved one may support them in the process.⁵⁰



Q28. Do you agree that a loved one should be able to support the person to self-administer the substance? substance?

The overall response to this question indicates majority agreement that a loved-one should be able to support a person to self-administer the substance. However, when responses are considered by views towards assisted dying, respondents strongly in support of assisted dying agreed (86% answering 'yes') but those strongly opposed to assisted dying disagreed (70% answering 'no').

Most respondents who agreed, stated that it should ultimately be the patient's decision as to whether they are supported by a family member. Others held the view that support from loved-one was particularly important in cases of a degenerative disease (e.g., Motor Neurone Disease).

Respondents that answered 'no' were overwhelmingly concerned over the possibility of coercion from the relative. A significant proportion of the responses also showed concern that this provision may create a burden or pressure on the relatives to actively support the person to die and the potential effect this may have on their mental health.

⁵⁰ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraph 295

"Only if they feel comfortable doing so and that they are not coerced into taking part in the death of a loved one." Survey respondent supportive of assisted dying answering 'Yes' at Q.28

"To my mind this is extremely important part of allowing people a choice about how they die, including who is with them at the time." **Survey respondent supportive of assisted dying answering 'Yes' at Q.28**

"In patients with significant mobility issues e.g. Parkinson's they may not be able to selfadminister unaided. It also can be very beneficial for the person and the family to be actively involved in the death. However, the person supporting should be identified by the Administering Practitioner and supported in carrying out this role." **Survey respondent supportive of assisted dying answering 'Yes' at Q.28**

"This could traumatise and place a burden on the families to be involved. This also raises concerns about safeguards, for example if the family were coercive and placing the burden on the patient to take it." **Survey respondent opposed to assisted dying answering 'No' at Q.28**

Stakeholder feedback (organisations and individuals)

Stakeholders that provided feedback stated that guidelines related to loved ones providing support must be explicitly clear, and that the Administering Practitioner must hold ultimate responsibility for the oversight of administering the substance. One submission noted possible complexities relating to eligibility for life insurance claims.

"We recommend the Assisted Dying Service produces clear guidance on this issue so that individuals, their loved ones and the wider public understand exactly what this support encompasses and they are clear that it does not change the fact that it is the individual themselves taking the final act of self-administering the substance." **Dignity in Dying**

"This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change. ... That said, it may be helpful to set out some GMC guidance relevant to this question:

"We recognise that loved ones can play a vital role in supporting and helping to deliver care and treatment to their loved ones (see guidance 'Treatment and care towards the end of life'). However, it is important to be clear that the treating doctor retains overall responsibility for their patient's care when, under their direction, particular treatments are being administered by others (including the patient themselves, with or without the help of loved ones). It is part of the doctor's responsibility to make sure that arrangements are appropriate and safe and that the person providing care has been suitably trained and has support." **GMC**

"If a system can be created that allows for a loved one to support an individual in a clear, unambiguous, safe manner then it should be allowed. However, if a loved one is able to support a person self-administering the substance, then we believe that the Administering Practitioner must be present to remove any ambiguity. We recommend that Jersey produces clear guidance on what it would mean to support self-administration. This guidance must be clear on what sort of support is acceptable, such as holding a straw or placing a switch in a person's hand." **Channel Islands Humanists** "It is a dangerous assumption to state that supporting self-administration would be an "extension of care" (para 295). There should be clear regulations set out as to who, if anyone, the person consents to have to help them administer the lethal substance, should the need arise" Living and Dying Well

"I would also like to emphasise that within the document and in reference to the part about insurance companies covering such deaths it says... 'The Association of British Insurers has indicated that, where an assisted death has taken place legally and a person benefiting from an insurance policy is <u>not directly involved in that death</u>, any claim on a life insurance policy would likely be payable, assuming all other terms and conditions of the policy had been satisfied."

Later on in the consultation document it says that, 'It is proposed that a loved one (i.e. friend or family member) <u>may support the person to self-administer the substance</u> as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.' ... I find this troubling and think you should again seek clarity from insurers." **Practising nurse, Jersey**

c. Administering Practitioner to remain nearby

The proposals set out that the Administering Practitioner (the doctor or nurse who either supports the person to self-administer the medication which will bring about their death, or administers the substance directly to the person), must remain with or nearby the person from the point when the assisted dying substance has been administered until their death.⁵¹



Q27. Do you agree that there should be an Administering Practitioner with the person or nearby?

⁵¹ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraphs 293 - 300

Yes		71.29%	643
No	-	8.31%	75
Don't know		20.40%	184
Please tell us the reasons for your response 405			•
Answered: 902 Skipped: 0	Response Total:		902

The overall response to this question shows clear agreement that the Administering Practitioner should remain with the person. Respondents strongly in support of assisted dying agreed (94%), as did respondents who did not hold a strong view on assisted dying (82%). Respondents strongly opposed to assisted dying showed a broadly equal proportion of agreement (45%) and uncertainty, with 40% answering 'don't know'.

The majority of responses in support of the Administering Practitioner being present with the patient or nearby during the administration of the substance, stated that the measure was reasonable and humane. Further responses noted that the Administering Practitioner should be present to ensure the safety of the patient; support the patient and the family members; prevent undue pain and suffering; ensure the substance is given with the patient's consent and to provide intervene if the administration fails.

Respondents that answered 'no' stated that medical professionals should not be placed in this position, and that the patient should decide and complete their own assisted death.

Respondents that answered 'don't know' mostly expressed a general opposition to assisted dying.

"There are too many reports of euthanasia not going according to plan, it is essential to have a skilled and knowledgeable medical practitioner nearby. This can be to deal with the extremely painful deaths experienced by some, and for others where the cocktail of drugs fails to work, for whatever reason." **Survey respondent opposed to assisted dying answering 'Yes' at Q.27**

"I like the idea of the administering person staying nearby. This could give the patient privacy, if this is their choice, but with the added confidence that there is professional help at hand if necessary." **Survey respondent supportive of assisted dying answering 'Yes' at Q.27**

"Who is present in their final moments should be the patient's to determine." **Survey respondent supportive of assisted dying answering 'No' at Q.27**

Stakeholder feedback (individuals and organisations)

Stakeholders that provided a written response to this issue were generally supportive of the proposal, however some noted a preference for the presence of more than one health professional in the event of any medical complications.

"We agree that this should be a necessary safeguard, in the event something goes wrong. Indeed, the patient may have provided a 'confirmation of consent' in case the selfadministration does not go to plan and an Administering Doctor would need to be present for precisely this type of eventuality." **GMC**

"The barbiturate cocktail is unpleasant to take orally, and may be regurgitated, or simply not fully effective. The common misconception is that the patient will fall asleep quickly and die within minutes. The reality is often different. It may take much longer before the patient dies, and sometimes they do not die following the prescribed dose. These are very distressing scenarios, for the patient if still aware, and especially for the family. It is not clear from the Proposals document how the AP [Administering Practitioner] should respond in these very difficult situations. Under para 296 the AP is told to stay with or nearby the patient until they die but no direction is given if they do not die. We are simply asked to accept that 'Detailed protocols will be developed should an unexpected medical event occur.' Whatever those protocols look like, we suggest that no AP should be expected to cope alone in such circumstances. Again, we recommend that a minimum of two APs be in attendance as a matter of course." **Christian Medical Fellowship**

"When I worked in Palliative care, I had a terminal patient who had a massive PE [pulmonary embolism], which caused pain & distress. My senior administered a, probably fatal, dose of midazolam to ease the distress. To our amazement she didn't die and woke up three days later. She subsequently had three weeks able to interact with her family. My point is that things will go wrong and somebody needs to be there to address the problem." **Practising GP, Jersey**

6.4.4. Post-death

The feedback in this section relates to the proposals regarding the recording of the cause of death in the medical certificate of the fact and cause of death (MCFCD). These are set out in paragraphs 314 to 318 of the Assisted Dying consultation report and propose that an assisted death is recorded in the same way as other deaths which means it could be inferred from the MCFCD that the person had died as a result of an assisted death.⁵²

⁵² Assisted Dying Consultation Report.pdf (gov.je), paragraphs 314 - 318




The overall response to this question demonstrates a strong agreement with the proposal to record the cause of death as assisted dying in the MCFCD. There was clear agreement across all views towards assisted dying.

