Government of JERSEY

Assisted Dying in Jersey

Consultation Report

OCTOBER 2022

Ways to respond to the consultation

Date published: 17 October 2022

Closing date: 14 January 2023

1. You can respond to the questions asked in this consultation report by completing the online survey or via email or post.

   Email: assisteddying@gov.je

   Post: Assisted dying public consultation
   Government of Jersey
   Ground floor, 19-21 Broad Street
   St Helier
   JE2 3RR

   You can also use these contact details to share your general comments on the proposals.

2. You can attend one of the public engagement meetings, by booking through Eventbrite:

Date	Time	Venue	Eventbrite link
Saturday 22 October	10am-12pm	Town library	Book here
Wednesday 26 October	12pm-2pm	Town library	Book here
Wednesday 2 November	12pm-2pm	Communicare, St Brelade	Book here
Thursday 10 November	6pm-8pm	Town library	Book here
Wednesday 23 November	10am-12pm	St Clement Parish Hall	Book here

What happens when the consultation period ends?

A consultation feedback report will be published, after the end of the consultation period. Responses to the consultation will be used to inform a Report and Proposition on detailed policy proposals which will be lodged for debate by the States Assembly in early 2023.

How we will use your information

The information you provide will be processed in compliance with the Data Protection (Jersey) Law 2018 for the purposes of this consultation. For more information, please read our privacy notice (see **Appendix 4**).

The Government of Jersey may quote or publish responses to this consultation (for example, quote in a published report, send to the Scrutiny Office or report in the media) but will not publish names and addresses of individuals without consent.

However, confidential responses will be included in any statistical summary of information received and views expressed. Under the Freedom of Information (Jersey) Law 2011, information submitted to this consultation may be released if a Freedom of Information request requires it, but no personal data may be released.

We recommend you answer these questions using the online survey.

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 ☐

Q.3 If yes, do you think assisted dying:

should be permitted ☐

should not be permitted ☐

Consultation

Assisted dying in Jersey

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Overview of proposals

This report sets out detailed proposals for establishing an assisted dying service in Jersey. A summary version of the proposals, including alternative and accessible formats can be found at www.gov.je/assisteddying.

Section 1 of the report provides background to the report, outlining previous decisions made by the States Assembly, the proposed next steps and detail on how these proposals were developed.

Section 2 of the report outlines the key principles that underpin these proposals.

Section 3 details the proposed eligibility criteria for assisted dying that will be set out in law, including some variations from the wording previously agreed by the States Assembly in P95/2021.

Section 4 outlines how the Jersey Assisted Dying Service would operate, including governance and oversight and detail on the roles of the professionals involved, including the right to conscientious objection.

Section 5 details how requests, assessments and approvals for assisted dying will operate (Steps 1 to 5 of the proposed assisted dying process).

Section 6 outlines proposals for the delivery of an assisted death, including planning and preparation, what happens at the time of an assisted death and what happens after an assisted death (Steps 6 to 9 of the proposed assisted dying process).

Section 7 details proposals for the regulation and oversight of an assisted dying service, including the role of the Jersey Care Commission.

Section 8 explains the next steps in the process of implementing assisted dying in Jersey, including the law drafting process and implementation phase.

Section 9 outlines the key financial and resource implications for the development of assisted dying legislation and the operation of an assisted dying service in Jersey.

Consultation questions: There are consultation questions at the end of Sections 3 to 7, which you may wish to respond to. A full list of questions can be found at Appendix 3.

Terms used

The following terms have been used in this consultation report:

- **Doctor:** the term doctor has been used in this report for ease of understanding. It refers to a medical practitioner who is registered with the UK's General Medical Council (GMC) and with the Jersey Care Commission. This may include someone who is a doctor, including a general practitioner (GP) or a consultant.

- **The person:** refers to the person who has requested an assisted death. They are not called a patient or a client because, in some cases, they will be individuals who are not receiving treatment or care from a service provider.

- **Physical medical condition:** a broad term that includes all diseases, lesions, injuries and disorders, but does not include mental illnesses.

- **Assisted dying substance:** the controlled substances or approved medications that will bring about the person's death.

- **Decision-making capacity:** refers to a person's ability to make day to day decisions about legal, medical/health care, financial and personal matters. In this context it refers to the person's capacity to make the decision to request an assisted death.

Section 1: background to consultation report

1. In November 2021 the States Assembly ('the Assembly") agreed, in principle, that assisted dying should be permitted in Jersey (P95/2021)[1] but that, prior to the preparation of the law drafting instructions, detailed proposals should be brought back to the Assembly for debate by October 2022.

2. Following the June 2022 elections, the new Minister for Health and Social Services ("the Minister") determined that the timetable should be revised to allow a 12-week consultation period on those detailed proposals, which will result in the Assembly debate taking place in early 2023.

3. Should the Assembly approve the policy proposals, a draft law will be prepared. The Assembly will then debate the draft law. If the draft law is approved by the Assembly, an 18-month implementation period will begin. During this period all the required systems and safeguards will be put in place. These must be established before the law the comes into effect.

Note: Indicative timeframe

The next steps for establishing an assisted dying service in Jersey are set out below. The dates may change depending on the feedback received:

- **Public consultation:** 17 October– 14 January
- **States Assembly debate on policy proposals:** March 2023
- **Law drafting** (minimum 12 months): March 2023 to March 2024
- **States Assembly debate on draft law:** Late spring / early summer 2024
- **Implementation period:** Early summer 2024 – to end 2025
- **Legislation comes into effect:** By end of 2025

4. The purpose of this consultation report is to describe the detailed proposals, as they currently stand, so that members of the public and key professional stakeholders can reflect on what is proposed and submit any comments they have.

5. This consultation report is divided into nine sections, each looking at a different aspect of the assisted dying proposals. At the end of Sections 3 to 7 there are key questions which members of the public and professional stakeholders may wish to answer, or they can provide any additional comments they have.

6. A consultation feedback report will be published after the end of the consultation period.

[1] https://statesassembly.gov.je/assemblypropositions/2021/p.95-2021.pdf

7. Comments provided in response to this consultation report will inform the Report and Proposition on detailed policy proposals which will be lodged for debate by the States Assembly in early 2023.

8. 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.

9. During the consultation period, in addition to engagement with Jersey-based stakeholders and members of the public, there will be ongoing discussion with:

    a. the UK professional registration bodies about the proposed involved of registered medical and care professionals in the Jersey Assisted Dying Service, as described in this paper. Those registration bodies will be asked to consider if the proposed arrangements create difficulties or risks in relation to those bodies' standards and requirements

    b. medical indemnity and personal insurance companies with a view to confirming whether the proposed arrangements will have any impact on:
        - the ability of individual health practitioners, or their employers, to secure medical indemnity insurance
        - individual people's life insurance.

Note: Engagement to date with insurance providers

Medical indemnity and medical malpractice insurance

Discussions with relevant insurance brokers indicates that insurance cover for health professionals takes account of the legislation in the jurisdiction in which the health professional is working. Therefore, if assisted dying becomes legal in Jersey, medical indemnity insurance would extend to assisted dying professionals operating within that legislative framework.

Personal life insurance

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 not directly involved in that death, any claim on a life insurance policy would likely be payable, assuming all other terms and conditions of the policy had been satisfied.

10. Many of the proposals in the report have already been subject to prior consultation and engagement, including:

a. Citizen's Jury

The proposition debated by the Assembly in November 2021 (P95/2021) was informed by the key recommendations of the Jersey Citizens' Jury on Assisted Dying which took place between March and May 2021, with the final Jury report being published on 16 September 2021. A Citizens' Jury is a form of deliberative democracy, where a small group of people, representative of wider demographics of a given area, come together to carefully consider a complex issue. The Jury consisted of 23 Jersey residents who were broadly representative of the Island's population in terms of age, gender, location, socio-economic status, place of birth and attitude to assisted dying. The members came together over 10 online sessions to examine evidence, hear from expert witnesses and consider the central question "Should assisted dying be permitted in Jersey and if so, under what circumstances?".

At the end of the Jury process, 78% of Jury members agreed that assisted dying should be permitted in Jersey[2].

Note: Citizen's deliberation processes

The use of citizen's deliberation processes, such as the Jury, is relatively new to Jersey and, as such, was challenged by some Assembly members during the P95/2021 debate. The Public Accounts Committee subsequently reviewed the use and effectiveness of such processes and concluded that the Assisted Dying Citizens' Jury should be utilised as the model of best practice when establishing future deliberative bodies.[3]

b. Public engagement – Phase 1

During March and April 2022, Islanders were asked to take part in the first phase of public engagement on assisted dying proposals. Following the 'in principle' decision made by the Assembly, Islanders were invited to share their comments, thoughts and questions on assisted dying in Jersey. Feedback from the public was collected online via email, social media and sli.do, and in person at a series of engagement events at various parish halls and the town library.

Views were collected and published as key themes and questions in the public engagement summary report on assisted dying in Jersey.[4]

[2] Detailed reports relating to the establishment of the Jury and the Jury's final recommendations can be found at www.gov.je/assisteddying
[3] p.a.c.1 2022 - use and operation of citizens' panels, assemblies and juries in jersey.pdf (gov.je)
[4] Public engagement summary report on assisted dying in Jersey (gov.je)

c. Professional leads

A professional leads advisory group was established to advise on matters relating to assisted dying service development and delivery.[5] The group consists of the Medical Director; Chief Nurse; Chief Pharmacist; Interim Chief Allied Health Professional; Director of Mental Health & Adult Social Care; Associate Medical Director for Prevention, Primary and Intermediate Care; Accident and Emergency Consultant – GMC lead contact, plus the Chief Inspector of the Jersey Care Commission as an observer. It is supported by policy representatives from SPPP (Strategic Policy, Planning and Performance) and HCS (Health & Community Services).

d. Professional bodies

Engagement with the UK professional registration bodies began in August 2021. Individual and collective sessions have taken place with General Medical Council (GMC); Nursing and Midwifery Council (NMC); Health and Care Professions Council (HCPC) and General Pharmaceutical Council (GPhC). Topics for consideration have included: conscientious objection; how the introduction of legislation may impact on professional registration requirements; guidance and training for professionals and oversight of registered professionals. In addition, preliminary conversations with the Academy of Medical Royal Colleges and the Royal College of Nursing have been scheduled.

e. Expertise in other jurisdictions

The policy proposals set out in this report are based on extensive research of assisted dying legislation and practice in jurisdictions where assisted dying is permitted. This is in addition to in-person / virtual discussions with professionals in other jurisdictions who have direct expertise and practical experience of assisted dying, including:

- The Netherlands – former Chairman of the Dutch Euthanasia Review Committee
- Canada – Palliative care consultant and assisted dying practitioner, former President, Canadian Medical Association
- Australia – Consultant anaesthetist and assisted dying practitioner

The professional leads group (see above) also arranged two briefing sessions at which Health & Community Services (HCS) and non-HCS healthcare professionals could hear from the Australian assisted dying practitioner about their practical experience of implementing an assisted dying service and experience of working to support people to have an assisted death.

[5] Professional leads working group Terms of Reference can be found at https://www.gov.je/Caring/AssistedDying/Pages/AssistedDying.aspx

Section 2: principles

11. 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 professional. Assisted dying is not the same as suicide. Assisted dying is a service provided to people in certain limited circumstances that will be set out in law.

12. The assisted dying proposals set out in this consultation report are underpinned by the following principles:

    a. Autonomy and choice - a person is entitled to genuine choice when determining their end-of-life care and treatment. Their autonomy to make the decisions that are right for them should be respected. It is already the case that some people refuse care and treatment, whether on religious grounds or to avoid what they deem to be a protracted dying process, whilst others make advanced directives setting out their refusal of treatments or interventions such as resuscitation.

       We know that some people will choose an assisted death because they want to exercise a degree of control over the end of their life and any associated suffering. This is a legitimate choice which is to be respected.

    b. Assisted dying is a voluntary, settled and informed wish – a person requesting an assisted death should only do so if they wish to end their life, and that wish must be free from coercion. Nobody should feel pressurised by family, friends or by wider society to choose, or not to choose, an assisted death.

       In making their decision, people will consider a lot of different factors, one of which may be the distress felt by loved ones if the last weeks of their life involve suffering. This is a legitimate consideration, one with which people currently grapple when considering their care options.

       The law, and the assisted dying process, must provide safeguards to help ensure that a person's wish is free from coercion or pressure but, in doing so, it must be recognised that a voluntary wish, that is freely made, may be influenced by our love of others.

    c. Palliative and end of life care services - assisted dying does not replace palliative care and end-of-life care services. A person approaching the end of their life or living with serious illness should be provided the care and treatment they need to maximise their quality of life and minimise any suffering or distress. Assisted dying is an additional choice that some people may make because they want more control over the manner and timing of their death. In jurisdictions where assisted dying is permitted, including Canada and Australia, the majority of

people requesting an assisted death are also receiving palliative care (82.8% and 82.2% respectively).[6] [7]

Any person seeking an assisted death should be making a real choice. They should not choose an assisted death on the basis that they cannot access – or believe they cannot access – high quality end-of-life or palliative care services. Hence, it is envisaged that the report and proposition which be presented to the Assembly in early 2023 will ask Members to agree, in principle, that legislation permitting assisted dying should not be brought into force until the Assembly is satisfied that all Islanders can access good palliative and end-of-life services.

This will require information and evidence, about the quality and availability of these services, to be presented to the Assembly as part of a future debate on the appointed day act which will bring the assisted dying law into force.

An End-of-Life Partnership, led by Jersey Hospice Care, is currently developing an End-of-Life and Palliative Care Strategy identifying and addressing gaps in current provision. Publication is scheduled for Q4 2022. Additional funding is being sought via the 2023 Government Plan.

d. Health professionals – the law will provide that no health or care professional can be compelled to directly participate in the assessment, approval or delivery of an assisted death. The right of any person to conscientiously object and decline to particate does not, however, extend to obstructing the choice of a person who wishes to have an assisted death. This means that a care professional, who is providing care to a patient who wishes to seek information about assisting dying, will be required to refer their patient to the assisted dying service.

Professionals who do choose to participate in the assisted dying process must have access to support services that help them process and reflect on the emotions associated with assisting someone to die.

e. Assisted dying is not suicide or assisted suicide – the decision to commit suicide and the taking of your own life are lonely acts, often accompanied by mental and physical pain and fear. Suicide invariably leaves behind a legacy of irresolvable grief for loved ones. Assisted dying can be the exact opposite, it provides a safe, calm and considered environment in which a person – most often with the support of their loved ones – can end their life and associated suffering.

During the first phase of public engagement on assisted dying some people expressed concern that the introduction of assisted dying would lead to a rise in the rate of suicides, whilst others suggested the reverse; that the introduction of assisted dying would provide an alternative for some people currently considering suicide because of the suffering associated with severe health conditions.

[6] Second Annual Report on Medical Assistance in Dying in Canada 2020 - Canada.ca
[7] Voluntary Assisted Dying Review Board report of operations: January to June 2021 (safercare.vic.gov.au)

A number of studies have been undertaken to try to understand whether assisted dying results in increased rates of suicide, but these studies reach different findings.[8][9][10] Recent data shows that overall suicide rates have increased in recent years in some jurisdictions since the introduction of assisted dying (the US[11] and the Netherlands[12]) but declined in others (Belgium[13] and Canada[14]).