473 respondents to the survey gave a reason for their response. The most common reason in the responses that answered 'yes' was transparency and accuracy. Some respondents elaborated further, stating that recording the cause of death as assisted dying would enable good data collection and ensure the production of accurate statistics which would in turn inform research and government policy. A smaller proportion of responses focused on recording all means that were used during an assisted death, including the active substance and the name of the Administering Practitioner.

Respondents who answered 'no' mostly disagreed with the proposals giving the reason for disagreeing as a right to personal choice and concerns related to privacy.

"This is essential for transparency and monitoring." **Survey respondent opposed to** assisted dying answering 'Yes' at Q.29

"Transparency will assist reviews, and ensure the law stays current and effective." **Survey respondent opposed to assisted dying answering 'Yes' at Q.29**

"I agree assisted dying should be the primary cause but I think the actual reason should also be given i.e. terminal illness cancer of the breast or suffering Motor Neurone disease or similar." **Survey respondent supportive of assisted dying answering 'Yes' at Q.29**

"It should be kept private due to discrimination by funeral services or the Church." **Survey respondent supportive of assisted dying answering 'No' at Q.29**

Stakeholder feedback (individuals and organisations)

Stakeholders that provided a written response were generally neutral or supportive of the proposal regardless of their position on assisted dying, with the exception of one campaigning group who hold the view that privacy of the individual has to be paramount, particularly given the small size of this jurisdiction.

"We do not provide specific advice to doctors on how to fill in death certificates. However, our guidance (see paragraph 71 of 'Good medical practice') makes clear that when completing certificates and other documents, doctors are expected to be honest and that any forms they sign should not be misleading." **GMC**

"Data in public documents, including the MCFCD, should record assisted deaths as suicide by lethal drugs. Otherwise, data on fatality rates and prognoses of diseases will be skewed: if the underlying condition is recorded as the cause of death, the data on this disease, over time, artificially changes, making it hard for medical research to assess the nature of the disease." Living and Dying Well

"While we object to use of the euphemism "assisted dying", many proposals for euthanasia and assisted suicide seek to obscure the real nature of such deaths on death certificates, instead listing underlying illnesses only. We would agree that the real cause of death – ingestion or injection of lethal drugs – should be listed as the cause of death in such circumstances." **Care Not Killing and Our Duty of Care Joint response**

"There should be no stigma attaching to an assisted death. It is also important for ongoing public confidence that there is full transparency about the scale of and reasons for assisted deaths." **My Death My Decision**

"Not only should the records show the means of death (e.g. ingestion or injection of lethal drugs) but also whether this was selfadministered or administered by someone else." **Anscombe Bioethics Centre**

"We recognise that practice in this area differs and the death certification process in Jersey does not necessarily map onto to those used in places where assisted dying is legal. In the same way that assisted deaths are not suicides, because the intent of the person who is dying is markedly different, we believe what is causing someone to die is not the assisted death but the underlying condition that has meant they are eligible to utilise this option at the end of their lives.

"We also believe the privacy of the individual has to be paramount. This is particularly relevant given it is anticipated there will be a relatively small number of assisted dying cases in Jersey compared to other jurisdictions. However, we also recommend that further consultation be conducted with dying people who have indicated they would want the option of an assisted death and bereaved relatives who have been affected by the lack of a safeguarded assisted dying law. Given the personal and sensitive nature of this element of the proposals it is critical that their views and wishes are prioritised." **Dignity in Dying**

6.5 Regulation and oversight

The feedback in this section refers to the proposals for regulation and oversight of an assisted dying service as set out Section 7 of the Assisted Dying consultation report.⁵³

6.5.1. Delivery and assurance board

The consultation proposed the formation of an HCS Service Delivery and Assurance Board. Its initial function would be to oversee the establishment of the Assisted Dying Service, and then would have an ongoing role to assure the Minister and the public about patient experience, clinical safety and service quality. See paragraph 34 - 35 and 321 of the Assisted Dying consultation report for further detail.⁵⁴



Q30. Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

A significant majority of respondents agreed that an HCS Delivery and Assurance Board is needed. Most respondents agreed regardless of their view towards assisted dying.

⁵³ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, pages 87 -90

⁵⁴ Assisted Dying Consultation Report.pdf (gov.je), paragraphs 34 – 35 and 321

The most common reason for agreement was an oversight board could provide assurance that an assisted dying service would be delivered to a high standard, helping to ensure safety, acting as an additional safeguard and supporting transparency. A number of respondents thought that a board would ensure accountability of government and everyone involved in the service. Responses from both those supportive of, and opposed to assisted dying, expressed concerns about the current lack of regulation, governance and / or oversight within HCS.

Respondents who did not agree mostly felt that a board would increase public costs, act as an unnecessary 'red tape' and would overcomplicate the process

Most respondents who answered 'don't know' were either opposed to assisted dying in principle or were opposed a board due to the associated costs.

"The oversight and governance of assisted dying is of vital importance if this becomes law. Other regulators such as the GMC will be observing this very closely." **Survey respondent opposed to assisted dying answering 'Yes' at Q.30**

"This is essential for transparency and monitoring." Survey respondent opposed to assisted dying answering 'Yes' at Q.30

"Yes, all services need to be monitored to ensure the best possible service is maintained, be accountable and resolve problems if and when they occur." **Survey respondent supportive of assisted dying answering 'Yes' at Q.30**

"To be kept up to date on the safety of assisted dying and to maintain the quality of the service." **Survey respondent supportive of assisted dying answering 'Yes' at Q.30**

"It does seem to be an administrative burden on the State so extra cost." **Survey respondent supportive of assisted dying answering 'No' at Q.30**

Stakeholder feedback (individuals and organisations)

Stakeholders written feedback was largely either neutral or supportive of establishing an HCS Delivery and Assurance Board, the exception being a small number of local health professionals. Feedback focussed mainly on the work required from the board prior to implementation, for example development of clear and effective guidance, protocols and clinical pathways.

"We note that, as yet there is no HCS Service Delivery and Assurance Board, no Assisted Dying Service, no training programmes, clinical protocols or clinical governance or complaints procedures... Should 'assisted dying' legislation is passed in Jersey, we strongly appeal that is should not come into force until after all the boards, commissions and committees involved in audit and review are up and running...we ask that urgent consideration be given to the development of clinical review processes, where independent physicians (not involved clinically with assisted deaths) are given the mandate to monitor and audit the clinical pathway in every case. We suggest this is necessary for the development of public confidence in the service and should include the right of family members to register their concerns directly with clinicians, before and/or after the death." **Christian Medical Fellowship** "This will help ensure public confidence." My Death My Decision

"This is essential for transparency and monitoring." **Association for Palliative Medicine of Great Britain and Ireland**

"At present, there is no regulation at all of community or hospital services. They are only just constructing an independent board to oversee health and community services. There is no CQC or regulator that oversees any services except care homes and a few day care facilities. Regulation is desperately needed to bring assurance to all areas of healthcare so a board to oversee the service would be welcome, but we urge members of the States Assembly to give particular consideration to whether a brand new, complex, life-ending service could be safely inspected and regulated in such a context." **Care Not Killing and Our Duty of Care Joint response**

"However, RCPsych members in Jersey have raised that a range of training, education materials, and assessments would need to be developed for psychiatrists prior to the implementation of an assisted dying service in Jersey. We would expect that any implementation plans allow enough time for such training, assessments, and education materials to be developed." **Royal College of Psychiatrists**

"Given the poor state of clinical governance in parts of HCS, particularly the General Hospital and the cannabis product prescribing service, it is unlikely that any regulatory service set up from HCS's present resources would be fit for this purpose." **Practising GP, Jersey**

6.5.2. Administrative review

The feedback in this section refers to the proposals set out in paragraphs 321-325 of the consultation report regarding post-death administrative reviews.⁵⁵



Q31. Do you agree that post-death administrative review of each assisted death is required?

⁵⁵ <u>Assisted Dying Consultation Report.pdf (gov.je)</u>, paragraphs 321 -325

Yes		66.52%	600
No		16.96%	153
Don't know		16.52%	149
Please tell us the reasons for your response 373			•
Answered: 902 Skipped: 0	Response Total:		902

Overall, respondents indicate clear agreement with the proposal that a post-death administrative review is required for each assisted death. The highest proportion of agreement was noted in the group of respondents that preferred not to disclose their views (80%), followed by those who were strongly opposed to assisted dying (78%) and respondents who held no strong view (69%). Respondents strongly in support of assisted dying mostly agreed (55%).

Of respondents that answered 'yes', the most common reasons given was that a post-death review would act as a safeguard, support identification of cases where coercion or malpractice had taken place, identify mistakes and support future service improvement. Some responses stated that a post-death administrative review was appropriate in order to increase transparency and accountability for those involved. A significant proportion of responses noted that a review of each assisted death was necessary at least for the first few years after implementation as the service becomes established. Finally, a distinct group answered 'yes' while expressing a strong opposition to assisted dying.

Respondents who answered 'no' mostly stated the review was uneccessary, if the previous steps have been followed properly. Some respondents raised concerns of high administrative cost, bureaucratic 'red tape' and administrative burden.

Respondents who answered 'don't know' were either opposed to assisted dying in principle or raised the same concerns as the respondents that answered 'no'.

"Review is essential to spot any abuse of the process, as with the European Court of Human Rights finding against Belgium in the case of Godelieva de Troyer." **Survey respondent opposed to assisted dying answering 'Yes' at Q.31**

"This is an important part of assessing any new service, especially one with such farreaching consequences." **Survey respondent opposed to assisted dying answering 'Yes' at Q.31**

"This must be rigorous, reviewing standard criteria to ensure that procedures have been followed. Where concerns arise, this review body must be able to institute a robust investigation by the Jersey Care Commission into the circumstances, or if necessary any practitioner or person who appears to have circumvented procedures." **Survey respondent opposed to assisted dying answering 'Yes' at Q.31**

"At least in the first years of implementation so that best practice can be developed and the service improved." **Survey respondent supportive of assisted dying answering 'Yes' at Q.31**

"If everything is administered in accordance with guidelines, i.e., all boxes ticked then there's not the need to review every time" **Survey respondent supportive of assisted dying answering 'Don't know' at Q.31**

Stakeholder feedback (individuals and organisations)

The range of feedback from stakeholders broadly echoed survey responses; with support for the proposed post-death review being very clearly expressed by organisations supportive of assisted dying. Some organisations voiced concerns that the process may in practice be a formality or 'tick box' exercise, rather than an opportunity for detailed scrutiny, and therefore recommended that the scope of the administrative review should be clearly set out in legislation.

One organisation suggested recording the assessment process to allow for further scrutiny as part of the post-death review.

"The law should prescribe the content of the administrative review to include care history, length of relationship with the Administering Doctors and a review of all the relevant assessment documents. 23 This is to avoid a situation where completing the administrative review becomes a quick and meaningless tickbox exercise which fails to evaluate and assess the assisted death. The current proposals lack these details and equate to a poorly detailed legislative framework." Living and Dying Well

"There is clearly a danger that an administrative review process amount to little more than a box-ticking exercise. Alongside the administrative review procedures, we ask that urgent consideration be given to the development of clinical review processes, where independent physicians (not involved clinically with assisted deaths) are given the mandate to monitor and audit the clinical pathway in every case. We suggest this is necessary for the development of public confidence in the service and should include the right of family members to register their concerns directly with clinicians, before and/or after the death." **Christian Medical Fellowship**

"As long as this review is constructed to be sensible and balanced and not a simple tick-box exercise again seems vital to me." Honorary Chair of the Jersey Disability Partnership

Some stakeholders stated that the role of a post-death review committee should be to ensure good practice and compliance with legislation or identification of trends, not to focus on the ethical considerations of an assisted death.

"While we understand the reasoning behind the suggestion that members of the committee may be specialists in end-of-life care, medical ethics or social care, we believe the most critical requirement is for committee members to be able to impartially consider whether the requirements of law have been followed, rather than focus on ethical debates on the principle of assisted dying, which risks undermining the integrity of the service." **Dignity in Dying**

"[It should be] only for research + audits - to identify trends for conditions, time from diagnosis to death etc." **Practising physiotherapist, Jersey**

Other organisations advised of learning from experiences elsewhere – including Switzerland, Belgium and the Netherlands.

We recommend careful examination of the European Court of Human Rights' ruling in the case of Tom Mortier (whose mother's euthanasia death we cited in our response to Q24) when considering the immense difficulties of developing a meaningfully robust system of

post-mortem review. The Government must be held accountable concerning its ECHR Article Two responsibilities. Care Not Killing and Our Duty of Care Joint response

"To compare with Swiss legislation: assisted dying is considered an "unusual death" which entails investigation to ensure compliance with the law of the procedures leading to the death. This review may also be understood as a duty of the state to protect life, in the sense of ensuring that no one will lose their life due to illegal actions by others. Clearance of the assisted dying case by the administrative review will also emotionally relieve everyone involved, e.g. medical professionals and loved ones, as they such will be assured of having acted correctly." **DIGNITAS**

6.5.3. Regulation by Jersey Care Commission (JCC)

The feedback in this section refers to the proposals set out in paragraphs 326 to 331 of the Assisted Dying consultation report and relates to the independent regulation and inspection of the Jersey Assisted Dying Service by the Jersey Care Commission (JCC).⁵⁶



Q32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?

The overall response to this question shows agreement that the JCC should independently regulate and inspect the assisted dying service. Respondents who held no strong view on

⁵⁶ Assisted Dying Consultation Report.pdf (gov.je), paragraphs 326 - 331

assisted dying mostly strongly agreed with the proposal (80%), followed by those strongly in support of assisted dying (79%). Respondents strongly opposed to assisted dying showed a broadly equal proportion of agreement (46% answering 'yes') and uncertainty (43% answering 'don't know').

The majority of respondents who answered 'yes' stated an assisted dying service needed independent regulation for reasons of transparency, accountability, quality and monitoring. However, some respondents in this group did not have confidence in the Jersey Care Commission to undertake this role.