A recent UK Office of National Statistics bulletin shows that there are elevated rates of suicide in patients with severe health conditions. For example, for people diagnosed with chronic obstructive pulmonary disease (COPD) and chronic heart conditions, the suicide rate is two times higher than for the rest of the population with similar socio-economic characteristics.[15]

f. Family and friends - family members and close personal contacts will be supported throughout the process, including being supported to openly discuss their loved one's preferences and choices. Ultimately, however, the choice of an assisted death can only be made by the person requesting it. The family cannot request an assisted death, nor can they block the person's wishes.

[8] How does legalization of physician assisted suicide affect rates of suicide? - St Mary's University Open Research Archive (stmarys.ac.uk)
[9] Perma | jemh.ca
[10] The effect of assisted dying on suicidality: a synthetic control analysis of population suicide rates in Belgium | SpringerLink
[11] Suicide mortality rate (per 100,000 population) - United States | Data (worldbank.org)
[12] Suicide mortality rate (per 100,000 population) - Netherlands | Data (worldbank.org)
[13] Suicide mortality rate (per 100,000 population) - Belgium | Data (worldbank.org)
[14] Suicide mortality rate (per 100,000 population) - Canada | Data (worldbank.org)
[15] Suicides among people diagnosed with severe health conditions, England - Office for National Statistics

Section 3: eligibility criteria

13. In adopting P95/2021 in November 2021 the Assembly agreed, in principle, that assisted dying should be permitted where a person is:

    a. aged 18 or over, and
    b. a Jersey resident, and
    c. has a voluntary, clear, settled and informed wish to end their own life, and
    d. has capacity to make the decision to end to their own life, and
    e. 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, OR
    f. has an incurable physical condition, resulting in unbearable suffering that cannot be alleviated.

14. Whilst the majority of the eligibility criteria remains as per P95/2021, it is proposed that there are some changes to sub-paras 'e' and 'f' above to reflect the feedback received to date.

15. It is also proposed that the law will provide a broad Regulation-making power allowing the Assembly to amend the eligibility criteria or the assisted dying process (as described in Sections 5 and 6) in the event the Assembly deems it appropriate to do so in future.

Changes to sub-para "e'

16. It is proposed that sub-para 'e' is amended to provide that assisted dying should be permitted where a person:
    a. *has been diagnosed with a terminal **physical medical condition**, which is expected to result in unbearable suffering that cannot be alleviated **in a manner the person deems tolerable** and where the person is reasonably expected to die within six months*

    OR

    b. ***has been diagnosed with a physical medical condition that is neurodegenerative, which is expected to result in unbearable suffering that cannot be alleviated** in a manner the person deems tolerable **and where the person is reasonably expected to die within twelve months**;*

17. The term 'physical medical condition' is used in place of 'illness' for the purposes of clarity. A 'physical medical condition' includes all physical diseases, lesions, injuries, and disorders, but does not include mental illnesses.

18. Sub-para 'e' is also amended to clarify that any unbearable suffering which is expected to arise includes that cannot be alleviated ***'in a manner that the person deems tolerable'.*** This is to deal with scenarios in which there may be treatments which could

alleviate suffering, but those treatments may, in turn, give rise to other consequences that are not acceptable to the person. For example, an invasive, painful or debilitating short-term treatment which may alleviate long-term suffering to a degree but which the person does not consider tolerable. A person always has the right to choose to decline treatment – for example, a patient may decline chemotherapy because of the associated side-effects, even if it could potentially result in longer life expectancy.

19. Sub-para 'e' is further amended to provide for people who have a terminal neurodegenerative disease which, due to the nature of the disease, is likely to see a significant deterioration in quality of life and associated potential for unbearable suffering significantly before they reach the point of having six month's life expectancy. The introduction of 12 months for neurodegenerative diseases mirrors provision in Australia (New South Wales, South Australia, Tasmania, Victoria and Western Australia). As with terminal non-neurodegenerative conditions there must be an expectation that the person's condition will result in unbearable suffering that cannot be alleviated.

20. Doctors cannot be exact when predicting life expectancy as different people will have different disease progression trajectories. Doctors must, therefore, rely on their medical knowledge and their examination / assessment of each individual person when determining likely life expectancy. Hence the law will refer to the timeframe in which death is 'reasonably expected'.

21. The challenges associated with exact determination of life expectancy are recognised in other jurisdictions hence some, for example, Canada, do not provide a statutory timeframe, they simply state that death is 'reasonably foreseeable'. Whilst 'reasonably foreseeable' overcomes the challenges associated a statutory timeframe, it gives rise to other challenges i.e., what does 'reasonably foreseeable' mean?

Note: Criteria only apply to physical conditions

The criteria only apply to physical conditions and do not include mental or psychiatric illness, as per P95/2021. Conditions such as dementia, which are conditions of the brain as opposed to mental or psychiatric illness, would fall within the physical conditions criteria but only **if** the person with dementia also had decision-making capacity.

Example of mental and psychiatric illness which do not fall within the criteria include anxiety disorders (for example, obsessive-compulsive disorders and phobias); depression, bipolar disorder and other mood disorders; eating disorders; personality disorders; post-traumatic stress disorder; psychotic disorders, including schizophrenia.

Changes to sub-para 'f'

22. It is proposed that sub-para 'f' is amended to provide that assisted dying should be permitted where a person:

    a. *has an incurable physical medical condition* ***that is giving rise to*** *unbearable suffering that cannot be alleviated* ***in a manner the person deems tolerable****.*

23. This makes explicit that the person must currently be experiencing unbearable suffering, rather than being expected to experience unbearable suffering at a future date. If there was no explicit requirement to be suffering in the 'here and now' (as opposed to be suffering in the future) the criteria would be too broad and could include, for example, a person with Crohn's disease who may (or may not) experience suffering but not for many years.

    It should be noted that an incurable physical medical condition is not a terminal condition OR is not a condition from which a person would be reasonably expected to die within 6 months or 12 months. The Assembly decided, in principle, that assisted dying should be permitted in relation to non-terminal illness, for example, where a person has life changing injuries as a result of a car crash, which causes unbearable suffering but does not necessarily shorten their life expectancy This mirrors the assisted dying laws in Canada, Belgium, the Netherlands, Spain, Switzerland and Austria but is different to the laws in Oregon and other US states, Australia and New Zealand which only permit assisted dying where a person has a terminal illness.

24. It is also proposed that sub-para 'f' is amended to clarify that the unbearable suffering is that which cannot be alleviated ***'in a manner that the person deems tolerable',*** as per sub-para 'e'.

    For ease, where the person has a terminal physical medical condition, as per sub-para 'e', this will be referred to as 'Route 1 (terminal illness)*'*. Where a person is experiencing unbearable suffering but is not expected to die, as per sub-para 'f', this will be referred to as 'Route 2 (unbearable suffering)*'*. This distinction is made because the approval processes for Route 1 and Route 2 are different (see Step 5: approval process)

Other eligibility criteria

25. The other eligibility criteria remain as per P95/2021 and require the person requesting the assisted death to:
    a. be aged 18 or over; and
    b. be a Jersey resident; and
    c. have a voluntary, clear, settled, and informed wish to end their own life, and
    d. have capacity to make the decision to end to their own life

26. **Appendix 1: assessment of eligibility criteria** describes how all criteria will be assessed.

Note: Age limit

P95/2021 set out the further consideration would be given as to whether people aged under 18 years should be permitted to access assisted dying as the Citizen's Jury did not provide a clear majority recommendation relating to age.

The proposed age limit was raised during the Phase 1 public engagement process. Many participants did not support children accessing assisted dying as they were concerned that those aged under 18 may not have the maturity to make such a complex and serious decision. Some participants did, however, feel that under 18s should not be denied an option which would be afforded to adults. Of those who supported access to assisted dying for under 18s, most stated that if this were to be permitted it should only come into force once the law, and the associated practice, were well established.

The previous Minister for Home Affairs corresponded with the Children's Commissioner to establish her views on the matter. The Commissioner noted concerns regarding the introduction of assisted dying legislation for all, including under 18s, citing views previously expressed by UN rapporteurs and treaty bodies. For example, the concluding observations of the Human Rights Committee in the Netherlands in 2009.[16]

In light of this, it is proposed that the law should only provide for assisted dying for people aged 18 or over. It is recognised, however, that the law should allow for the Assembly, by Regulation, to lower the age limit if, at some point in the future, they determine it was the correct course of action.

Note: Jersey resident

For the purposes of the law, it is envisaged that Jersey resident will be defined as a person who has been ordinarily resident in Jersey for at least 12 months. The 12-month time limit will act as a barrier to 'death tourism'. 'Ordinarily resident' means a person who lives in Jersey and spends all their time here except for short visits abroad on business or holiday. It does not include people who temporarily live in Jersey for work or for study, or who are on holiday in Jersey.

The majority of people who participated in the Phase 1 public engagement process expressed the view that an assisted dying service should only be available to residents, and that Jersey should not become a destination for 'death tourism'. A minority felt it would be more equitable if Jersey provided for anyone who wanted an assisted death and others noted the potential financial benefits of providing assisted dying to non-residents.

[16] Refworld | Concluding observations of the Human Rights Committee : Netherlands

Application of eligibility criteria

27. The eligibility criteria must apply at the point at which a person, who has requested an assisted death, undergoes their first assisted dying assessment. (See Step 2: First assessment).

28. If the person does not meet all the eligibility criteria at the time of the first assessment, they cannot proceed through the rest of the assisted dying process. This does not preclude them from starting the process again should there be changes in their circumstances.

We recommend you answer these questions using the online survey.

Key questions on Section 3 – eligibility criteria

Life expectancy for neurodegenerative diseases (see paragraphs (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 12 months or less.

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?

Yes ☐
No ☐
Don't know ☐
Please tell us the reasons for your response:……

Key questions on Section 3 – continued

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:……

Section 4: assisted dying service

29. It is proposed that the Health and Social Services Minister ("the Minister") will establish an assisted dying service ("Jersey Assisted Dying Service") which will be managed and delivered by the Health and Community Services Department (HCS). In most other jurisdictions assisted dying services are also delivered by the public health system, Switzerland and Germany being the exceptions.

30. The Jersey Assisted Dying Service will be available free of charge to any person who meets all the criteria in law. This will be regardless of whether the assisted death takes place in a location other than an HCS facility.

31. The criteria will provide that, to be eligible for an assisted death, a person must have been ordinarily resident in Jersey for at least 12 months, immediately prior to making their first request. A person who has been ordinarily resident in Jersey for 12 months is also entitled to free HCS care under the terms of HCS's charging policy[17].

32. The requirement to have been ordinarily resident in Jersey for at least 12 months will apply to all people. A person who is, for example, Jersey born but has been living elsewhere cannot bypass the 12 month ordinarily resident criteria even if they are entitled to free health care under HCS's charging policy.

33. It is not intended that the Minister will facilitate the provision of a private assisted dying service – anyone who wishes to access the Jersey Assisted Dying Service will do so as a public patient. The law will, however, include a schedule to which other assisted dying providers may be added if the Assembly should deem it appropriate at some future point.

Delivery and assurance board

34. It is anticipated that the law will provide that a service delivery and assurance board will be established to deliver the functions set out below. The board may form part of, or be a sub-committee of, the Independent Health Board which is to be established (as announced by the Minister in August 2022[18]). Members of the Assisted Dying Service Assurance and Delivery Board may include:

    a. Non-executive Board members; independent Chair and independent advisor

    b. Executive board members; HCS Director General, Chief Nurse, Medical Director, Chief Pharmacist, Director of Mental Health & Adults Social Care and Chief Allied Health Professional

[17] P Resident and Non resident Charging Policy 20140829 MM.pdf (gov.je)
[18] Independent Health Board to be established in response to hospital review (gov.je)

c. Representatives from services that provide care to people who are at end-of-life, for example; hospice, care homes and home care providers.

35. Roles and responsibilities for a Jersey Assisted Dying Service:

Minister

1. Receives assurance from the Board that:
   - the Medical Director is held to account for clinical governance (i.e., the assisted dying service is safe, that risk is managed, that standards of care are met, and the quality of care provided by the service is continuously being improved)
   - the Director General is held to account for corporate governance (i.e., that the service is well led, directed, and controlled ensuring fair access to the service and value for money for the taxpayer)

Board

1. Oversee establishment of the Jersey Assisted Dying Service, including development of training programme, plus service and clinical protocols
2. Ensure robust clinical governance
3. Oversight of service safety and quality, through continuous monitoring of the service
4. Development of competencies frameworks for all involved professionals
5. Oversight of the management and response to complaints and / or potential patient safety concerns related to the service
6. Provide assurance to the Minister and the public about patient experience, clinical safety and service quality

HCS

1. Accountable for service development and delivery
2. Accountable for clinical standards and safety, plus continuous improvement
3. Employs Care Navigators
4. Engages staff involved in service delivery and ensures their performance within the Board's competencies frameworks
5. Dispenses the substance used in AD

Jersey Assisted Dying Service

36. The Jersey Assisted Dying Service will:

a. provide a point of contact for anyone who wants information about assisted dying or is considering requesting an assisted death

b. support people to navigate the assisted dying process

c. support the loved ones of people who have requested an assisted death

d. coordinate and deploy the professionals engaged in the assisted dying process

37. HCS will engage the professionals required to deliver the Jersey Assisted Dying Service. This may be on a contract or employment basis, and may include:

a. HCS employees

b. HCS bank staff

c. locums and agency staff (this many include on-island and off-island professionals)

d. professionals on special contracts (for example, HCS may contract local GPs to fulfil any of the roles described below).

38. HCS will ensure that all professionals engaged in the Jersey Assisted Dying Service meet the relevant competency framework developed by the Assurance and Delivery Board.

Note: Staffing

It is possible that HCS will not be able to recruit or contract the staff needed to deliver the Jersey Assisted Dying Service. In the event this were to happen, whilst assisted dying would be permitted in law, there would be no service and hence people could not have assisted deaths in Jersey.

39. Due to the nature of the workforce in Jersey there is a need to ensure flexibility in the deployment of professionals engaged in the assisted dying process. Therefore, a doctor could be deployed / contracted to undertake different roles, for example a GP could act as a Coordinating Doctor for person A and as the Independent Assessment Doctor for person B.

40. The specific 'assisted dying practitioner' roles to be undertaken in relation to assisted dying – which are in addition to any other nursing, medical and care support provided to the person - will include:

a. **Care Navigators** – non-clinical staff who will: support the person requesting an assisted death (and their family / loved ones), ensuring that the assessment and approval process is focused on the person and their wishes; support the Coordinating Doctor to coordinate the whole process; provide support and information to the general public and health and care professionals

b. **Coordinating (first assessment) Doctor** – the doctor who undertakes the first assessment of the person who has requested an assisted death and coordinates the whole assessment process

c. **Independent Assessment Doctor** – the doctor who undertakes the second assessment of the person who has requested an assisted death

d. **Second Opinion Doctor** – the doctor who undertakes an additional first or second assessment, if requested by the person (see paras 116-123)

e. **Pharmacy Professionals** – pharmacists and pharmacy technicians who will prepare and dispense the substance used in assisted dying

f. **Administering Practitioner** – the doctor or nurse who will directly administer the substance used in assisted dying or support the person to self-administer.

41. The Coordinating Doctor, the Independent Assessing Doctor (and Second Opinion Doctor, where relevant) – are collectively referred to as "Assessing Doctors". They will assess the person who has requested an assisted death to determine if they meet the statutory criteria.

42. "Involved professional" is the collective term used to describe the professionals involved in the assisted dying process (i.e., all those people whose role is described in paragraph 40 above). A description of functions to be delivered by the involved professionals is set out in Section 5 and 6.