Some respondents who answered 'no' stated that independent regulation was not needed if the process was robust; or thought the costs would be too high, or stated that consideration should be given to using an off-island independent regulator. A distinct group of respondents was opposed to assisted dying in principle.

Respondents who answered 'don't know' were either opposed to assisted dying or uncertain about independent regulation.

"Independent regulation is imperative to ensure transparency by and standards are adhered to and do not slip and alter." Survey respondent preferred not to disclose view towards assisted dying answering 'Yes' at Q.32

"For accountability and to give islanders trust in the process." **Survey respondent supportive of assisted dying answering 'Yes' at Q.32**

"For quality assurance" **Survey** *respondent* **supportive of assisted dying answering 'Yes' at Q.32**

"Somebody needs to inspect it, but I'm not sure if the Jersey Care Commission is the right choice." **Survey respondent opposed to assisted dying answering 'No' at Q.32**

Stakeholder feedback (individuals and organisations)

Feedback from stakeholders supportive of and opposed to assisted dying agreed that the service should be subject to independent oversight and regulation, as a safeguarding measure and to support public confidence in the assisted dying service.

Some responses noted that there would be unique challenges associated with the regulation of an assisted dying service, and that these aspects would need to be carefully considered when developing the processes for oversight and inspection.

"We understand that public confidence in the assisted dying service is vital. Individuals and their families must have complete trust in the entire process in order for the service to run effectively. The role of the JCC in regulating the service will help the people of Jersey feel that the service is safe." **Channel Islands Humanists**

"You have to see a service like this as very high risk for the care of Jersey residents, for the reputation of Jersey's health service. It may attract practitioners whose motives are not that altruistic. It needs regulation of the strictest kind." *Emeritus* Professor of Liaison Psychiatry, School of Medicine, Leeds University

"We also welcome the proposal that the Jersey Care Commission (JCC) provide independent regulatory oversight of the Jersey Assisted Dying Service and any internal review and audit procedures. However, we are not aware that the JCC has any experience of regulating community services in Jersey, so we are sceptical of their capacity to delivery on this aspiration." **Christian Medical Fellowship**

"Members in Jersey have also expressed concern that there is no regulatory body akin to the CQC in Jersey, and that it is unclear whether the necessary infrastructure currently exists to support the setting up and monitoring of an assisted dying service. We would expect that any future legislation, and plans to implement such a change in law, would require the development of robust governance processes to ensure that practices come under sufficient professional scrutiny." **Royal College of Psychiatrists**

Organisations both supportive and opposed to assisted dying gave further comment on the proposal that the JCC would publish an annual report on assisted dying.

"The annual report on assisted dying is the correct step to keep Jersey in line with international examples and play an important oversight role for safety, monitoring, and research." **Channel Islands Humanists**

"The same need for prescription arises in relation to the annual report that the Jersey Care Commission will be required to publish. This report must include an identification of groups of people with similar characteristics. This should be based on ethnic background, reason for requesting assisted dying, complications, length of relationship to the doctor, drugs used and the length of time between ingestion and death. The JCC annual report should be published every year, including any years where there are no assisted deaths in Jersey. The latter situation provides an opportunity to review and assess the requests made and the assessments that have led to disapproval." Living and Dying Well

"While it is appropriate that the Jersey Care Commission (JCC) would independently regulate and inspect the Assisted Dying Service, it is less clear that the JCC should be responsible for publishing an annual data report on the service. We recommend consideration be given as to whether the assisted dying review committee might be better placed to publish such a report, which would more closely mirror the role of the Voluntary Assisted Dying Review Board in Victoria, Australia. This would ensure the annual report will be as informative and insightful as possible, given the committee will have reviewed all assisted dying cases. In addition to the quantitative datasets listed in paragraph 327(g) of the consultation document, we also recommend the annual report includes qualitative data to shed light on the value of the service." Dignity in Dying

6.5.4. Assisted dying as an essential service

The Regulation of Care Law currently provides that the JCC may cancel the registration of a service provider who fails to comply with conditions imposed on them by the JCC unless that service is 'essential' (i.e., a service for which the Minister is the sole provider). The consultation proposed that the Regulation of Care Law is amended to ensure that the assisted dying service falls outside of the definition of an

essential service which would mean that, the service could be shut down by the JCC in the event of serious failings or breaches of standards.⁵⁷

Q33. Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down)



The overall response to this question suggests a lack of consensus as to whether an assisted dying service should be an essential service. However, when responses are considered by views towards assisted dying, respondents strongly opposed to assisted dying agreed with the proposals that it should not be an essential service (85%) but only a small minority of those who strongly support assisted dying agreed (13%). Respondents who preferred not to disclose their view mostly stated it should not be an essential service (67%).

368 respondents to the survey gave a reason to their response.

The majority of respondents who agreed it should not be considered an essential service were opposed to assisted dying in principle. Some respondents stated that palliative care should be an essential service (i.e., should be protected in law from being effectively closed by the JCC), and some responses highlighted the important safeguard that the JCC should suspend the service if it identifies issues.

Respondents who disagreed with proposals and wanted it to be considered as an essential service most frequently stated that the JCC should not have the authority to suspend the service without prior consultation with the government and providing recommendations.

⁵⁷ Assisted Dying Consultation Report.pdf (gov.je), paragraphs 330 -331

Respondents who answered 'don't know' were mostly opposed to assisted dying in principle.

"If legitimate concerns at any time, the JCC must have the powers to limit or suspend any part of the service it deems to be necessary." **Survey respondent opposed to assisted dying answering 'Yes - I agree, it should not be considered an essential service' at Q.33**

"The health service exists to provide enhanced quality of life, and palliative care for the dying. These are essential, but Assisted Dying is not an essential service in that same way." Survey respondent opposed to assisted dying answering 'Yes - I agree, it should not be considered an essential service' at Q.33

"Assisted dying does nothing to promote the positive life prospects of the population as a whole. It should not be considered an essential service in any shape or form." **Survey** *respondent* opposed to assisted dying answering 'Yes - I agree, it should not be considered an essential service' at Q.33

"It should be for the Government, with consent of the elected members of the Assembly, to decide this." **Survey respondent supportive of assisted dying answering 'No - I disagree, it should be considered an essential service' at Q.33**

"Everyone needs the choice which would make it essential" **Survey respondent supportive of assisted dying answering 'No - I disagree, it should be considered an essential service' at Q.33**

Stakeholder feedback (individuals and organisations)

Feedback from stakeholders varied, those with a neutral position did not comment on this aspect of the proposals, those opposed to assisted dying were more likely to support the proposal and those supportive of assisted dying were less likely to agree with the proposal, or agreed with the proposal but only in certain circumstances.

"Euthanasia and assisted suicide are essentially elective and, even if they are tolerated by law, they should not be deemed essential services that others have a duty to provide." **Anscombe Bioethics Centre**

"Yes, assisted suicide has no health benefits. It is not a medical procedure and should not be considered as such." Lives Worth Living – A Campaign of SPUC [Society for the Protection of Unborn Children] Pro-life

"The Assisted Dying Service will have been approved through the democratic process, so no separate body should have the ability to stop its operation." **My Death My Decision**

"The Jersey Care Commission (JCC) should not be given the power to unilaterally withdraw the option of assisted dying, which would undo a thorough and informed democratic process. We recommend the States proceed with caution and explore possible alternatives to giving the JCC this power, such as clarifying a mechanism for which the JCC can provide a recommendation for the Assembly to consider should the JCC believe there is a need to close down the Assisted Dying Service." **Dignity in Dying**

"We are concerned that if the Jersey Assisted Dying Service was not considered an essential service then, despite it being the will of the people and the Jersey Assembly, people who are in pain, suffering, or indignity may not be able to access the choices they deserve. However, it is important that the Jersey Assisted Dying Service always complies with all conditions imposed on them. The JCC should be allowed to temporarily suspend the service if it were to find alleged or confirmed breaches of the law or its standards. Not suspending the service in this unlikely scenario could harm public confidence in it, which is paramount." **Channel Islands Humanists**

7: Summary of responses – Consultation process feedback

Feedback received on the consultation process itself is summarised below.

7.1 Positive feedback

Several submissions gave positive feedback on the level of detail provided in the full consultation report. Others were complimentary about the public engagement sessions.

"I repeat my appreciation to the Assisted Dying team... for the impressive and detailed effort that you have put in to move the debate forward in Jersey. I hope that positive progress and acceptance continues and strengthens." Written submission, member of the public Ref AD3

"I just want to congratulate those involved on how well put together the proposal being presented at the Phase 2 events is.

I'm really impressed with the proposals that have been put together (I have completed the survey) and the sheer amount of detail, circumstances and people that have been considered at every stage. Well done to everyone involved in drafting the proposals and putting together the presentation, they have handled a very sensitive subject with the utmost of respect and care." Written submission, member of the public Ref AD29

7.2 Criticism of the consultation process

However, a larger number of responses received were critical of certain aspects of the consultation process.

7.2.1. HCS staff public engagement sessions

One area of feedback was concern that the HCS staff events were held too late in the consultation process and were not well attended. The HCS staff meetings were held on 11 and 12 January, and the consultation closed on 14 January. 11 staff members attended the sessions, (one staff member was also accompanied by a client with lived experience of a family member with dementia). HCS staff also chose to attend the public engagement sessions, the exact number was not recorded but it estimated around 10-15 people attending the public sessions were current health and care professionals.

7.2.2 Consultation survey

Feedback on the consultation survey was received in written email submissions (11 emails in total), in responses to the survey itself (57 respondents), and in one customer feedback complaint.

Survey design and bias

The consultation proposals were developed to reflect the 'in principle' decision already taken by the States Assembly that assisted dying <u>should be permitted in Jersey</u>. Survey questions were intentionally narrow in focus, asking respondents for their views on these proposals, the survey did not ask questions on the principle of assisted dying. Put another way, the purpose of the survey questions was not to ask, *"should assisted dying be permitted?"* but rather *"if there was an assisted dying service in Jersey, do you agree it should work this way?"*

Those who wished to share their views on the principles, or any wider issues related to assisted dying were able to do so either by submitting a response by post or by email or by attending a public engagement session.

Some feedback received expressed a dissatisfaction that the survey did not seek general views on assisted dying, instead asking only questions specific to the proposals. Others held the view that questions about specific proposals held an intrinsic 'bias', in that they assumed that assisted dying should, or would, be introduced in Jersey. A small number commented on the fact that the consultation was open to those based outside of Jersey.

"Unfortunately, all the questions with the exception of the first one assumed I was in favour of the proposal." Written submission, member of the public Ref AD31

"I was shocked and saddened to find that after the first question there was an inherent assumption that the user was in favour of assisted dying. In fact the answers of Yes, No and Don't Know all were slanted towards that assumption. This naturally made completing the questionnaire very difficult." Written submission, member of the public Ref AD30

"I just tried to fill in the survey, it is overly complicated and way to in depth, also if you oppose assisted dying and Euthanasia then 80% of the questions can't be answered. To answer them is to put any statistical analysis at risk of serious distortion." **Written submission, member of the public Ref AD32**

"As a Jersey resident, I am disappointed that the online Assisted Dying Consultation Survey was open to contributions from anybody in the world." Written submission, member of the public Ref AD14

Phrasing of questions

Some feedback on the survey criticised the question wording, noting some questions were long or complex and that some included a double negative, with the question and answer combinations - for example "'Do you agree the Jersey Assisted Dying Service should not be considered as an essential service?' / 'Yes - I agree, it should not be considered an essential service'."

Recognising these concerns, there was additional analysis of responses to the potentially problematic questions (including questions 15, 16, 17 and 21) was carried out to check understanding. This analysis found some written responses appeared to contradict the initial *yes/no* response to the question – suggesting there was misunderstanding - but only in a small number of responses.

"I have to say that having worked in research for many years, this was both poorly constructed and extremely biased in favour of those who believe that assisted dying should

be introduced. Some questions have double negatives in both the questions and answers and are therefore confusing and likely to yield unsafe responses." Written submission, member of the public Ref AD33

"May I also add that I am only emailing as the wording of the survey was so poor that I could not express my concerns by that route and I am worried that analysis of that survey alone will give you a very biased outcome." **Practising GP, Jersey**

Technical issues

The online survey was hosted by SmartSurvey - survey software used by a large number of government and public sector organisations. A small number of responses noted challenges with access and useability of the online survey. Different software platforms will be considered for future consultation surveys, including the Citizen Space consultation hub.⁵⁸

"I decided not to use the online survey form. I'm not very tech savvy, but as I began the survey, I wanted to see ALL the questions before I answered, but seemed unable to do so without completing permission information on the initial page." Written submission, member of the public Ref AD23

"When I search for "assisted dying survey" on the <u>gov.je</u> page, nothing (as is consistently so for the <u>gov.je</u> search, in my experience). I searched again on the assisted dying page, and again nothing comes up.

Having then eventually found it scrolling down the pages, I spent 15+mins filling it in, had got 50% through and had to break off for a caller, looked for some way to save what I had done, found nothing, tried to send the half that I had saved, was unable to do that, did what I could to save which didn't work." Written submission, member of the public Ref AD3

⁵⁸ Government of Jersey - Citizen Space

Appendix 1 - Promoting participation in the consultation

Media/location	Format	Detail
Jersey Evening Post	Full page advertisement	3 advertisements
Jersey Evening Post	Half-page advertisement	4 advertisements
Jersey Evening Post	Digital advertisement	15 November
Bailiwick Express	Digital advertisement	17 October – 23 October 31 October – 6 November
Parish halls	A3 + A4 posters	Throughout consultation period
Jersey Library	Digital screens	Throughout consultation period
Parish magazines (excl. St Helier, St Ouen and Grouville)	Full page advertisement	October edition
Channel 103	Radio advertisements promoting public engagement sessions	17 October – 22 November
Gov.je	Banner and link to consultation on homepage	Throughout consultation period
Social media – see appendix 2		

Summary of Phase 2 consultation promotion:

Sample JEP advertisement: Tuesday 18 October 2022, p.11 Jersey Evening Post

PHASE 2 ASSISTED DYING IN JERSEY

We want you to share your views on Jersey's assisted dying service:

- Jersey's assisted dying service will be free to Islanders who are eligible (To see the criteria, visit gov.je/AssistedDying)
- Safeguards will be built into every step

 the service will be overseen by a
 dedicated Board and inspected by the
 Jersey Care Commission. In some cases, a
 specialist Tribunal will approve a person's
 eligibility.
- Those who want an assisted death, and their family and friends, will be supported through the process by specially trained staff.
- The service will be person-centred, the person requesting an assisted death will control the pace of the process, and when and how they are supported to end their life.
- Health professionals can choose to opt-in to work as an assisted dying practitioner or can conscientiously object to directly participating in the service.