43. "Other attending practitioners and carers" is the term used to describe other service providers who may be involved in care or treatment of the person (for example, a domiciliary care provider, a community or hospital nurse, a GP). Those providers will not be directly involved in the assisted dying request, assessment, approval or administration process, except for:

    a. where they have been asked by an Assessing Doctor, Tribunal or Court to:
        - undertake a supporting assessment, or
        - provide information or advice to support an assessment or determination

    b. they agree to be involved in supporting the administration process (for example, supporting the Administering Practitioner to set up intravenous tubes).

44. Other attending practitioners and carers may, or may not, be informed of the person's request for an assisted death. It will be for the person to determine whether they consent to other attending practitioners or carers being informed.

45. In addition to the roles described above, there will be a requirement, in some cases, for other professionals to be engaged in assisted dying assessment process by undertaking supporting assessments. For example, social workers may be asked to review the family circumstances of a person who has requested an assisted death, or

there may be a requirement for a capacity or psychological assessment. (See Supporting opinions/assessments, paras 157-167)

Conscientious objection

46. 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*.' A right to conscientious objection ensures that people are free to act in accordance with their own personal beliefs about assisted dying.

47. In accordance with the Assembly's decision, the Law will explicitly provide that no person can be compelled to *directly* participate in the assessment, approval or delivery of an assisted death but, in drafting the law, consideration will need to be given as to which tasks or activities constitute direct participation in assisted dying, as opposed to tasks which are ancillary to the provision of an assisted death service.

48. Jersey Law currently sets out that a person can refuse to participate in the termination of a pregnancy if they conscientiously object. This is provided for under Article 5 of the Termination of Pregnancy (Jersey) Law 1997 which mirrors UK's 1967 Abortion Act. In 2014, the Supreme Court ruled that the conscientious objection clause in the Act should be interpretated as being 'narrow' in scope as opposed to 'wide' scope i.e., that participation in termination of pregnancy means "actually taking part" or performing the tasks involved in the course of treatment[19] which would broadly include the administration of drugs to induce labour, the medical and nursing care associated with labour and giving birth but would not include, for example, the ordinary nursing or pastoral care of a patient, the associated administrative tasks or the hospital managers who determine how the service is organised.

49. It is proposed that the assisted dying law provides for a conscientious objection clause which relates to *directly* participating in the assisted dying assessment and delivery process - i.e., it is framed to mirror the existing termination of pregnancy law. This is on the basis that, if the intent of the law is to provide a safe, compassionate and accessible assisted dying service, any objection clause that is cast too 'wide' could potentially have the effect of negating the underlying policy intent (i.e., the service could not be delivered if ancillary tasks were not undertaken). This would broadly mean that staff and service providers:

    a. could refuse, on the basis of conscientious objection, to:

        - support a person to access the assisted dying service, including providing them advice, counselling or advocacy support

[19] *Greater Glasgow Health Board (Appellant) v Doogan and another (Respondents) (Scotland) (supremecourt.uk)

- undertake any of the specified roles (i.e., refuse to act as Care Navigator, Coordinating Doctor, Independent Assessment Doctor, Pharmacy Professional or Administering Doctor or Nurse)
- be present at the time of administration of the assisted dying substance, or directly support the administration
- sit on the Tribunal or directly support the Tribunal (for example, act as the Tribunal Secretary)

b. could not refuse, on the basis of conscientious objection, to carry out tasks which are within the normal duties of their work and which are not directly related to the assessment or delivery of an assisted death, for example:

- providing usual nursing, medical or personal care to a person who happens to have requested an assisted death (for example, a care home could not refuse to care of a resident because that resident wants an assisted death; an ambulance or patient transport driver could not refuse to transport a patient to an assisted dying appointment)
- related administrative tasks (for example, providing patient records to an Assessing Doctor, booking appointments for additional assessments, undertaking residency checks)
- related management or governance tasks (for example, refusing to act as a Responsible Officer for an assisted dying doctor, or refusing to undertake financial planning tasks associated with the delivery of the service)
- delivery of equipment or medical supplies that may be used for the purpose of an assisted dying assessment or the delivery of an assisted death.

50. In scoping the law consideration will need to be given to whether the matters below constitute direct involvement:

a. 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, for example:
- information and 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
- social worker providing advice on family circumstances

b. permission from the provider of a care facility to allow a resident to have an assisted death on their premise (for example, in a care home or hospice)

➢ **Note:** at the end of this section there are a series of questions about which tasks should fall within a conscientious objection clause.

51. If a task is within the agreed scope of a conscientious objection clause, a care professional can refuse to directly participate. However, in doing so, they must not:

a. treat patients who wants an assisted death unfairly

b. deny patients access to appropriate medical treatment or services

c. cause distress to the patient

52. The law will require the Minister to bring forward guidance setting out how care professionals who object to assisted dying should interact with people who want information about an assisted death or who have requested an assisted death. This guidance will stipulate that the care professional:

a. must provide them the contact details of the Care Navigators

b. must inform the person of their conscientious objection

c. must not express their personal beliefs on assisted dying to the patient in a way that exploits their vulnerability or are likely to cause them distress.

53. Where the care professional is registered with a professional registration body, they will need to operate in accordance with any practice guidance that the body has in place with regard to conscientious objection (for example, the GMC's guidance on personal beliefs and medical practice[20]), as failure to do so may result in them being subject to disciplinary proceedings by the professional registration body.

54. Guidance will be brought forward by the Minister that will apply to:

a. health and care professionals who are not registered with professional registration bodies OR are registered with professional registrations bodies that do not have practice guidance / rules on conscientious objection, and will provide them with a framework for operating within, and

b. health and care professionals who are registered with professional registration bodies that do have practice guidance / rules on conscientious objection, and this guidance will accord with (as opposed to contradict) the guidance set out by their professional registration body.

55. For the purposes of clarity, it will not be an offence not to comply with the guidance issued by the Minister, but failure to comply may result in action or investigation by a professional registration body (as failure to comply with the Ministerial guidance may be tantamount to failure to comply with professional standards) or an employer.

[20] https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice

Note: conscientious objection and premise owners / operators
As set out in para 50 above, consideration needs to be given as to whether the scope of the conscientious objection clause will permit a premise owner / operator to refuse to allow for an assisted death on their premises (for example, a care home provider not to permit a resident to have an assisted death in resident's room in their care home). Regardless of whether it does, or does not, fall within the scope of the conscientious objection it is envisaged that, in most cases, premises owners / operators will respect the wishes of their residents or patients, and will take the view that it is in the best interests of that person to support their end-of-life wishes.

If a premise owner / operator did refuse to allow an assisted death on their premises, the Jersey Assisted Dying Service would liaise with the person to identify a suitable alternative location.

Opt-in registration

56. The law will set out the arrangements via which professionals who want to be directly engaged in providing the Jersey Assisted Dying Service can 'opt-in' to do so either as:

    a. Assessing Doctors
    b. Administering Practitioners
    c. Pharmacy Professionals.

57. The details of the opt-in process are subject to further discussion with Jersey Care Commission (JCC) and UK professional registration bodies but are likely to require entry onto a register held by the Jersey Assisted Dying Service. The law will provide for opt-in arrangements including:

    a. training and qualification requirements (see below)
    b. registration application procedures
    c. suspension and cancellation of registration procedures
    d. the powers and duties of the registering body to share information with other relevant bodies (for example, UK professional registration bodies, States of Jersey Police)
    e. arrangements for publication of the register.

58. In determining arrangements for publication of the register, consideration needs to be given as to benefits of putting the names of involved professionals in the public domain (i.e., openness and transparency) versus the potential risks (i.e., protecting the privacy of practitioners in a small island community).

59. In the event that the names of involved professionals are published via a register, the law will provide that the names of the individual professionals involved in any individual assisted death cannot be made public – i.e., there will be no information in the public domain about the named professionals who are assisting, or who assisted, a specific

person to have an assisted death. (Note: This will also be the case if it is determined that names in the register should not be in the public domain.)

Training and qualifications

60. The training and qualifications required to be an assisted dying practitioner will be prescribed by Order of the Minister.

61. A bespoke training programme will be developed by the HCS Delivery and Assurance Board for:

    a. Assessing Doctors
    b. Administering Practitioners
    c. Pharmacy Professionals
    d. Care Navigators.

62. The training will cover, in detail:

    a. the requirements, duties, competencies and obligations associated with each role
    b. an overview and understanding of all the different roles within the assisted dying process
    c. the assisted dying legislative provisions
    d. the assisted dying guidance and all associated clinical and service provision protocols
    e. specific training on assessing eligibility and administering an assisted death
    f. practitioner safety and wellbeing.

63. The training will be valid for a period of 3 years, after which, practitioners will be required to undergo refresher training.

64. The roles of Coordinating Doctor and Independent Assessment Doctor will be undertaken by a doctor who must:

    a. be registered with the JCC to work in Jersey, and more than 12 months post full GMC registration
    b. have opted-in to work as assisted dying practitioner
    c. have completed assisted dying training; and
    d. be able to demonstrate the skills outlined in the assisted dying practitioner competencies framework which will be developed and published by the Delivery and Assurance Board.

65. The Coordinating Doctor and the Independent Assessment Doctor are not required to be an expert / specialist in the medical condition of the persons they are assessing but, as set out in paras157-167 below, they must seek opinion for experts as required.

66. The role of Administering Practitioner will be undertaken by a doctor or a nurse who must:

    a. be registered with the JCC to work in Jersey, and more than 12 months post full GMC/NMC registration
    b. have opted-in to work as assisted dying practitioner
    c. have completed assisted dying training; and
    d. be able to demonstrate the skills outlined in the assisted dying practitioner competencies framework which will be developed and published by the Delivery and Assurance Board.

67. The role of Pharmacy Professionals will be undertaken by a dispensing pharmacist or pharmacy technician who must:

    a. be registered with the appropriate professional registration body in Jersey (currently the Chief Pharmacist)
    b. has opted-in to work as assisted dying Pharmacy Professional
    c. have completed the Pharmacy Professionals assisted dying training
    d. be able to demonstrate the skills outlined in the assisted dying practitioner competencies framework which will be developed and published by the Delivery and Assurance Board.

68. It is envisaged, subject to further discussion with professional stakeholders, that law may provide that:

    a. a doctor may not opt-in as an assisted dying practitioner if, at the point of doing so, the doctor does not have a responsible officer for the purpose of GMC revalidation. A responsible officer is a doctor who helps to ensure the conduct and performance of doctors working in their local area and who makes recommendations to the GMC about their fitness to practice and whether they should be revalidated as a doctor

    b. the Jersey Assisted Dying Service in overseeing the opt-in process (see para 56-59) must, before allowing that doctor to opt-in, seek assurance from that responsible officer that they are not aware of any concerns that may impact on their recommendations to the GMC about the doctor's engagement with their annual appraisal process and subsequent revalidation and, if there are, the opt-in body must not register that doctor as an assisted dying practitioner

    c. the responsible officer must immediately inform Jersey Assisted Dying process if the responsible officer becomes aware of any significant concerns related to a doctor who is opted in as assisted dying practitioner.

<u>Support systems</u>

69. It is known from other jurisdictions that supporting someone to end their own life has a direct impact on the professionals involved, even though those professionals are

committed to supporting people in their choices. HCS must, therefore, ensure that support services are available to help professionals process and reflect on the emotions associated with assisting someone to die. It is envisaged that this will include:

a. access to psychological support

b. debriefing and collegial support / networking sessions.

70. The support systems should be available to both involved professional (i.e., those who are directly involved in the assisted death) and other attending practitioners and carers (i.e., those who are caring for someone who chooses to have an assisted death).

71. Support systems should also be available to family and friends during the assisted dying process and after an assisted death. The Care Navigator will signpost people to existing bereavement support services. Based on the experience of other jurisdictions, bereaved families who have experienced an assisted death may wish to be supported to meet together to share their experiences. The Jersey Assisted Dying Service should look to facilitate this.

Note: Other providers

P95/2021 required GoJ to make arrangements for the provision of an assisted dying service but did not specify that the service should be delivered by GoJ. Consideration was, therefore, given to other potential options for delivery, short summaries are provided below:

- **Commissioning for an off-island external provision:**
  would go against Assembly decision to make provision for an 'assisted dying service in Jersey'.
- **Commissioning off-island external providers to operate in Jersey:**
  majority of jurisdictions operate assisted dying service provision within their national health service (i.e., no external providers). The exception being Switzerland (& Germany) where service is provided by not-for-profit organisations (NPOs), including Dignitas. These NPOs operate in jurisdictions without explicit legislative and regulatory frameworks for assisted dying provision, and therefore are not experienced in operating within the context proposed for Jersey.
- **Commissioning on-island external providers to operate in Jersey:**
  currently no providers on Island with expertise or experience.

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 ☐

No, it should be paid for ☐

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 ☐

No, they should not have the right to refuse ☐

Don't know ☐

Please tell us the reasons for your response…….

Key questions on Section 4 – continued

Conscientious objection -Premises owner right of refusal (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 ☐

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 ☐

Don't know ☐

Please tell us the reasons for your response…….

Public or private register (para 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?

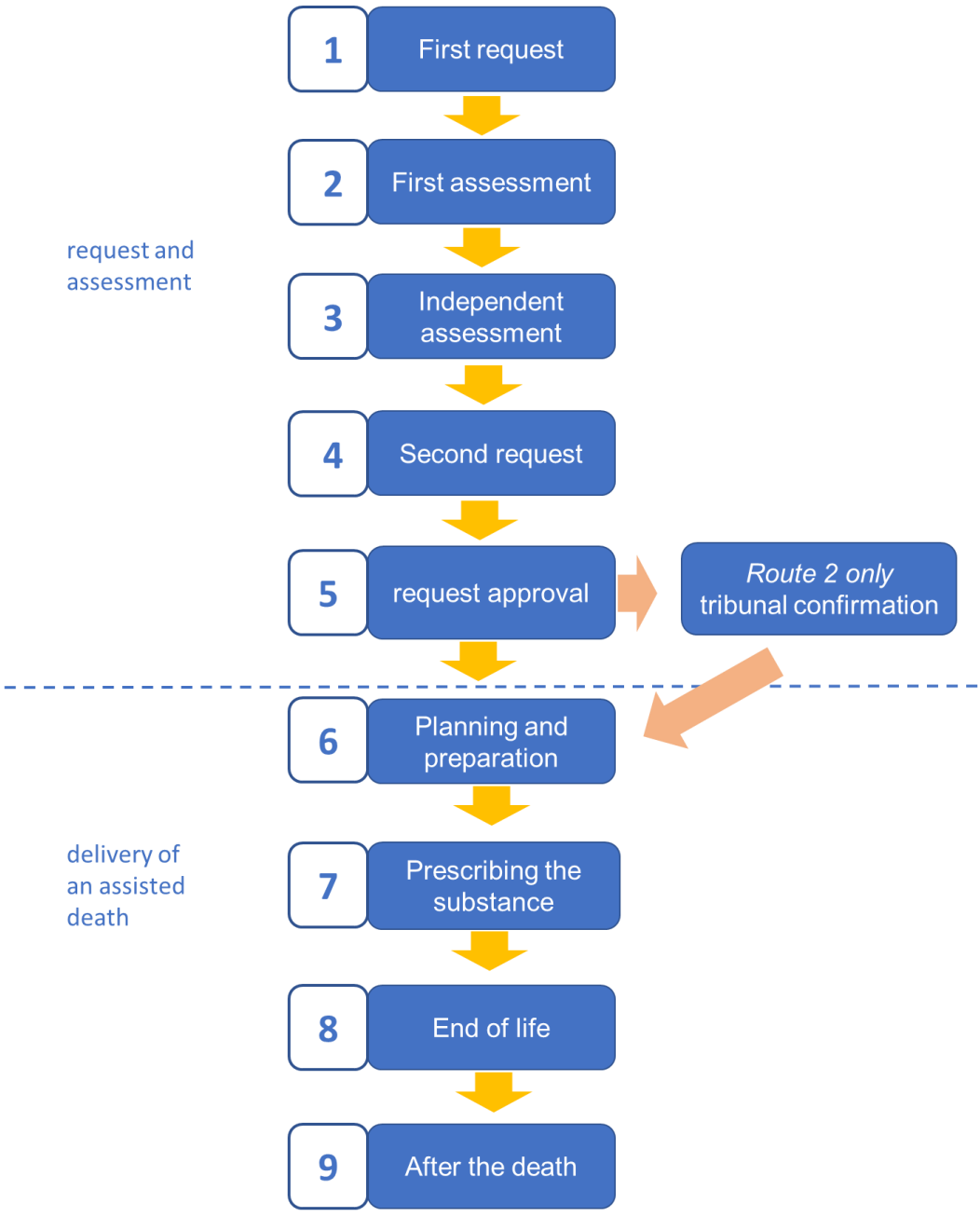
Yes ☐

No ☐

Don't know ☐

Please tell us the reasons for your response…….