TELL US YOUR THOUGHTS ON THESE PROPOSALS AND OTHERS SET OUT IN THE CONSULTATION

You can feedback to the team by booking to attend one of our in-person engagement sessions. (Book via Eventbrite)

SATURDAY 22 OCTOBER 10am - 12pm Town library WEDNESDAY 26 OCTOBER 12pm - 2pm Town library WEDNESDAY 2 NOVEMBER 12pm - 2pm Communicare, St Brelade THURSDAY IO NOVEMBER 6pm - 8pm Town library

23 NOVEMBER 10am - 12pm St Clement Parish Hall

WEDNESDAY

Or give us your views online at: gov.je/AssistedDying

Appendix 2 – Social media analytics

The social data analytics listed below were collected for each post across Facebook, Twitter and Instagram. They are categorised by:

- reach: the number of people who saw each post at least once
- **impressions:** the estimated total number of times each post was seen. This is different to reach as it may include multiple views of a post by the same person
- engagement: the number of reactions, comments, shares or clicks on each post.

Tagged Published Posts		
18 7-		
18 /-		

Published Post Performance Summary

View your key aggregated tag performance metrics from the publishing period.

Impressions 60,311 —	Engagements 1,692 —	Engagement Rate (per Impression) 2.8% —
Post Link Clicks		

2.8%
N/A
2.8%
2%
3.4%
0.6%
N/A

Top Posts

View the top tagged published posts from the publishing period.

Descending by Lifetime Engagements



Appendix 3 – Survey questions

Thank you for responding to this consultation survey on assisted dying proposals in Jersey.

In order to complete this survey, you should first read the Assisted Dying in Jersey Consultation Report, which sets out the proposals for an assisted dying service in Jersey: Assisted Dying Consultation Report.pdf (gov.je) (opens in a new tab)

The consultation will run until 14 January 2023. For more details, visit gov.je/assisteddying

Questions on sharing your responses - we are asking these questions so we can process your data correctly and understand more about who is responding to this consultation.

Q. 1 Do you give permission for your comments to be quoted?

No Yes, anonymously Yes, attributed Name to attribute comments to: Organisation to attribute comments to, if applicable

Q. 2 Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes 🗆

No 🗆

Prefer not to say \Box

Q.3 If yes, do you think assisted dying:

should be permitted \Box

should not be permitted \Box

Key questions on Section 3 – eligibility criteria

Life expectancy for neurodegenerative diseases (see paras 16-19)

The Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months

It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of <u>12 months or less.</u>

Q.4 Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy or 12 months or less?

∕es □
lo 🗆
Don't know
Please tell us the reasons for your response:

Resident definition (see paras 25 & 26 and note 'Jersey resident' on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid 'death tourism". It is proposed that a person will only be considered 'resident' if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Q. 5 Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

Yes 🗆
No 🗆
Don't know 🗆
Other, please state
Please tell us the reasons for your response:

.....

Eligibility - age (see paras 25 & 26 and note 'Age limit' on p.17)

Q.6 Do you agree that assisted dying should only be permitted for people aged 18 or over?

Yes 🗆

No 🗆

Don't know □

Please tell us the reasons for your response:

Key questions on Section 4 – Assisted Dying Service

Q. 7 Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and who meet all the criteria?

Yes, it should be free \Box

No, it should be paid for \Box

Don't know 🗆

Please tell us the reasons for your response.....

.....

Conscientious objection - Supporting assessments (see para 50)

The Law will explicitly provide that no person can be compelled to *directly* participate in the assessment, approval or delivery of an assisted death.

In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as 'Coordinating Doctor' or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)

It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example:

- professional opinion provided by a specialist on the person's prognosis or life expectancy
- pulmonary function tests, carried out by a physiotherapist
- assessment to determine decision-making capacity by a psychiatrist or psychologist

Q.8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes, they should have the right to refuse \Box
No, they should not have the right to refuse \Box
Don't know 🗆
Please tell us the reasons for your response

Conscientious objection -Premises owner right of refusal (see para 50)

Q.9 Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

Yes, they should have the right to refuse \Box

No, they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises \Box

Don't know 🗆

Please	tell us t	he rea	sons foi	r your re	esponse	.	 	 	
•••••		•••••					 	 	 • • • • • •

Public or private register (paras 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they 'opt-in' to be an assisted dying practitioner.

The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Q.10 Do you agree that the assisted dying register should be public?

Yes 🗆

No 🗆

Don't know 🗆

Please tell us the reasons for your response.....

Key questions on Section 5 (part 1 of 3) – assisted dying process: request and approval

Request and approval process

Page 33 includes a diagram of the nine proposed steps in the assisted dying process.

Q. 11 Do you agree that the nine proposed steps are all necessary?

Yes 🗆

No 🗆

Don't know 🗆

Please tell us the reasons for your response.....

Q. 12 Do you think there are any further steps / actions that should be included?

Yes □

No 🗆

Don't know 🗆

Please tell us the reasons for your response.....

(Please note, further Sections of this document include more detailed questions about specific steps)

Period of reflection (paras 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the <u>minimum</u> amount of time between the first request (step 1) and the end of life (step 8):

- **14 days minimum** for those eligible under 'Route 1 (terminal illness)
- 90 days minimum those eligible under 'Route 2 (unbearable suffering)

Q.13 Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

Yes – I agree □

No – I do not agree □

Don't know □

Please tell us the reasons for your response	

Q.14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

Yes – I agree □ No – I do not agree □ Don't know □

Please tell us the reasons for your response.....

Key questions on Section 5 (part 2 of 3) – assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (paras 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Q. 15 Do you agree that the law <u>should not</u> prohibit professionals for raising the subject of assisted dying?

Yes – I agree □

No – I do not agree \Box

Don't know □

Please tell us the reasons for your response.....

.....

Q. 16 Do you agree that the law <u>should not</u> place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes – I agree □

No – I do not agree □

Don't know 🗆

Please tell us the reasons for your response.....

.....

Second opinion (see paras 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for **one** second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Q. 17 Do you agree that a person should only be entitled to one second opinion?

Yes 🗆

No 🗆

Don't know □

Please tell us the reasons for your response	
	•

Confirmation of consent to proceed (see para 143-146)

It is proposed that the law provides for the person to complete a 'confirmation of consent to proceed form', allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Q. 18 Should the law allow for confirmation of consent to proceed?

Yes 🗆

No 🗆

Don't know 🗆

Please tell us the reasons for your response.....

.....

Waiver of final consent (see paras 147-156)

It is proposed that the law should include the option for the person to complete a 'waiver of final consent'.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Q. 19 Should the law allow for the option of a waiver of final consent?

Yes- the law should allow for a waiver of final consent \square

No – the law should not allow for a waiver of final consent \square

Don't know 🗆

Please tell us the reasons for your response.....

.....

Key questions on Section 5 (part 3 of 3) – approval process

Routes for approval (see paras 189-203)

It is proposed that there are two different approval routes:

- a. **Route 1 (terminal illness)** which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments),
- b. **Route 2 (unbearable suffering)**, which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal

Q. 20 Do you agree with the two different approval routes as proposed?

Yes □

No – all approvals should be by the Coordinating Doctor based their assessment and that of the Independent Assessing Doctor only (ie. no requirement for a Tribunal) \Box No – all approvals by the Coordinating Doctor should be confirmation by a Tribunal (ie. a Tribunal involved in <u>all cases</u> \Box Don't know \Box

Other, please state

Please tell us the reasons for your response.....

Tribunal (see paras 211-235)

It is proposed that the Tribunal:

- always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard)
- does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).

Q. 21 Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

Yes □

No 🗆

Don't know 🗆

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Appeals (see paras 236-255)

It is proposed that the law will provide for appeals to the Royal Court on the following grounds:

- whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months
- a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person's wish is, or is not, voluntary, clear, settled and informed
- a failure, or perceived failure, to make determinations or act in accordance process set out in law

Q22. Do you agree that the Law should provide for appeals to the Royal Court?

Yes 🗆
No 🗆
Don't know 🗆
Please tell us the reasons for your response

Q23. Do you agree with proposed grounds for appeal?

es 🗆
on't know 🗆
ease tell us the reasons for your response

Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Q.24 Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

Yes – I agree □

No– I do not agree, there should be no minimum time period for appeals \Box

No– I do not agree, there should be a time period longer than 48-hours \square

Don't know 🗆

Please tell us the reasons for your response.....

.....

Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the

person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Q. 25 Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

Yes □ No □ Don't know □ Please tell us the reasons for your response.....

Expiry of approval (see paras 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Q.26 Do you agree that there should be no expiry date for the approval of an assisted death?

Yes – I agree, there should be no expiry date \Box
No - I disagree, I think there should be an expiry date \Box Other, please state \Box
Don't know □
Please tell us the reasons for your response

Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see paras 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Q.27 Do you agree that there should be an Administering Practitioner with the person or nearby?

Yes 🗆

No 🗆

Don't know □

Please tell us the reasons for your response

It is proposed that a loved one (ie. friend or family member) may support the person to selfadminister the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Q.28 Do you agree that a loved one should be able to support the person to selfadminister the substance?

Yes
No
No
Don't know
Please tell us the reasons for your response.....

Recording the cause of death (see paras 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Q.29 Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes 🗆

No 🗆

Don't know □

Please tell us the reasons for your response.....

Key questions on Section 7 – Regulation and oversight

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include:

- a. an HCS Service Delivery and Assurance Board
- b. an assisted dying review committee to undertake a post-death administrative review of each individual assisted death
- c. independent regulatory oversight by the Jersey Care Commission.

Q. 30 Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes 🗆

No 🗆

Don't know 🗆

Please tell us the reasons for your response.....

.....

Q.31 Do you agree that post-death administrative review of each assisted death is required?

Yes 🗆

No 🗆

Don't know 🗆

Please tell us the reasons for your response.....

.....

.....

Q. 32 Do you agree that the Jersey Care Commission should independently regulate and inspect the Assisted dying service

Yes 🗆

No 🗆

Don't know 🗆

Please tell us the reasons for your response.....

.....

.....

Assisted dying as an 'essential service' (see paras 333-334)

The Regulation of Care (Jersey) Law 2014 currently provides that the Jersey Care Commission (JCC) may cancel the registration of a service provider who fails to comply with conditions imposed on them, unless that service is 'essential' (i.e.: a service for which the Minister is the sole provider).

It is proposed that the Regulation of Care Law is amended to ensure that the assisted dying service falls outside of the definition of an essential service – which would mean that its registration may be cancelled, and a Jersey Assisted Dying Service may, in effect, be shut down by the JCC.

Q. 33 Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e., that the JCC should have the powers to close the service down)

Yes – I agree, it should not be considered an essential service \Box	
No– I disagree, it should be considered an essential service \Box	
Don't know 🗆	
Please tell us the reasons for your response	

Appendix 4 – Public engagement sessions

This document summarises the key themes emerging from the analysis of transcripts and notes taken by GOJ staff during the public engagement sessions (this includes events held at the Town library and Parish Halls). It also summarises themes from the Health and Community Services Department staff sessions and Citizens' Jury participant sessions. In addition, the appendix includes the questions raised by the participants during these sessions. This document provides a summary of issues raised and does not seek to capture the entirety of the discussion.

Key themes

This section summarises key themes related to the Assisted dying proposals.

Definitions and terminology

- Assisted suicide versus Assisted dying
- Mental suffering versus Physical Suffering
- 'Unbearable suffering'
- End of life care
- Eligibility criteria
 - Exemption for Jersey-born people
 - Capacity
 - Age (young people)

Decision-making capacity

- Involve family members
- Advanced directive (e.g. patients under coma)
- Include Alzheimer and dementia patients
- Consider individual communication needs

Consent

- Danger of manipulation (terminally ill patients may feel fearful and uncertain)
- Waiver of final consent: Risk of change of mind later

Timeframe – period of reflection for Route 1 terminally ill patients (14 days)

- Advance preparation for the last stages
- Too short
- Or too long if personal at end stage of disease
- Stressful for the patient

Timeframe – period of reflection for Route 2- 'unbearable suffering' patients (90

days)

- Too long
 - Or too short if not had opportunity to explore all other options
- Assisted dying service
 - Staff
 - o Importance of professional standards
 - Workload
 - Resources
 - Costs
 - Substances
 - Accessibility for people with communication needs
 - Cause of death (insurance policies, stigmatisation)
 - Record name of initiator of discussion
 - Length of time (impact on other services)
 - Safety and governance
 - Delivery under safe circumstances

- Long term Care savings to fund service
- Certificate of approval gives patient a sense of control
- Confidentiality from professionals who support people with communication needs

Doctors

- Training
- Initiation of discussion
- Conscientious objection clause
- Legal protection
- Professional indemnity
- Public register: Effect on their reputation
- Decline if unsure of prognosis
- Conflict between 'alleviate suffering' versus 'extending life'

Care Homes

- Obstructive objection
- Religious views (manager/owner)
- Upsetting for other residents
- Effects on staff
- End of life care offered only by some care homes
- Clear terms and conditions

Tribunal

• Add independent third-party to challenge its decisions.

Appeal

- Makes the process more complex
- Allows for challenge of decisions

Jersey Care Commission

• Jersey Care Commission different level of accountability and structure than the Care and Quality Commission (CQC)

Law

- Future relaxation of the law (e.g. Canada)
- Include mental suffering?

General themes

This section lists general themes around assisted dying, not specific to the proposals. Jersev

- Small size
- Effects on reputation
- Size of economy

Palliative care

- Prioritise support and funding of current services (including chemotherapy and radiotherapy)
- Good palliative care is sufficient vs. even the best palliative care can't prevent 'bad deaths'
- Jersey Hospice is opposed to Assisted Dying. Their role is to provide good end of life care.

Coercion

- Family members
- Government (Alter demographics, reduce healthcare funding)
- Doctors
- Care homes

Consultation

Lengthy

• Implementation of the service should run alongside debate

Quality of life Personal Autonomy/ Personal choice Pain/Suffering Dignity 'Thin edge of the cultural wedge' Support for family members Support for health professionals Training for chaplaincy team

Questions

This section lists a sample of the questions that were asked by participants during the public engagement sessions.

Definitions and terminology

- Who can define unbearable suffering?
- What is a lay member?
- In regard to mental suffering is it included in unbearable suffering or is unbearable suffering is defined as having purely physical causes?
- End of life care currently under supported what does 'good as it could be' mean? How is it defined/determined?
- Possibly expand the definition of Terminal Illness?