Section 5: assisted dying process – request and approval



Proceeding through the steps / timeframe

72. The assisted dying process includes 9 distinct steps. Step 1 to Step 5 are part of the request and assessment process; Steps 6 to 9 are part of the delivery of an assisted death; Step 9 takes place after the assisted death.

73. The person requesting the assisted death is in control of the process:

a. each step in the process can only be initiated by the person expressing a wish to proceed with that step

b. the person may withdraw their request at any point in the process (see paras 137-142; withdrawal of request).

74. The law will set out minimum timeframes for the assisted dying process. P95/2021 set out that assisted dying should be subject a period of reflection. Where a person meets the Route 1 (terminal illness) criteria the proposed minimum timeframe is 14 days. Where a person meets the Route 2 (unbearable suffering) criteria the proposed minimum timeframe is 90 days.

75. The timeframe will, in both cases, be from the date on which the person makes their first formal request (Step 1) for an assisted death, to the date on which they are assisted to end their life (Step 8).

76. The statutory minimum timeframes will help to ensure that the person who has requested an assisted death has had time to reflect on their decision i.e., help safeguard against hasty decision making or fluctuating wishes for an assisted death:

a. **a 14-day minimum timeframe** is proposed for Route 1 (terminal illness), on the basis that 14 days allows sufficient time for all assessments to be completed, and time for the Assessing Doctors to be confident that the request for an assisted death is enduring, whilst not unduly extending any suffering and uncertainty for the person. This is in line with legislation in the US, Spain, Austria and the proposals set in the UK assisted dying Bill and Scottish consultation.

In Western Australia, there must be a period of 9 days between the first request and final request, unless the assessing doctor is of the opinion that the person is likely to die, or to lose decision-making capacity in relation to voluntary assisted dying before the end of the 9-day period.

In Canada, Belgium, the Netherlands and New Zealand there is no minimum timeframe in law. The rationale being that by the time a person makes a formal first request, they have already carefully considered their decision and the minimum timeframe can prejudice those who request an assisted death when they are already very close to the end of their life. In New Zealand, although there is no statutory minimum timeframe, the Ministry of Health notes that the expected minimum timeframe for all stages of the process to be completed in practice would be 4 days in a hospital setting and 15 days in a community setting (private residence).[21]

b. **a 90-day minimum timeframe** is proposed for Route 2 (unbearable suffering) due to the gravity of the decision made – a person who meets Route 2 (unbearable suffering) criteria does not have a terminal illness, therefore a decision to end their life is altering the trajectory of their life in a way that is

[21] 0ef8505fb4c7a82902a17f262f5f1d850a1057c2 (www.parliament.nz), p.46

fundamentally different from a person who has a terminal illness. A three-month assessment period allows time for additional assessments and opinions to be sought and confirmation that the request is enduring, as well as time to ensure that all other options for the person have been explored in terms of treatment, pain relief and the provision of any other services that may be able to alleviate the person's suffering. This is in line with legislation in Canada and Austria.

77. The law will provide that the Assembly may increase or decrease the maximum timeframes by regulation.

78. There will be no maximum timeframe set out in law on the grounds that;

    a. the person must be able to dictate the pace at which they move through the process (beyond the minimum timeframes); and

    b. in some cases, there will be a requirement to involve specialist professionals and access to those professionals may be limited.

79. The Minister will, however, publish services standards including target maximum timeframes for the Jersey Assisted Dying Service.

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)

Key questions on Section 5 (part 1 of 3) - continued

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 minimum 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……

Pre-process steps: information and referral to the Jersey Assisted Dying Service

80. The Jersey Assisted Dying Service will work to ensure people have access to information that supports them to make informed decisions about end-of-life matters. This will include information about assisted dying, palliative care and end-of-life care and related matters, such as care funding and financial planning. This will include:

    a. a dedicated website

    b. a telephone and email advice line

    c. information leaflets for members of public

    d. advice and guidance for professionals on matters such as:
        - having 'open conversations' with patients / clients about assisted dying
        - referring patients / clients who are considering an assisted death
        - opting in as an assisted dying practitioner.

81. The service will provide information about assisted dying and will also support people to access information on other end-of-life matters through referral to other providers.

82. The assisted dying information will be available in accessible formats, including other languages, formats accessible to those with sight and hearing impairments, and easy read. The service will work with other providers, for example, GPs to ensure they have information 'on hand' to provide to their patients where those patients inquire about assisted dying.

83. A person who is considering an assisted death may make direct contact with the Assisted Dying Service, or they can be referred by another professional, but referral by another professional is not a requirement.

84. As set out above, the service will provide advice and guidance to support professionals to have 'open conversations' with their patients / clients about assisted dying. Assisted dying should never be 'recommended' but health and care professionals do need to be able to engage in open and informed conversations about end-of-life options, which may include assisted dying. There is a balance to be struck between the risk that a patient may feel that assisted dying is being suggested to them as a preferred option, and the risk that a patient is unable to have an informed discussion with a trusted professional, or access to information is inequitable.

85. For the purpose of clarity, the law will 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. Instead, guidance and training will set out when such conversations are appropriate, and what information should be provided in these conversations.

86. This is in line with Canadian legislation. In New Zealand and certain Australian states, the law actively prohibits all or certain health professionals from initiating any discussion which can give rise to two key disadvantages:

    a. it can generate uncertainty and confusion amongst professionals as to when the topic is being raised by a patient or not, which results in a reluctance to discuss the topic openly

    b. it creates an imbalance in access to information for certain minority groups – particularly those with English as an additional language and those with additional communication support needs.

87. The law will not prohibit professionals from raising the subject of assisted dying, nor will it place an explicit requirement on relevant professionals (for example, those working in GP surgeries or hospital departments) to tell people about assisted dying. Whilst an explicit requirement to tell people may improve equity of access to information, it may also have unintended consequences, particularly around the sensitivity and nuance as to when is the best time for a conversation about assisted dying. As per para 84 above, it is proposed that guidance is developed for all health and care professionals to support them to manage conversations around assisted dying on an individual level.

88. When a person is referred to the Assisted Dying Service or self-refers to the service, they will have an initial conversation with a Care Navigator who will provide them with the information they need to consider their options. This conversation may be a one-off conversation or may take place over a period of time.

89. If the person tells the Care Navigator they wish to formally start the process of accessing an assisted death, the Care Navigator will arrange for a Coordinating Doctor to meet with the person to commence Step 1: first formal request.

Step 1: first formal request

90. The first formal request starts the assisted dying process and signifies a shift from informal consideration of assisted dying to formal intent of a person to initiate the assisted death assessment process.

91. The first request can be made in writing (including via electronic communication – in this instance it must be confirmed that the request comes from the person), verbally or in another away, such as gestures, unlike the second request which must take the form of a written declaration. It must, however, be clear and unambiguous.

92. The first formal request must be made by the person to the Coordinating Doctor.

93. It may be that, in practice, the person makes an informal request to:

a. the Care Navigator who will, in many cases, already be in contact with the person. If this happens, the Care Navigator will arrange for a Coordinating Doctor to speak with the person so that they may make a first formal request

b. family and friends – publicly available information will direct Islanders to the Jersey Assisted Dying Service to support to person to make a formal request

c. another health practitioner or care provider:

- where that person is a Jersey assisted dying doctor they may offer to act as the Coordinating Doctor, if the person wishes them to so act (for, example if the person makes an informal request to their GP who is Jersey assisted dying doctor)

- where the health practitioner or care provider is not a Jersey assisted dying doctor, or is a Jersey assisted dying doctor who does not offer to act as Coordinating Doctor, they must notify the Assisted Dying Service in accordance with guidance.

The guidance will set out how other providers should refer a request to the Assisted Dying service if a request is made to them, which should be done within 2 working days, including where the provider conscientiously objects to assisted dying. Whilst there is no obligation to directly support or participate in the assisted dying process, health professionals must not deny patients access to the service (see also conscientious objection).

94. The Coordinating Doctor must complete:

a. Coordinating Doctor declaration form setting out:
- if they will be, or believe they maybe a beneficiary under the will of the person, or if they may in any other way receive a financial or other material benefit resulting from that person's death; or
- if they know or believe that they are connected to the person in any other way that would affect their objectivity

b. first request form whilst the first request may be verbal / non-written, the details of the request must be captured, in writing, by the Coordinating Doctor.

95. The Coordinating Doctor declaration form and first request form will be prescribed by the Minister by Order.

96. The person who makes a first request may decide at any time not to continue the request and assessment process. The process ends if the person decides not to continue the process. If the person changes their mind at a later date, they may start the process again by making a new first request.

97. Although the first request may be verbal / non-written, the details of the request must be captured in the first request form.

Step 2: first assessment

98. A first assessment will be undertaken by the Coordinating Doctor who must be a Jersey assisted dying practitioner.

99. Before the assessment begins the person must confirm to the Coordinating Doctor that they wish for the assessment to be undertaken. The first assessment may take place immediately after the first formal request or at a later date, depending on the wishes of the person.

100. The purpose of the first assessment is:

a. for the person to fully explore, in dialogue with the doctor:
   - their request for an assisted death and the fears, anxieties and suffering that gives rise to that request
   - other care / treatment options and other ways to alleviate their fears and anxieties (for example, they may have financial concerns or concerns about being a burden on family carers)

b. for the doctor to determine if the person meets the eligibility criteria in law and, if so, on the grounds of
   - **Route 1** (terminal illness); i.e., they have a physical medical condition, which is expected to result in unbearable suffering that cannot be alleviated and are reasonably expected to die within six months or 12 months or
   - **Route 2** (unbearable suffering); i.e., they have an incurable physical medical condition, that is giving rise to unbearable suffering that cannot be alleviated in a manner that the person deems tolerable

c. to consider the decision-making capacity of the person.

101. The first assessment will include consideration, by the doctor, of:

a. the person's medical history and prognosis

b. care and treatment options and likely outcome of care and treatment including ensuring the person is:
   - informed about counselling services, mental health and disability support services, community services, hospice and palliative care services; and
   - offered consultations with the professionals providing such services or care

- if the person is determined to be eligible under 'Route 2' (unbearable suffering) this part of the assessment is likely to take a significant amount of time and may involve multiple consultations for the assessing doctor to be satisfied that all options and changes to circumstances that could alleviate the person's suffering have been explored with the person.

c. the person's wishes and preferences in relation to the assisted dying process, options and risks including:
   - options to self-administer or have assisted dying substance administered; and which of these options may be appropriate for the person
   - potential risks of self-administering or being administered assisted dying substance for the purposes of causing death
   - that the expected outcome of self-administering or being administered assisted dying substance is death
   - the request and assessment process, including the requirement for a written declaration signed in the presence of a witness
   - the location of their assisted death
   - involvement of their friends and family
   - whether they wish to provide:
     - confirmation of consent to proceed (see para 143-146) and / or
     - a waiver of final consent (Route 1 only) (see para 147-156) and / or
     - an advanced directive, refusing resuscitation or similar emergency life-saving interventions.

102. The Coordinating Doctor will:

a. remind the person of the option to withdraw their request at any point during the process (see withdrawal of request), and that they must confirm their wish to proceed at each step (i.e., the pace and progress of the process is driven by the person, not by the Assisted Dying Service)

b. encourage the person to talk to their family and friends about their request

c. support the person to determine whether they want other attending practitioners and carers to be informed of their wishes.

103. The Coordinating Doctor must be satisfied that the person:

a. has understood the information discussed during the assessment

b. meets the eligibility criteria in law (age and residency-status will be pre-assessed):
   - is aged 18 or over
   - has been ordinarily resident in Jersey for at least 12 months

- has a voluntary, clear, settled and informed wish to end their own life, which includes being satisfied that the request is made in absence of any undue pressure or coercion by any other person
- has decision-making capacity
- has a terminal illness and is reasonably expected to die within 6 months (or 12 months if a neurodegenerative illness); OR
- has a physical condition that is giving rise to unbearable suffering that cannot be alleviated in a manner that the person deems tolerable.

104. The proof of residency check will be undertaken by the HCS team that currently deals with eligibility matters but the Coordinating Doctor must confirm they are satisfied these checks have been undertaken. To assist, the person will be asked to consent to the HCS team contacting any relevant GOJ department in order that the department may provide supporting information. The law will also provide that the relevant department may share information surrounding age or proof of residential status with the Assisted Dying Service.

105. If the Coordinating Doctor is unable to determine matters relating to:

    a. the person's illness, health condition, prognosis, life expectancy and treatment options, or

    b. their decision-making capacity

    they *must*, providing they have the person's consent, seek the opinion of another relevant professional with appropriate skills and training to support the Assessing Doctor to make a determination.

106. The relevant professional may be asked, for example, to:

    a. undertake an assessment of the person

    b. review the person's medical notes and / or treatment and care plan

    c. provide generic professional advice and opinion.

107. If the Coordinating Doctor is unable to determine matters relating to the nature of the person's wish (i.e., that their request for an assisted death is voluntary, settled and informed) they *must*, providing they have the person's consent, seek input from other third persons that they deem relevant such as family and friends.

108. Whilst they *must* seek input if they are unable to make a determination, they may also seek any other input or advice if it is helpful to their determination, for example, advice from law officers.

109. See paras 157-167 on *Supporting opinions / assessments*

110. As part of the first assessment the Coordinating Doctor will complete a first assessment report form, the details of which will be prescribed by Order by the Minister.

Post first assessment

111. The Coordinating Doctor:

a. will inform the person of their determination which may be done with input from the Care Navigator

b. may, in discussion with the person, refer them to additional support services

c. will provide a copy of the completed first assessment report form to the assisted dying review committee (see para 324-328) for oversight and reporting purposes.

Does not meet criteria on grounds of residency or age

112. Where it is found that the person does not meet the criteria on grounds of age, they cannot make a further first request until they are aged 18 or over.

113. Where it is found that the person does not meet the criteria on grounds of residency, they cannot make a further first request until they have been resident for at least 12 months.

Where a person contests that they meet the residency criteria (i.e., they claim they have been resident in Jersey for 12 months or more) despite being initially assessed as not meeting those criteria, the HCS team will undertake further proof of residency checks. If the person is then found to meet the residency criteria, they may proceed to the next stage. If they are still not found to meet the residency criteria – but claim that they do - they may appeal to the Court (see appeals).

Does not meet criteria on other grounds

114. If the person is assessed as not meeting the criteria by the Coordinating Doctor on other grounds the assisted dying process will stop unless the person seeks a second opinion assessment.

115. The law will provide that the person is entitled to one second opinion assessment (whether at Step 2 first assessment or Step 3 second assessment) from an independent “Second Opinion Doctor” except where the grounds for not meeting the criteria relate to age or residency status, in which case there are no grounds for a second opinion. An Second Opinion Doctor is an assessing doctor who has not been involved in the person’s request.

116. A second opinion may only be requested by the person. A third person – whether they are a family member or an attending practitioner or carer - cannot request a second opinion on the grounds that the third person does not agree that the person meets or does not meet the criteria. Where a third party has a concern, they should raise that concern with the Coordinating Doctor who will be required, by law, to give due consideration to that concern. If the third person is not satisfied that their concern has been given due consideration, they may make a complaint (See Section xx).

117. If the person is deemed at Step 2 as meeting the criteria by the Second Opinion Doctor:

    a. they may progress to the next step in the process which is assessment by the Independent Assessment Doctor (Step 3)

    b. the person and the Coordinating Doctor will need to jointly consider if the Coordinating Doctor should continue to act in that role or whether another professional will need to take on the role, for example:
        - the Second Opinion Doctor
        - an entirely different Assessing Doctor.

118. This decision will depend, in part, on whether the Coordinating Doctor agrees with the Second Opinion Doctor that the criteria are met.

119. If the person is found by a Second Opinion Doctor not to meet the criteria at Step 2, the assisted dying process will stop.

120. If a person who is found not to meet the other criteria at this stage (whether or not they have requested a second opinion) wishes to make another first request on the grounds that their circumstances have changed, a Coordinating Doctor has the right to refuse this new first request, unless they believe the changes to the person's circumstances are such that they will now be eligible for an assisted death. The Coordinating Doctor may make this decision following a review of the person's medical notes.

121. It may be difficult for a person seeking to access assisted dying to accept that they are not eligible. Following the decision, the person may continue to be supported by the Coordinating Doctor or the Assisted Dying Service, particularly in relation to onward referrals for additional support.

<u>Meets criteria</u>

122. If the person is deemed to meet the criteria (whether by the first Coordinating Doctor or the Second Opinion Doctor) the Coordinating Doctor must ensure that:

    a. it is established if the person wishes to proceed to a second assessment (Step 3)

b. the Independent Assessment Doctor is informed and provided the completed first assessment form (and the second opinion assessment form if relevant) plus any supporting documents in order that they may undertake the second assessment

This task will generally be completed by the Care Navigator under the direction of the Coordinating Doctor.

123. The Coordinating Doctor (and / or the Second Opinion Doctor) may share information with the Independent Assessment Doctor as required, but the Independent Assessment Doctor must make an independent assessment and must separately determine if the person is eligible for an assisted death before the person makes their second request (Step 4).

Matters relevant to all steps

Complaints / safety concerns

124. HCS must bring forward an assisted dying complaints policy to ensure there is a robust process in place to investigate and response to:
    a. service standard complaints
    b. safety concerns.

125. Given the nature of the assisted dying service the complaints policy must ensure all complaints are investigated and responded to in the shortest possible timeframe.

126. A service standard complaint (a “poor service” complaint) may be made, for example, by the person, their family or friends or any other attending practitioner and carer. Poor service complaints should, in the first instance, be considered and responded to by the Assisted Dying Service. Where the person who raised the poor service complaint is not satisfied with the response received, or the action taken, the complaint will be escalated to the HCS Delivery and Assurance Board for consideration and response.

127. Even where the poor service complaint is resolved to the satisfaction of the complainant by the Assisted Dying Service, the Service will nevertheless provide a summary of all poor service complaints to the Board for consideration at their meetings.

128. Where the poor service complaint is made to someone other than the Assisted Dying Service, for example, to HCS’s patient advisory services, it will be redirected to the Assisted Dying Service.

129. A safety concern may be raised by any person whether or not as part of a ‘poor service’ complaint. A safety concern will typically relate to concerns that one of the involved professionals is not acting in accordance with the law or is acting in such a way that their decision making may put a person at risk.

130. Where a safety concern issue is raised this will initially be directed to the Assisted Dying Service who must immediately notify:
    a. the HCS Delivery and Assurance Board
    b. the Assessing Doctors
    c. the tribunal, if relevant (see paras 211-235)
    d. the Court, if there is an appeal (see paras 236-255).

131. The Assisted Dying Service will immediately suspend the assisted dying process until the safety concern is investigated and resolved, regardless of which step in the process has been reached.

132. On notification of the safety concern, the Board must make arrangements to review the concern and may escalate to the JCC and / or any relevant UK professional

registration body and / or the responsible officer who oversees the medical practitioner's GMC revalidation as deemed necessary.

133. The assisted dying process cannot be unsuspended until the Board is satisfied that the safety issue has been fully resolved. This may require, for example, the deployment of different assessing doctors.

134. A robust complaints process is required regardless of the proposed introduction of a Jersey Public Services Ombuds as the Ombuds will only engage in 'poor service' complaints which have been subject to review by the public service in the first instance.

Matters relevant to first assessment (Step 2) and independent assessment (Step 3)

Withdrawal of request

135. The person may withdraw their request for an assisted death at any point in the process, including after approval has been given and / or confirmed by a tribunal. The process ends as soon as the person withdraws their request.

136. The person may withdraw verbally or by any other appropriate means of communication to any involved professional.

137. The involved professional must immediately alert the Coordinating Doctor (if the Coordinating Doctor is not the involved professional who was informed) who must then:
    a. speak with the person to confirm their withdrawal request
    b. complete and sign a withdrawal of request form (the details of which will be prescribed by Order of the Minister)
    c. make arrangements for the Tribunal, if relevant, to be informed of the withdrawal
    d. inform other attending practitioners or carers who are informed of the request of the subsequent withdrawal. They must have the consent of the person to do so
    e. inform other family members, friends and other third parties of the subsequent withdrawal, where they have been involved in the process to date. They must have the consent of the person to do so.

138. Where the person has given their consent to any other attending practitioners or carers or family members and friends to being informed of the assisted dying request, those people will be provided guidance on how to notify the assisted dying service that the person wishes to withdraw their request, in the event the person informs them of their wish to do so.

139. The completed withdrawal of request form must be retained by the assisted dying service in line with the JCC retention schedule for regulatory, oversight and reporting purposes. The assisted dying service must report to the JCC, on an annual basis:
    a. the numbers of withdrawal of requests
    b. the stage of the application/delivery process when the request was withdrawn.

140. A person who has withdrawn their request may, at any later date, start the request processes again from the beginning, but the fact that they had previously withdrawn a request must be considered when determining whether their wish for an assisted death is clear and settled.

Confirmation of consent to proceed

141. The Assessing Doctors will talk with the person about whether they wish to provide *confirmation of consent to proceed.*

142. *Confirmation of consent to proceed* allows the Administering Practitioner (see para 66), 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).

143. 'Confirmation of consent to proceed' is a written declaration which the person makes as part of their second formal request (Step 4) but which does not become valid until their assisted death is approved (Step 5). It applies in relation to both Route 1 (terminal illness) and Route 2 (unbearable suffering).

144. A person is not required to provide confirmation of consent to proceed.

Waiver of final consent

145. The one recommendation from the Citizens' Jury that was not brought forward in P95/2021 was the option for people to make an advance decision for an assisted death. Advance decisions are a mechanism via which people, with decision-making capacity, set out the types of care and treatment they do, or do not want, in the event they lack decision-making capacity at some point in the future, for example, if they are in a coma or lose capacity due to dementia. If advanced decisions were permitted for assisted dying this would allow a person to say, for example: "I want an assisted death if, as some point in the future, I have advanced dementia and I can no longer move, eat or speak".

146. A narrow majority (52.4%) of Citizen's Jury members were in favour of assisted dying being possible with an advance decision after losing capacity, but only under certain circumstances. Similarly, a number of people who participated in the Phase 1 public engagement process supported advance decisions, particularly people who had lost a loved one due to dementia. However, both Jury members and those involved in Phase 1 engagement acknowledged the potential risks and difficulties associated for advance decisions in relation to assisted dying, for example:
    a. how can you be assured that someone still wants an assisted death if they cannot communicate with you, or if they can communicate but have lost decision-making capacity?

    b. how do you know a person has not changed their mind about an assisted death if there is a long period of time between an advance decision being made and the assisted death taking place?

147. In addition, how could the assessment process be completed if the individual did not have decision-making capacity? – both in terms of driving the process forward and ensuring the request is voluntary, clear, settled, and informed.

148. Advanced decisions are, therefore, not proposed in relation to assisted dying in Jersey. However, an alternative system of 'waiver of final consent' is proposed. This mirrors changes to Canadian assisted dying legislation brought forward in 2021. It would allow a person to decide in advance that, if they lose 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), the assisted death can still take place.

149. The rational for 'waiver of final consent' is that it ensures 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.

150. The waiver of final consent is a written declaration which the person may choose to make as part of their second formal request (Step 4) but which does not become valid until their assisted death is approved (Step 5). The waiver of final consent must be made before the approval of an assisted death to ensure that the person has capacity at the point of signing the waiver.

151. A waiver of final consent can only be made:

    a. if the person is assessed as having a terminal illness (Route 1), and

    b. while they had decision-making capacity, and

c. have been advised by an assessing or Administering Practitioner that they are at risk of losing their ability to give consent to assisted dying.

152. If a person makes a waiver of final consent they will, as part of their second formal request (Step 4) need to agree their wishes for their assisted death with the Coordinating Doctor, for example, date and location. In the event their assisted death is approved, and the waiver needs to be relied on - because they have subsequently lost decision-making capacity - the Coordinating Doctor and Administering Practitioner will seek to ensure their assisted death accords with those wishes.

153. A person is not required to provide a waiver of final consent.

154. **Note on advanced directives:** whilst it is not proposed that advanced decisions are provided for with regard to assisted dying (i.e., no advanced decision to have an assisted death) the Assessing Doctors will talk with the person about putting in place an advance directive to refuse treatment more generally. This would prevent, for example, attempts at resuscitation should the person need emergency medical treatment attendance during any step of the assisted dying process.

Supporting opinions / assessments

155. Any Assessing Doctor (including the Coordinating Doctor, any Second Opinion Assessment Doctors and the Independent Assessment Doctor) *must* contact other relevant professionals, with the person's consent, for a supporting opinion or assessment of specific matters related to a person's eligibility for assisted dying, if they are unable to make a determination as to whether the person meets the criteria.

156. If they are able to make a determination, there is no requirement in law to seek supporting opinions or assessments unless the person has been assessed as being on Route 2 (unbearable suffering) and neither the Coordinating Doctor nor the Independent Assessment Doctor are an expert / specialist in the person's condition. In these circumstances, the law will set out that the Independent Assessment Doctor *must* seek opinion from a professional who does have expertise in the person's condition but only if the Coordinating Doctor has not already done so. This provision is made on the grounds that the law will not require Assessing Doctors to be experts / specialists in the person's condition (i.e., if the person is dying of cancer, the Assessing Doctors do not need to be oncologists) as there may be no doctors with relevant expertise who have opted-in as assisted death practitioners. Whilst this is not seen as problematic where a person has a terminal illness with a short life expectancy (if the Assessing Doctors are confident they can make a determination of the person's eligibility), it is deemed essential to provide greater safeguards where a person is not expected to die in the shorter term.

157. The relevant professional providing the professional opinion / carrying out supporting assessments will not be making an explicit determination of eligibility for assisted dying. They will instead be providing their opinion - on matters which they are qualified to assess / determine – in order for the Assessing Doctor to consider that option / determination as part of their determination of eligibility for an assisted death.

158. The opinion / assessment provided may relate to:

    a. the person's medical history, diagnosis, treatment options or their decision-making capacity to make the request for an assisted death (for example, a respiratory consultant may provide opinion on treatment and care options), or

    b. the voluntary, settled and informed nature of the person's wish (for example, a social worker providing an opinion on the context of family circumstances and the voluntariness of the person's request).

159. Those providing professional opinion and / or carrying out supporting assessments are not required to:

    a. have opted-in as assisted dying practitioner

    b. undergo assisted dying training as they are not an assisted dying practitioner.

160. The person providing the professional opinion and / or carrying out supporting assessments will be informed by the Assessing Doctor that the opinion being sought relates to an assisted dying request and, as set out in para 50 above, consideration needs to be given as to whether those can refuse to do so conscious objection grounds.

161. Where the person chooses not to consent to the Assessing Doctor informing the relevant professional of their assisted dying request, or relevant third parties such as family and friends (as per para 108 above) there can be no supporting opinions / assessment. The person must understand that this may mean the Assessing Doctor is unable to confirm eligibility.

162. Where the professional agrees to provide their opinion, they must confirm in writing:

    a. if they will be, or believe they maybe a beneficiary under the will of the person, or if they may in any other way receive a financial or other material benefit resulting from that person's death; or

    b. if they know or believe that they are connected to the person in any other way that would affect their objectivity.

163. It is the Assessing Doctor who is responsible for the determination of eligibility. They may, therefore, adopt the opinion / determination provided to them, or they may choose to rely on their own determination. If they choose not to adopt the opinion / determination provided to them, they must have clear and robust reasons for doing so. Both the opinion / determination provided to them, and their subsequent decision-making, must be well documented. This is essential for regulatory oversight plus an Assessing Doctor who chooses not the rely on the opinion / determination provided to them could potentially expose themselves to liability.

164. It must be recognised that it is standard practice, for which doctors are trained to use their professional judgement, to make determinations that do not accord with the opinions or determinations of all other professionals.

165. Furthermore, it must be recognised that if the professional were to seek advice, for example, regarding a different course of treatment for the person which may extend their life / alleviate their suffering:

    a. the person may choose not to accept the treatment, as no person should have to undergo treatment they do not want

    b. it may not impact on the person's eligibility, for example, the treatment could extend life by one month, but overall life expectancy may still be less than 6 months / 12 months.

Step 3: Independent assessment

166. A second assessment will be undertaken by the Independent Assessment Doctor who must have undergone assisted dying training (see paras 60-63).

167. The Independent Assessment Doctor must, independently of the Coordinating Doctor (and the Second Opinion Doctor, if relevant) form their own opinions on the matters to be determined but, in doing so, they may consult with the Coordinating Doctor (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.

168. Before the independent assessment begins the person must confirm to the Independent Assessment Doctor that they wish for the second assessment to be undertaken.

169. The purpose of the second assessment directly mirrors that of the first assessment, i.e., it is for:

    a. the person to fully explore, in dialogue with the doctor:
        - their request for an assisted death and the fears, anxieties and suffering that gives rise to that request

- other care / treatment options and other ways to alleviate their fears and anxieties (for example, they may have financial concerns or concerns about being a burden on family carers)
- if the person is determined to be eligible under 'Route 2' (unbearable suffering) this part of the assessment is likely to take a significant amount of time and may involve multiple consultations for the assessing doctor to be satisfied that all options and changes to circumstances that could alleviate the person's suffering have been explored with the person

b. for the doctor to determine if the person meets the eligibility criteria in law and, if so, on the grounds of
   - **Route 1** (terminal illness); i.e., they have a medical condition, which is expected to result in unbearable suffering that cannot be alleviated and are reasonably expected to die within six months or 12 months or
   - **Route 2** (unbearable suffering); i.e. they have an incurable physical condition, that is giving rise to unbearable suffering that cannot be alleviated in a manner that the person deems tolerable

c. for the person to fully explore, in dialogue with the doctor, their request for an assisted death and other care / treatment options.