Eligibility criteria

- What about someone a child for example who isn't on Jersey but wants to come back for an AD, could an exception be made for Jersey born out of island individuals?
- Would they be given reasons that they are not eligible?
- Is there a potential to reduce the age below 18?
- Will young people be treated as priority?
- So, if they don't give consent, then that has an impact on their eligibility to take assisted dying?
- Is there a risk that someone brings a UK resident over to Jersey and they then qualify for assisted dying?
- Will there be something to substantiate the law of 12 months, if not the person would not get any medical support/finance?

Decision-making capacity

- Which professionals will assess the capability of a patient to take such a decision?
- What happens if someone has "locked in syndrome"?
- Is there any proposal for (a person) living in a coma for example, where someone can make an advanced directive to stop treatment?
- Who assesses the ability of the patient to take an informed decision before assisted dying?
- Why people with Alzheimer's aren't included in this process at the first stages of their disease?
- Will there be provision in the law that people with communication disabilities will be supported in the process?
- Is English a requirement for them to take the decision?
- Just in terms of if you're going through the process and you have capacity and you feel settled and informed, but then by the time it's gone to -- or might have

gone to appeal or by the time you have a decision, you might have lost your capacity, where do you now stand?

- And then additional to that is if you're going through the second route and you have your piece of paper which is approved and has no end date on it, but by the time you get to saying "I want to have it" or somebody finds your piece of paper and now you've lost capacity and you haven't done a waiver because you didn't think you were going to lose your capacity and it's two years down the line, then . . .?
- When the doctors were doing the assessment, when they were seeking information, they also looked to make sure that they had always different avenues so that they can make an informed choice about assisted dying?
- What about disabled people and their understanding?
- Who does the mental capacity assessment?
- Concerned about how communication changes when people have motoneuron disease for example I am a speech therapist and I am concerned about capacity and resourcing the AD, is there a potential for someone to sign and an interpreter (different language)?

Consent

- How could anyone know if they would have regretted this (taking the assisted dying route if it had been available)
- Can a "living will" be foreseen in the future so I can decide whilst I am capable?
- Is there a "living will" in other jurisdictions?
- If you are healthy at the present moment, could you sign up for assisted dying before in case you got sick in the future?
- So, thinking about it being an awful lot of hoops to jump through, am I right in thinking somebody could start that process actually fairly early within that sort of suggested six months? But actually, do it when they are ready, but that they could start it before they got quite so poorly, quite at the end?
- Do you have to see the doctor first and go through the assessment and then agree to be given the medication?
- The waiver of final consent how far in advance can this be made?

Route 1 & Route 2

- Route 2 does this apply to dementia?
- After 90 days (minimum has passed) is the timescale following on from this open?
- Does unbearable suffering include mental anguish?
- Is it better (for the AD proposal) to go for just Terminal Illness rather than include Route 2 may end up with nothing if asking for too much.?
- Who is route 2 approved by?

Timeframe-period of reflection

- If someone is experiencing unbearable suffering why make them wait for 90 days and not 14 days?
- So you're saying it's like a minimum of two weeks. If they change their mind and they don't want to take the medication, you know, they might say, no, I'm feeling I can cope better with it now, you know, they feel that they can carry on, they can feel that they can meet people or talk to people, and could cope more, so they are allowed to change their mind?
- After 90 days (minimum has passed) is the timescale following on from this open?

Assisted Dying Service

- How much will this system cost and who is paying?
- Will there be continued cost?

- What about (health) insurance?
- Is there a choice of medication (used during an assisted death)?
- Will there be additional funding for the doctors that offer this service?
- Is it completely new funding or already stretching the present funding?
- Will it be a private service?
- I'm just thinking about medication. Presumably that is held somewhere safe, and the assisted death is planned to the time which the medication will be administered is at a specific time?
- What's the impact of choosing to end your life on your life insurance and things like that?
- What is on the death certificate?

Doctors- Health professionals

- What if there is a lack of opt in medical professionals on island? Will we start flying in locums "death certificates for hire"?
- Can a hospital opt out? What if everybody opted out?
- Is there a correlation between medical objection and abortion laws (objection)?
- What discussions have been had with pharmacists? They have a duty to issue and dispense. How are pharmacists engaged with the process? What if the pharmacy team are too restricted in staffing levels? There needs to be protocols to ensure that those who opt in are the ones to dispense and not just left with the pharmacy team. Pharmacists will no longer be just providing medicines to help / heal people and so there will be a stigma attached. This is subjecting the hospital pharmacy to social pressure.
- What if a doctor agreed to offer the service but they were opposed to assisted dying and used their position to decline the service?
- Are medical professional bodies supportive of assisted dying?
- Who is responsible of the training since it has not been done before?
- What happens with medical indemnities since they are being currently regulated in the UK? Will there be reassurance for the medical professionals?
- Are the deadlines for implementation take into consideration the present workload of healthcare professionals?
- If it was me and my GP has conscientiously objected, does the assessing doctor because they are my notes are provided to access that information even if my GP objects?
- Do those assessing and administering have to be health practitioners?
- Who does the mental capacity assessment?
- The co-ordinating doctor is this the only job or will they also have a practice to run?
- Can retired doctors do the assessments?
- Would a register be created in terms of who would/would not object to AD and a register for health professions?
- Has a survey been done in terms of who is interested?
- Do doctors need to be in the UK or Jersey?
- If my GP did not support AD how do my details get passed on and is it documented on my notes?
- Will there be support for end-of-life i.e. training for staff?
- Who oversees the medical authorities?
- Could the GMC raise an objection that will delay progress and become overfocussed on the details?

Care Homes

• If a care home declines to host the service, can the patient go somewhere else?

• A care home could object but this can this be overridden if a person cannot be moved?

Tribunal

- How obstructive could the tribunal be? They are powerful.
- What is the constitution of the Tribunal and what is their timescale?

Appeal

- Would the law require a specialised judge to preside over an appeal?
- Is there an appeal against a board decision?
- What constitutes a 3⁻⁻ party person in an appeal and the type of evidence they can produce?
- Why add the complexity of an appeal process? It starts to become subject to the complexities of the legal process, timescales and delaying tactics.

Jersey Care Commission

• Speaking of the Jersey Care Commission, I'm wondering, because there isn't the equivalent in the U.K. in terms of assisted dying, and so I'm not sure where they're going to structure that in a way that it's in?

General queries

- Will it be implemented by March 2025?
- Will Jersey be used as training centre if assisted dying gets implemented in Wales or England?
- Does the training happen before or after the legislation has been implemented?
- Will there be online training?
- Who can be a witness? What if stand to gain from death? Should it be an unknown/randomly selected?
- Should this be a non-medical decision?
- What about funding for all other services?
- What about Viscount involvement if issues prior to AD? le gets AD as a result of suffering from medical malpractice or a criminal activity??
- How long would that take, you know, if it was an injection or a tablet, how long does the process of dying take?
- So it's important when you say support for the people who are involved, for the family and for the team, the doctors and the nurses, and the practitioners who are involved, I feel that's very important in terms of, you know, providing counselling and questioning their views and my question is will that be there? Will they have that for sure?
- So what happens after the death?
- What has been the demographic throughout your consultation?
- Are there any jurisdictions that support AD from an environmental perspective, so I don't use the worlds resources?
- What is the reason the UK government have not passed this legislation?
- Best practice which countries were consulted and how well was this integrated into the proposals?
- Is Jersey looking for the "perfect model"? Should we be looking at other jurisdictions with years of experience?
- In the timetable, is there opportunities to dither and procrastinate?
- Why does the implementation phase take so long? Training shouldn't be that complex.
- Could other pieces of legislation connect with this proposal?