170. The independent assessment will include discussion of the same issues as the first assessment (see paras 103 -104) with the Independent Assessment Doctor completing an Independent Assessment Report Form, the details of which will be prescribed by Order by the Minister.

171. The Independent Assessment Doctor (as per the Coordinating Doctor) must be satisfied that the person:

a. has understood the information discussed during the assessment

b. meets the eligibility criteria in law (excluding pre-assessed age and residency status):
   - has a voluntary, clear, settled and informed wish to end their own life, which including being satisfied that the request is made in absence of any undue pressure or coercion by any other person
   - has decision—making capacity
   - has a terminal illness and is reasonably expected to die within 6 months (or 12 months if a neurodegenerative illness); or
   - has a physical condition that is giving rise to unbearable suffering.

172. As per the first assessment, the Independent Assessment Doctor:

a. must seek further advice, professional opinion or additional assessment /s, as necessary, to support them in their determination

b. will establish with the person if they wish to provide confirmation of consent to proceed and / or waiver of final consent (Route 1 only) and / or an advanced

directive, refusing resuscitation or similar emergency life-saving interventions if they have not already done so.

Post independent assessment

173. The Independent Assessment Doctor:

    a. will inform the person of their determination which may be done with input from the Care Navigator

    b. will inform the Coordinating Doctor and the Care Navigator

    c. may, in discussion with the person, refer them to additional support services

    d. will provide a copy of the completed second assessment report form, plus supporting documents, to the assisted dying review committee for oversight and reporting purposes.

Does not meet the criteria

174. If the person is assessed as not meeting the criteria by the Independent Assessment Doctor, the assisted dying process will stop unless the person seeks a second opinion assessment.

175. The law will provide that the person may only request one second opinion assessment. If they requested a second opinion assessment at Step 2 (first assessment) on the basis that the Coordinating Doctor did not assess them as eligible, they cannot then request another second opinion at Step 3. The rational being if two doctors have already assessed the person as ineligible (i.e., the Coordinating Doctor and the Independent Assessment Doctor) the grounds for eligibility must be open to doubt. A person may, however, make an appeal at this stage (See Appeals)

Step 4: Second formal request - written declaration

176. On being informed that the person has been assessed as meeting the criteria by the Independent Assessing Doctor (or Second Opinion Doctor), the Coordinating Doctor will ask the person if they wish to make a second formal request of an assisted death.

177. The second request confirms the person's enduring wish for an assisted death and will take the form of a written declaration.

178. The person must make the written request in the presence of a witness and an involved professional who must sign and date the request form attesting to:

a. the signing and dating of the request, in their presence;

b. that to the best of their knowledge, the person signing the declaration did so freely and voluntarily.

179. The witness plays no role with respect to the assessment of eligibility or application of other safeguards.

180. The witness must be someone who knows the person sufficiently well, so that they feel able to attest to the fact the fact that the person is acting freely and voluntarily. This may be, for example:

a. a health or care professional who has provided care and treatment to the person, providing they have not been involved in the assisted dying application or assessment process

b. a friend, neighbour, someone who know the person in a personal or professional capacity.

It cannot be a close family member, a beneficiary of the person's will or person who is likely to receive a financial benefit from the person's death.

181. The request will take the form of a legal declaration (for example: *I declare of my own free will, without coercion from others, that I am requesting an assisted death because it is my wish to be supported to end my life. My wish it a settled wish, made in full knowledge of alternative options for my ongoing care*).

182. If person is unable to make a written request, they may:

a. request a third person to complete the written declaration on their behalf, or

b. request that an interpreter is appointed to assist a person to complete the written declaration. Guidance will specify that the interpreter should, ideally, hold a nationally recognised interpretation qualification and is registered with the NRPSI (National Register of Public Service Interpreters) or equivalent body.

183. If the written declaration is completed by a third person, the witness must also confirm that:
a. in the presence of the witness, the patient appeared to freely and voluntarily direct the third person to sign the declaration; and
b. the third person signed the declaration in the presence of the patient and in the presence of the witness.

184. The details of written declaration, which will be prescribed by Order of the Minister, will require the witness to describe their relationship to the person.

185. As set out above, as part of the second request process the Coordinating Doctor will discuss with the person if they wish to make a confirmation of consent to proceed and /

or a waiver of final consent (Route 1 only) and / or an advanced directive, refusing resuscitation or similar emergency life-saving interventions, if they have not already done so.

186. Where the person has already made or makes a waiver of final consent at this point, the Coordinating Doctor will agree with them their wishes for their assisted death, in the event their request is approved and the waiver needs to be relied on. In these circumstances, the Coordinating Doctor and Administering Practitioner will seek to ensure their assisted death accords with those wishes. In the event the waiver of final consent does not need to be relied on, because the person maintains decision-making capacity, they may review and revise their wishes during the planning and preparation stage (Step 6).

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 should not prohibit professionals for raising the subject of assisted dying?

Yes – I agree ☐
No – I do not agree ☐
Don't know ☐

Please tell us the reasons for your response…….

Q. 16 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?

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) – continued

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…….

Key questions on Section 5 (part 2 of 3) – continued

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 ☐

No – the law should not allow for a waiver of final consent ☐

Don't know ☐

Please tell us the reasons for your response…….

Step 5: Approval process

187. P 95/2021 set out that assisted dying *should be subject to a pre-approval process which, subject to further consultation, may involve a decision by a court or specialist tribunal.*

188. Whilst the majority of Citizen's Jury members (77%) had recommended that a court or specialist tribunal should be involved in the approval processes – in part because the draft UK assisted dying Bill proposed involvement of the Family Division of the Court[22] - it was noted that involvement of a Court or Tribunal was significantly out of step with most other jurisdictions that permit assisted dying. These jurisdictions provide that it is the responsibility of doctors to approve a request for an assisted death (with the exception of Spain who provide for decision-making by a specialist tribunal). It was in light of the position taken in other jurisdictions that the Assembly agreed that more detailed considered needed to be given the question of approval processes.

189. Concerns about approval processes were a recurrent, unprompted theme raised by participants during the Phase 1 public engagement period (March and April 2022). Numerous participants expressed concern that involvement of a court or tribunal would:

    a. place an unnecessary burden on the person requesting an assisted death and on their loved ones

    b. increase the time taken to determine requests for an assisted death

    c. result in unnecessary cost.

    These participants thought that court or tribunal involvement was an unworkable measure that was disproportionate to the risk of a doctor-only assessment process.

190. Conversely, a small number of participants stated that judicial / quasi-judicial involvement was an important safeguard which added integrity and accountability to the process which was of benefit to both the person and the medical professionals involved.

191. Whilst the Phase 1 engagement process did not give weight to the responses received - as participants were all self-selecting - it was nevertheless the case that the greater majority of participants did not support court or tribunal involvement.

192. In light of the initial public engagement feedback and the findings of further research, it is proposed there are two different approval routes:

[22] https://bills.parliament.uk/publications/41676/documents/322

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 assessment), where a person:
   - *has been diagnosed with a terminal physical medical condition, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months; OR*
   - *has been diagnosed with terminal* neurodegenerative *physical medical condition, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within twelve months; OR*

b. **Route 2** (unbearable suffering), which will entail confirmation of the Coordinating Doctor's approval by a specialist tribunal, where a person *has an incurable physical medical condition, that is giving rise to unbearable suffering that cannot be alleviated*.

Rational for different approval routes

193. The key reasons for proposing two different routes are:

    a. parallels with current practice / decision making, and

    b. differences between objectivity and subjectivity in decision making.

Parallels with current practice / decision making

194. As it stands today, when a patient is at end of life / approaching end-of-life and is suffering, their doctor may make care or treatment decisions that will eventually result in death (e.g.: palliative sedation). Furthermore, some patients already exercise control over the time of their death (for example, by refusing treatment or hydration) or over their treatment in the event they are unable to decisions at some point in the future (for example, an advance directive or 'DNR'). Doctors (and patients) are, therefore, already experienced in making such decisions / assessments and in responding to patient choice and will.

195. Whilst the primary purpose of an assisted death is to end life, there are distinct parallels with the assessment and decision-making processes that doctors currently make when alleviating suffering, knowing that it may hasten death. It is not clear why a doctor who is currently able to make treatment decisions that can hasten end of life would require court or tribunal approval to end that life, providing it is done in accordance with the law. It is for this reason that most other jurisdictions do not require a Court or tribunal to be engaged in an assisted dying process.

196. The same does not apply in the case of people who are experiencing unbearable suffering but are not dying. In these circumstances the assisted dying intervention is not as readily comparable with existing medical practice and decision-making processes and hence it can be argued that the assisted death should have a tribunal

approval. This acknowledges the shift from shortening a person's life by days or months, to altering the trajectory of someone's life and possibly bringing their death forward by many months or potentially years.

Objectivity / subjectivity

197. Whilst any assessment of 'time remaining' cannot be exact, the doctors undertaking the first and second assessment will assess whether a condition is likely terminal and, based on a significant body of knowledge, can reasonably predict end-of-life. Hence the assessments made by two independent doctors of people with a terminal illness can be considered to be objective (i.e., based on medical knowledge, it is an objective determination that a person can reasonably be expected to die within a given timeframe). It is, therefore, unclear as to why a court or tribunal needs to be engaged in the decision-making process.

198. By contrast, where a person is experiencing unbearable suffering but is not at end of life, the assessments made by the doctors are more subjective (i.e., they must seek first and foremost, to determine if the person finds their suffering to be unbearable).

199. The question of when suffering is unbearable has no readily identifiable answer. Different people experience suffering in different ways. It is only the person affected who can determine if they can bear their suffering:

    a. unbearable suffering is not fixed, the physical pain and the mental, emotional, social, spiritual or existential anxiety and suffering associated with an incurable physical medical condition may fluctuate

    b. a person's ability to tolerate unbearable suffering may be impacted by life events or circumstances, for example:
        - the emotional joy associated with the birth of a grandchild may make the suffering more tolerable for a period of time;
        - the fear of disease progression and deteriorating quality of life may be greater than current quality of life.

200. It is the complexity around determining unbearable suffering, as opposed to the much more straightforward assessment of life expectancy, that has resulted in many other jurisdictions only permitting assisted dying in cases of terminal illness as opposed to unbearable suffering where end of life is not reasonably foreseeable (see Appendix 2 for breakdown of different jurisdictions approach).

201. It is this complexity that underpins the proposal that a tribunal should approve a non-terminal illness request for assisted dying, as opposed to a system of approval based on two doctors' assessment.

Route 1 (terminal illness) approval

202. Route 1 (terminal illness) approval by the Coordinating Doctor will apply if both Assessing Doctors determine that the person requesting an assisted death meets all the eligibility criteria and:

    a. *has been diagnosed with a terminal physical medical condition, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months;*

    OR

    b. *has been diagnosed with terminal neurodegenerative physical medical condition, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within twelve months.*

203. Under the Route 1 (terminal illness) approval process, after the person has made their second formal request (Step 7), the Coordinating Doctor will complete and sign the request approval form, which confirm the person's request for an assisted dying has been approved in order that:

    a. the person may prepare for their death, for example, conversations with loved ones or funeral arrangements

    b. the person and the Administering Practitioner may agree / finalise options for the person's assisted death including:
        - method of administration of the substance that will bring about the death
        - plans for administration of the substance including, for example, conversations with loved ones who will support the process;
        - location of the assisted death and, if necessary, arrangements for the person to move to the location or preparation of the location;
        - proposed date for the assisted death.

204. The details of request approval form will be prescribed by Order of the Minister.

205. The Coordinating Doctor cannot sign the approval form unless:

    a. they (or Step 2 Second Opinion Doctor) have assessed the person as meeting all the criteria under Route 1 (terminal illness)

    b. the Independent Assessment Doctor (or a Second Opinion Doctor as Step 3) has assessed the person as meeting all the criteria under Route 1 (terminal illness)

    c. the person has made a second written request

    d. the person has confirmed that they wish the Coordinating Doctor to sign the approval form.

206. Approval is not granted until the Coordinating Doctor signs the approval form. Therefore, if the person has been assessed by both Assessing Doctors as meeting the criteria but withholds consent for the Coordinating Doctor to sign the approval form, there is no approval in place. If the person were to lose decision-making capacity before the approval form is signed by the Coordinating Doctor, they would be unable to

have an assisted death, even if they had made a waiver of final consent. This is because the waiver of final consent form only comes into force once the assisted death has been approved.

207. For Route 1 (terminal illness) approvals, there must be at least 48 hours between the request approval form being signed (Step 5) and the final review (step 8) to allow for appeals (see appeals).

208. The Care Navigator, having confirmed with the person that they have consent to do so, will then provide a copy of the signed request approval form to the Administering Practitioner (where this is a person other than the Coordinating Doctor). This will allow the process to move to Step 6 – Planning and Preparation.

Route 2 (unbearable suffering) approval – Tribunal

209. Route 2 (unbearable suffering) approval will apply if both Assessing Doctors determine that the person requesting an assisted death *has an incurable physical medical condition that is giving rise to unbearable suffering that cannot be alleviated in a manner the person deems tolerable* (i.e., the person has a non-terminal illness but is not expected to die within the foreseeable future).

210. Under the Route 2 (unbearable suffering) process, a special Tribunal will be established to review decisions made by Coordinating Doctors to approve assisted dying requests.

211. Under the Route 2 (unbearable suffering) approval process, after the person has made their second formal request, the Coordinating Doctor will complete and sign the request approval form which, when received by the Tribunal - along with other relevant information (see para 222) - will trigger the formal involvement of the Tribunal.

212. The details of the request approval form will be prescribed by Order of the Minister.

213. The Coordinating Doctor cannot sign the request approval form unless:

    a. they (or Second Opinion Doctor at Step 2) have assessed the person as meeting all the criteria under Route 2 (unbearable suffering)

    b. the Independent Assessment Doctor (or the Second Opinion Doctor at Step 3) has assessed the person as meeting all the criteria under Route 2 (unbearable suffering)

    c. the person has made a second written request

    d. the person has confirmed that they wish for the Coordinating Doctor to sign the approval form prior to review by the Tribunal.

214. The Tribunal will not review decisions concerning the refusal of an assisted dying request. This will be a matter for the appeals process dealt with by the Royal Court (see appeals section below).

215. The rationale for the Tribunal not reviewing a decision not to approve an assisted dying request is that:
    a. it avoids a multi-stage process, involving both the Tribunal and Court, which would simply serve to create increased uncertainty, stress and delays for the person, and
    b. if the Court finds, on appeal, that the Assessing Doctors' opinion was wrong, and the person meets the eligibility criteria, there is a remedy (i.e., the Court can approve the request).

216. The rationale for the Tribunal always reviewing a decision to approve an assisted dying request is that there is no remedy if the Assessing Doctors' opinion was wrong - unless there is an appeal – i.e., it provides an additional safeguard where a person is experiencing unbearable suffering but does not have a terminal illness.

217. The Tribunal will form part of the Tribunal Service (a department of the Court Services of the Judicial Greffe established to hear certain types of claims and appeals under various laws).

218. The principal function of the Tribunal is to review the approval decision made by the Coordinating Doctor. The directions which may be given by the Tribunal, having undertaken that review, are to:

    a. confirm the Coordinating Doctor's approval of the request

    b. reject the Coordinating Doctor's approval of the request.

219. A determination by the Tribunal to confirm or reject the Coordinating Doctor's approval may be made on the basis of the relevant information provided by the Coordinating Doctor if the Tribunal is satisfied by the relevant information.

220. Relevant information includes:
    a. first request form
    b. Coordinating Doctor declaration form
    c. first assessment form
    d. independent assessment form
    e. consent to proceed (if made)
    f. advanced directive (if made)
    g. second written request form
    h. any other supporting documentation, including additional assessments or advice and opinions that formed part of either the first or independent assessment.

221. If the Tribunal is not satisfied with the relevant information provided, they may:

    a. request further assessments of the person

    b. compel any person who has already been involved in the assessment process to provide additional information, evidence or testimony (in writing, in person, via

video-link) which will support the Tribunal to re-examine the information they have been provided:

- the person
- the Coordinating Doctor or the Independent Assessment Doctor (plus any second opinion doctors)
- Care Navigator or other staff from the Jersey Assisted Dying Service
- other professionals who provided supporting assessments
- other attending practitioners and carers
- friends or family
- any other person that the Tribunal deems relevant

c. compel people who have not, to date, been involved in the assessment process to provide additional information, evidence or testimony but only where the person has given their consent to them (for example, family and friends).

222. The law will provide that, as part of the second formal request that relates to Route 2 (unbearable suffering), the person:

a. must consent to the relevant information being shared with the Tribunal

b. may consent to the Tribunal undertaking addition assessments

c. may consent to the Tribunal calling on others who have not yet been involved in the assessment process.

223. If the person declines to give their consent to the Tribunal undertaking addition assessments or calling on others, they must be advised that this may impact the Tribunal's ability to make a determination.

224. It will be for the Tribunal to determine who it hears from, except that the Tribunal must hear from the person if the person determines they wish to be heard. The law will provide that the Tribunal must ensure the person is provided an opportunity to state whether they wish to be heard.

225. In hearing from the person, the Tribunal will need to give due consideration to the burden placed on the person. Testimony may be heard, for example, via an in-person visit by all / some members of the Tribunal to the person in their place of care or a video-link.

<u>Establishing the Tribunal</u>

226. The Bailiff will appoint and maintain an assisted dying review Tribunal panel from which the members of an assisted dying review Tribunal will be convened.

227. Each Tribunal convened will consist of:

a. 1 x legal member (the Chair) – advocate or solicitor of Royal Court for 5-year minimum

b. 1 x medical member - medical practitioner with relevant experience

c. 1 x lay member.

228. Panel members must not be:

a. a States member, Bailiff or Jurat

b. anyone who is involved in the medical care of the person

c. anyone who is a beneficiary under the will of the person or may in any other way receive a financial or other material benefit resulting from that person's death.

229. The Minister will establish remuneration for panel members by Ministerial Decision.

230. The law will provide that the Tribunal must review the decision made by the Coordinating Doctor to approve the assisted dying request within a maximum of 30 days. 'Day 30' being the day the Tribunal issue their determination and 'Day 1' being the day the Tribunal receive the relevant information from the Jersey Assisted Dying service.

231. There will be an advanced notice process to support Tribunal planning. The law will set out that the Coordinating Doctor must ensure that:

a. the Tribunal service is alerted to the possible need for Tribunal determination as soon a practicably possible after a person is assessed by the Coordinating Doctor as meeting the Route 2 (unbearable suffering) eligibility criteria

b. a follow up alert is issued immediately after the second Assessing Doctor confirms eligibility under Route 2 (unbearable suffering)

c. the Tribunal service is formally notified of the need to set up a Tribunal hearing after the person makes their second formal request, at which point they must also provide the Tribunal service with all relevant information.

232. Following a decision on eligibility by the Tribunal to confirm or reject the Coordinating Doctor's approval of the request, an application may be made to the Royal Court for appeal. An appeal of the Tribunal's decision may be made on a point of law only.

233. There must be at least 48 hours between the determination of the Tribunal (Step 5) and the final review (Step 8) to allow for appeals (see appeals).

Note: Establishing a specialist Tribunal

There will be resource implications, which include:

- set-up and recruitment costs
- accommodation and other fixed costs, including administrative support

- remuneration of Tribunal members (whilst the Tribunal is sitting and in the preparation stage)
- ongoing training requirements
- costs involved in making a determination (including additional medical assessments).

There may be inherent difficulties in ensuring the Tribunal has the skills and knowledge necessary to make assisted dying determinations. This is partly because:

- the Tribunal would sit on relatively irregular basis as the number of assisted deaths in Jersey may be as few at 2 per year (based on the number of assisted deaths in other jurisdictions, it is estimated that there would be between 2 to 38 per year in Jersey) – and only those following 'route 2 approval' would go to Tribunal
- individuals with the prerequisite skills may decline to participate in an assisted dying Tribunal.

Appeals

234. The law will set out an appeals process. Clear information about the appeals process will be given to all persons who request, or ask about, an assisted death. The information will be available online.

235. Whilst most jurisdictions do not provide for an appeal process within their assisted dying legislation (an exception being Western Australia), it is proposed that provision is made in Jersey law to help support public confidence.

236. Subject to further consultation it is proposed that the law will provide that there must be a minimum of 48 hours between an approval being made by the Coordinating Doctor under Route 1 (terminal illness), or the Tribunal confirming a Coordinating Doctor's approval under Route 2 (unbearable suffering) and the final review (Step 8).

237. The 48 hour period will provide an opportunity for a person (for example, a family member) to make an application to appeal, but only where that person is aware of the assisted dying application in the first instance (whilst the Assessing Doctors will encourage persons to involve their family and friends they may have chosen not to do so, hence family and friends may not be aware of the request at any point in the process).

238. 48-hours is a limited period of time but it aims to strike a balance between giving sufficient time for third parties to appeal, whilst not significantly impeding the assisted dying process where the person wishes to proceed.

239. In addition, an application to appeal must be made within a maximum of 28 days following the approval decision (if the person has not already proceeded to Step 8 (End of life) following the 48-hour minimum time period). This time period is in line with other tribunal processes within Jersey, and with other assisted dying appeals processes, such as Western Australia.

240. The appeals process is in addition to the ability of a person to request a second opinion from a doctor as part of the first assessment process (Step 2) and the independent assessment process (Step 3).

241. An appeal can be made in relation to:

    a. a Route 1 (terminal illness) request that was approved

    b. a Route 1 (terminal illness) request that was not approved

    c. a Route 2 (unbearable suffering) request that was not approved

    d. a Route 2 (unbearable suffering) request that the Coordinating Doctor approved, and the Tribunal confirmed, but only on a point of law

    e. a Route 2 (unbearable suffering) request that the Coordinating Doctor approved, and the Tribunal rejected, but only on a point of law.

242. Route 2 (unbearable suffering) appeals that have been to Tribunal can only be reviewed on a point of law as the Tribunal will already have covered all other matters in their examination of the approval.

243. The grounds for appeal will not include matters relating to the determination of the person's diagnosis and prognosis as detailed consideration of the diagnosis and prognosis is already provided for in the assessment process.

244. The grounds of appeal will only relate to:

    a. a decision of the Coordinating Doctor to accept a determination that the person has been, or has not been, ordinarily resident in Jersey for at least 12 months. For clarity, the person who has not been resident for at least 12 months cannot appeal to the Court to allow them an assisted death. The appeal to the Court will only relate to whether the period of residency has been correctly determined (i.e., "they say I haven't been resident for 12 months but I have")

    b. a determination taken by either of the Assessing Doctors that:

        - the person has the decision-making capacity to request an assisted death
        - the person does not have the decision-making capacity to request an assisted death
        - the person's wish is voluntary, clear, settled and informed

    c. a failure, or perceived failure, to make determinations or act in accordance with the process set out in law (i.e., service failing or maladministration).

245. The following people may appeal to the Royal Court:

a. the person who has requested the assisted death

b. an agent of person who has requested the assisted death (i.e., someone who the person has asked to act on their behalf); or

c. any other person who the Court is satisfied has a special interest in the care and treatment of the person, such as a family member. This will not include an unconnected third party (such as a representative of a lobby group) who is appealing on the basis that they do not support assisted dying.

246. A person with a special interest in the care and treatment of the person may only appeal a decision to approve a 'Route 1 (terminal illness)' or 'Route 2 (unbearable suffering)' request. They cannot appeal a decision not to approve an assisted dying request.

247. Following an appeal that relates to Route 1 (terminal illness) approval / non-approval or to Route 2 (unbearable suffering) non-approval the Court may either uphold or overturn the Coordinating Doctor's decision by determining that:

a. the person is eligible for an assisted death

b. the person is not eligible for an assisted death.

248. Following an appeal that relates to a decision made by the Tribunal, the Court may decide that:

c. the Tribunal's determination should stand (and approval for an assisted death is or is not given)

d. the Tribunal's determination should not stand (and approval for an assisted death is or is not given).

249. A determination must be made within 7 working days of the application being made.

250. The decision of the Royal Court will be final. There will be no further right of appeal.

251. The law will need to provide for the making of Court Rules related to assisted dying appeals. This may include matters relating to:

a. provision of further evidence, information or testimony and associated timeframes

b. notification procedures at the point at which an appeal application is submitted, as it is imperative that the assisted dying process is immediately suspended until the Court has ruled.

252. If the Court determines that the person is eligible for assisted dying the assessment and delivery process may continue.

253. If the Court determines that the patient is ineligible for assisted dying the assessment and delivery process ends. This does not preclude the person from making another First Request if the situation giving rise to the Court decision changes.

Expiry of approval

254. Consideration has been given as to whether assisted dying approvals should have an expiry date. There is no expiry date associated with approvals in most other jurisdictions; New Zealand being an exception where approval expires six months after the date initially chosen for the administration of the substance.[23]

255. The issue of expiry dates gives rise to several considerations:

    a. any expiry date should provide sufficient time for the person to say their goodbyes and settle their personal affairs. The time needed will vary from person to person, hence any expiry date should not be too restrictive

    b. any expiry date may place pressure on the person to end their life through an assisted death when they are not yet ready to

    c. if a person takes time to act on their approval, it could be argued that their suffering or fear of suffering cannot be unbearable and, therefore, the approval should not have been granted in the first place. An argument that is counterbalanced by the known cathartic or palliative effect of being granted approval (i.e., "because I know I can end my suffering, or my fear of suffering, I can bear my suffering but I cannot bear the suffering or the fear that I cannot end"). Evidence from other jurisdictions suggests that, in some cases, the knowledge that a person may take control of the end of their life suffering brings such comfort that they choose not to proceed to an assisted death[24][25]

    d. an expiry date would be obsolete where a person who has lost decision-making capacity has made a waiver of final consent (Route 1) because they will have pre-determined the date of their assisted death with the Coordinating Doctor as part of their second formal request (Step 4).

256. Having given consideration to the matters above it is proposed that assisted dying approvals do not have an expiry date.

[23] End of Life Choice Act 2019 No 67 (as at 28 October 2021), Public Act 20 Administration of medication – New Zealand Legislation
[24] VADRB Report of operations August 2020 FINAL_0.pdf (safercare.vic.gov.au) [p.3]
[25] Third annual report on Medical Assistance in Dying in Canada 2021 - Canada.ca [section 7.4]

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 (i.e., no requirement for a Tribunal) ☐
No – all approvals by the Coordinating Doctor should be confirmation by a Tribunal (i.e., a Tribunal involved in all cases ☐
Don't know ☐

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 ☐

Please tell us the reasons for your response…….

Key questions on Section 5 (part 3 of 3) – continued

Appeals (see paras 236-255)

It is proposed that the law will provide for appeals to the Royal Court on the following grounds:

a. whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months
b. 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
c. 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?

Yes ☐

No ☐

Don't know ☐

Please 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 ☐

No– I do not agree, there should be a time period longer than 48-hours ☐

Don't know ☐

Please tell us the reasons for your response……

Key questions on Section 5 (part 3 of 3) – continued

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 ☐

No - I disagree, I think there should be an expiry date ☐

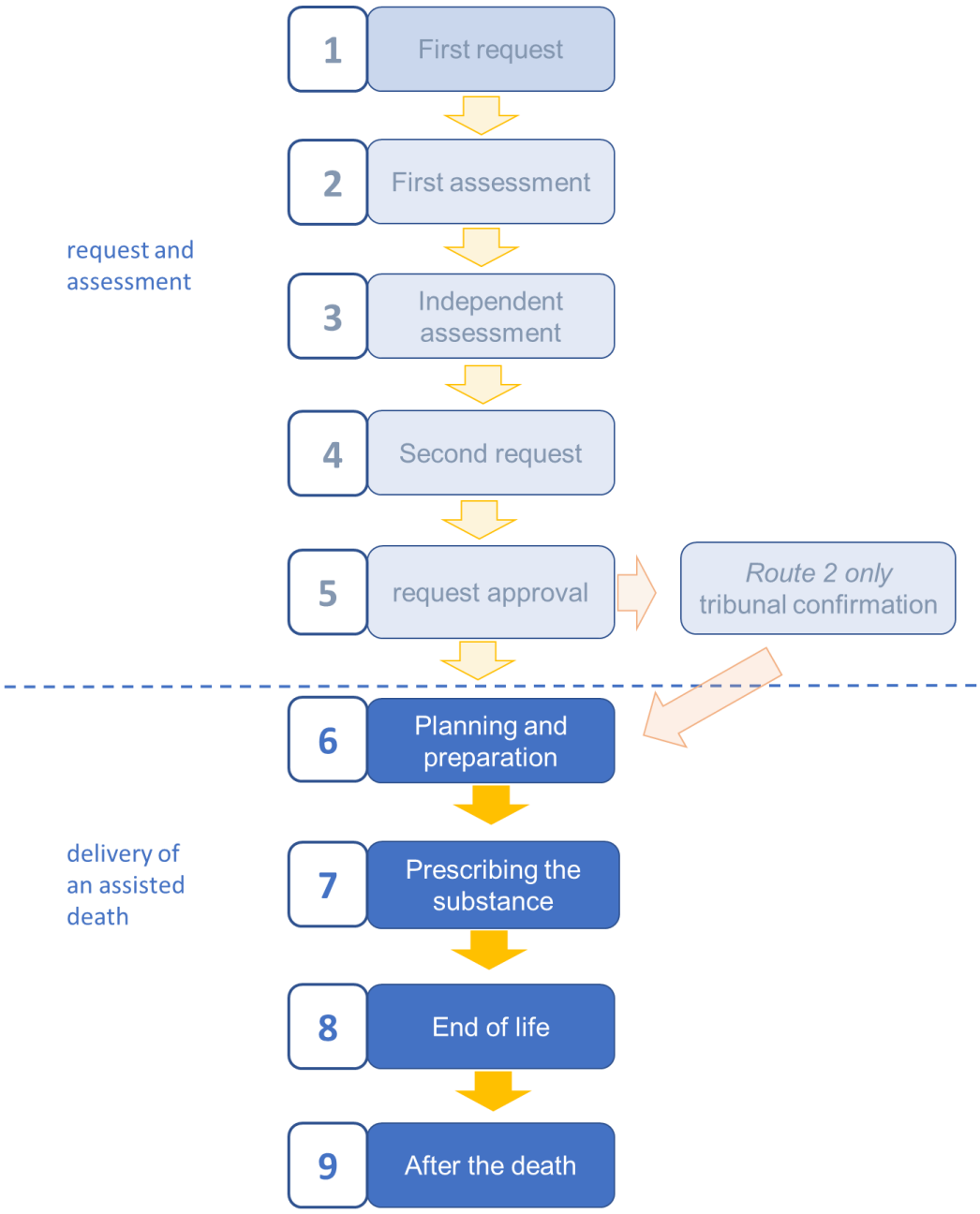
Other, please state ☐.....

Don't know ☐

Please tell us the reasons for your response…….

Section 6: assisted dying process – planning and delivery of an assisted death

257. Overview of delivery of an assisted death



258. The planning and delivery of an assisted death will be support by the Jersey Assisted Dying Service with involvement from the:
   a. Care Navigator
   b. Administering Practitioner
   c. Pharmacy Professionals.

259. The Administering Practitioner may be the Coordinating Doctor but not the Independent Assessment Doctor as, by definition, they are independent.

260. The Care Navigator will liaise with the person and the Coordinating Doctor to agree assignment of an Administering Practitioner (if the Administering Practitioner is a different person from the Coordinating Doctor).

261. Once it has been agreed who will act as Administering Practitioner, the Care Navigator will provide them with the relevant information which includes:
    a. first request form
    b. Coordinating Doctor declaration form
    c. first assessment form
    d. independent assessment form
    e. waiver of final consent (if made for Route 1)
    f. consent to proceed (if made)
    g. advanced directive (if made)
    h. second written request form
    i. any other supporting documentation, including additional assessments, advice and opinions that formed part of either the first or independent assessment.

Step 6: Planning and preparation

262. Once the person has approval for an assisted death they may proceed to the planning and delivery phase which may take as long, or move as swiftly, as the person wishes providing:

    a. it accords with the minimum timeframes set out in law (minimum of 14 days for Route 1 and 90 days for route 2)

    b. there has been a minimum of 48 hours between an approval being made by the Coordinating Doctor under Route 1 (terminal illness), or the Tribunal confirming a Coordinating Doctor's approval under Route 2 (unbearable suffering) and the final review before the assisted death (Step 8), in order to allow for an appeal.

263. The planning and preparation phase allows for the person and the Administering Practitioner to review and / or complete an assisted death plan which accords with the person's wishes and preferences, as far as possible, for an assisted death.

264. Discussions with the person about their wishes that began during the first assessment (Step 2) will continue throughout the process and will have been recorded on the assessment forms. Where the person has decided to waive final consent, the assisted death plan will need to have been finalised at the second formal request (Step 4), but this does not preclude it being reviewed and / or amended post approval if the person still has decision-making capacity.

265. The assisted death plan will set out:

a. the preferred method for an assisted death (see paras 293-300)

b. how those present at the death will be prepared for what happens during the process of death and what, if anything, they need to do at that time

c. any cultural considerations and rituals that are important to the patient and their family

d. the location where the person wants to be at the end of their life.

Approval of location

266. Possible locations for an assisted death include:

    a. private homes

    b. care and nursing facilities owned by GoJ or managed by GoJ

    c. care and nursing facilities not owned by GoJ (these may be privately owned, parish-owned or owned by a charity or community organisation)

    d. hospital facilities.

267. In each case the location must be approved by the Administering Practitioner. A location cannot be approved unless:

    a. permission has been given for an assisted death to take place at that location, for example, if the person wishes to die in their residential care home (or similar) the consent of the care home manager or provider will be required

    b. an assisted death can be safely supported in that location, for example, if the person wishes to die at home but lives in shared accommodation with people who are opposed, consideration will need to be given as to whether that may result in disruption and / or distress and /or potential harm.

268. Appropriate plans must be made, for example, if the assisted death is to take place in a care facility, there will need to be consideration of other individuals that may be present or close by during the assisted death (for example, patients and staff in the same hospital ward, even if the assisted death takes place in a private room).

269. Whilst the Administering Practitioner must approve the location, discussions will have taken place throughout the assessment process and the Care Navigator will, in most cases, have undertaken the checks necessary for Administering Practitioner to give approval.

270. If the person's preferred location cannot be approved or is unlikely to be approved by the Administering Practitioner, the Care Navigator will work to identify an alternative location for the person to consider.

271. To ensure consistency the law will provide that the Administering Practitioner will be responsible for final approval of the location. This may, however, create practical problems in the unlikely event that a person, who has signed a waiver of final consent losses capacity before the Administrating Practitioner approved their preferred place of death - which they would have determined at the point of making their second formal request – and the Administration Practitioner subsequently has grounds not to approve that location. To mitigate against this potential, albeit unlikely event, the person will be asked to state both their preferred place of death and an alternative place of death when they make their waiver of final consent. The alternative place must be a place where it is known that approval will be given (for example, an appropriate hospital facility).

272. Assisted deaths will be permitted in GoJ care facilities but, as above, appropriate plans must be put in place to provide for others being cared for, or working in, that facility.

273. The assisted dying plan also provides for re-confirmation of a waiver of final consent (Route 1 only), consent to proceed and any advance directive that may be in place or discussion about the making of these consent / directives at this Step in the process.

274. The Administering Practitioner must arrange for a dedicated registered medical practitioner (RMP) to attend to the person at this stage if this has not already taken place. The RMP, who will be responsible for certifying the death, must by law have attended the person within the 14 days prior to their death (See paras 306-312).

275. The Care Navigator will support the person to involve their family and friends in the planning or in communicating the plan to family and friends, if the person so wishes, as those who will be present at the death should are aware of these details in advance. The final decisions, however, rest with the person.

276. There will be further discussion of potential complications and what may happen in those circumstances, particularly if there is no consent to proceed or advanced directive in place. Where there are complications with, for example, oral self-administration of the substance the administrating practitioner:

    a. may move to IV administration with consent of the person if they still have decision-making capacity or there is a consent to proceed in place

    b. will not be able to take appropriate measures to administer the substance where there is no consent to proceed in place and will instead only be able to provide the person with suitable treatment to ensure they are comfortable. It is possible,

albeit extremely unlikely, that the person may require transfer to hospital in these circumstances.

277. In the highly unlikely event that there is also no advance directive in place refusing care, and the person has lost the capacity to refuse treatment at this point in time, the Administering Practitioner (and/or hospital staff) may need to attempt life sustaining measures but only if it were deemed appropriate to do so (i.e. the life sustaining measures is likely to be successful and it would not cause additional harm to the person). The Administering Practitioner (and/or hospital staff) would also need to consider if it were in the person's best interest which would generally be considered unlikely given that it is directly contradicts their assisted dying request. Advanced directives provide the necessary clarity.

Step 7: Prescribing the assisted dying substance

278. 'Assisted dying substance' refers to the medications used to bring about the person's death. The drug regime and protocols for the substances used in the different administration methods will be agreed by the Delivery and Assurance Board. The protocols will set out how the substance will be prescribed, prepared and dispensed in such a way as to ensure:

    a. a minimal number of individuals handle the substance

    b. there is a clear chain of command and clear documentation

    c. the substance is always held securely.

279. The Jersey General Hospital (JGH) Pharmacy will compound, store, pack and dispense substances used for the assisted dying substance. No other pharmacy will do so.

280. Pharmacy Professionals must 'opt-in' and undertake the specified assisted dying training. JGH pharmacy staff will be able to conscientiously object to acting as dispensing pharmacists in relation to assisted dying, as this will constitute direct participation in the assisted dying.

281. The Administering Practitioner will prescribe the substance in most instances. Where this is not possible, for example if the designated Administering Practitioner is not registered as an independent prescriber, another assisted dying professional may prescribe the substance.

282. The prescription will vary depending on the agreed administration method (i.e., orally or via IV, see paras 293-300). The prescription will include:

a. additional therapies for symptom control (e.g., anti-emetics to control vomiting and nausea; sedatives to control refractory systems such as pain and agitation)

b. back-up IV substances, both for those who choose oral medication and those who chose IV medication.

283. The protocols will set out that the assisted dying substance should, wherever practical, be prescribed with sufficient notice, in advance of the agreed date for administration of the substance. Where the assisted death is to take place as soon as practically possible after approval has been given, the 48-hour period to allow for appeals between Step 5 (Approval) and Step 8 (End of life) is still required.

284. The General Hospital Pharmacy will hold a list of authorised prescribers. When a person has approval for an assisted death, the Care Navigator will notify the Pharmacy. The Pharmacy will only dispense or deliver the substance to the Administering Practitioner or the prescriber.

285. The substance will be dispensed in a sealed and individually numbered box, clearly marked with a warning of its purpose – i.e., "If ingested, this substance will cause death". Only the dispenser and Administering Practitioner will have access and authorisation to open the box with the locked key or code.

Step 8: End of life

286. The Administering Practitioner will arrive at the agreed location, on the agreed date and time, to support the administration of the assisted dying substance. On arrival they will:

a. re-confirm, and record, who will be present during the assisted death as this may been subject to change since the assisted death plan was developed (for example, some family members who previously declined to attend may have subsequently changed their mind)

b. re-confirm the roles and responsibilities of all present

c. re-confirm the mode of assisted death and the anticipated process, including what will happen immediately after the person dies.

287. Immediately prior to the administration of the substance, the Administering Practitioner will carry out a final review to determine if they are satisfied that the person has decision-making capacity.

288. If it is determined that the person has decision-making capacity, the administrating practitioner will then assess whether the person:

a. continues to have a voluntary, clear, settled and informed wish to proceed. If the Administrating Practitioner determines this is not the case the process must stop; and

b. is giving their final consent (or is withdrawing their consent). If the person does not provide their final consent or is withdrawing their consent the process will stop.

289. If the administrating practitioner determines that the person does not have decision-making capacity, the administrating practitioner will stop the process unless the person made a waiver of final consent (Route 1).

290. Even if the person has in place a waiver of final consent in place the process will not proceed if, during the final review or in the lead up to the assisted dying substance being administered, the person demonstrates a refusal or resistance to the administration of the substance by words, sounds or gestures (for clarity, reflexes and other types of involuntary movements, such as response to touch or the insertion of a needle, would not constitute refusal).

291. The Administering Practitioner will complete a final review form, the details of which will be prescribed by Order of the Minister. Copies of the signed final review form must be submitted to the assisted dying review committee, and this should be done within 2 working days of the person's death.

292. Once the final review, and the associated form, have been completed the Administering Practitioner may begin administration of the assisted dying substance.

Methods for administration of an assisted death

293. There are four modes of administration, the mode of administration will have been agreed in advance between the person and the Administering Practitioner (or Coordinating Doctor if a waiver of final consent was made and the person lost capacity AFTER approval and BEFORE the person and the Administering Practitioner made the assisted death plan. The four modes are:

a. self-administration – oral or by a percutaneous endoscopic gastrostomy (PEG) or nasogastric tube (NG)

b. self-administration - intravenous delivery, triggered by the person

c. practitioner administration – IV injection

d. practitioner administration – orally, including by a percutaneous endoscopic gastrostomy (PEG) or nasogastric tube (NG).

294. For modes involving self-administration the Administering Practitioner will:

a. prepare the substance and remind the person how the substance should be taken (this will have been previously discussed)

b. stay with or nearby the person, as the person wishes, whilst the person takes the substance and up until the person dies (they do not have to be in the same room, but they must remain close by)

c. check and confirm the death

d. as soon as practicably possible, remove any items related to the substance, such as IV lines or feeding tubes, and remove these for safe disposal, and return to the General Hospital Pharmacy any unused substance.

295. If the person has chosen to self-administer the substance a family member or loved one may support them in the process, for example supporting the person to bring the cup to their lips. This would likely be an extension of the care and support that loved ones have been providing over the previous days and weeks.

296. For modes involving practitioner administration, the Administering Practitioner will:

a. prepare and administer the substance

b. stay with or nearby the person, as the person wishes, until they die (they do not have to be in the same room, but they must remain close by)

c. check and confirm the death

d. as soon as practicably possible, remove any items related to the substance, such as IV lines or feeding tubes, and remove these for safe disposal and return to the General Hospital Pharmacy any unused substance.

297. Other health professionals may assist the Administering Practitioner with the process, for example, setting up IV tubes and preparing the substance. Detailed guidance will be developed. However, the only persons authorised in law to administer the substance will be:

a. the Administering Practitioner, or

b. the person, with or without the assistance of a loved one.

298. Other attending practitioners and carers may determine whether they are willing to be present at the administration of the substance and whether they are comfortable assisting the Administering Practitioner with aspects not directly related to the administration of the substance. As this would constitute direct involvement in assisted dying, they would have the right to conscientiously object.

299. In settings such as the General Hospital, efforts will be made to ensure that those who are known to object to assisted dying will not have to work in close proximity during the administration of the substance.

300. Detailed protocols will be developed should an unexpected medical event occur, such as complications with the administration of the assisted dying substance. This could include the person taking longer to die than expected or issues with the administration of the substance. In most cases it is anticipated that the person will have:

    a. made an advance decision to refuse treatment which would prevent medical staff from attempting resuscitation

    b. provided confirmation of consent to proceed, which would permit the Administering Practitioner to administer the assisted dying substance via IV if the oral mode fails.

Step 9: After an assisted death

301. Once the Administering Practitioner has confirmed the death of the person, they must then complete a post-assisted death administration form, the details of which will be prescribed by Order of the Minister, recording:

    a. the time of the administration of the substance
    b. the time of death
    c. dosage and substances used
    d. details of the administration process including any support provided by loved ones or any intervention made by them
    e. details of any complications relating to the administration of the substance.

302. Copies of the signed post-assisted death administration form must be submitted to the assisted dying review committee (see para x) and this should be done within 2 working days.

Note: Final review form and post-assisted death administration form

303. The final review form and the post-assisted death administration form will be used:

    a. by the assisted dying review committee for a post-death administrative review of the individual case (see paras 324-328)
    b. by the JCC to extract anonymised information, to inform the JCC's annual report on assisted dying in Jersey (see para 330).

Death Certification

304. In addition to the post-assisted death administration form, a medical certificate of the fact and cause of death (MCFCD) must be completed as with any other death in Jersey. This is required under Article 64 of the Marriage and Civil Status (Jersey) Law 2001[26]("the 2001 Law").

305. The MCFCD is usually completed by a qualified registered medical practitioner (RMP). A medical practitioner is qualified if they have attended to the deceased during their last illness and within the 14 days prior to their death. If no doctor is qualified, the 2001 Law requires that the Viscount is notified. The Viscount may, after further enquiries, authorise the unqualified registered medical practitioner to complete the certificate, i.e., someone who did not attend to the deceased within the 14 days prior to their death.

306. It is proposed that, for all assisted deaths, there is a dedicated RMP service which will consist of medical practitioners who have had specific training on death certification for assisted deaths. The RMP must have attended the person within the 14 days prior to their death, with the Administering Practitioner ensuring this has happened either before, or during Stage 6 'planning and preparation'.

307. Within a maximum timeframe of 48 hours after the death, the Administering Practitioner must notify the RMP of the death and must provide to them the signed and dated copies of the:

    a. final review form

    b. post-assisted death administration form.

308. The qualified registered medical practitioner will then examine the body, review the medical notes and history and complete the MCFCD in a similar way to any other death that occurs.

309. An amendment will be required to the Inquests and Post-Mortem Examinations (Jersey) Law 1995 ("the 1995 Law") to generally exempt deaths brought about by assisted dying.[27] Otherwise, these deaths would be deemed reportable which would result in automatic involvement of the Viscount. It is intended that an assisted dying death would not have to be reported to the Viscount as a matter of course, other than where the death was not in accordance with, or suspected not to be in accordance, with assisted dying legislation.

310. The level of involvement of coroners (in Jersey this function is carried out by the Viscount's Department) for assisted deaths varies across jurisdictions. In Western Australia, deaths brought about by assisted dying are generally exempt from automatic involvement of the Coroner. In Ontario, Canada Administering Practitioners are

[26] Marriage and Civil Status (Jersey) Law 2001 (jerseylaw.je)
[27] Inquests and Post-Mortem Examinations (Jersey) Law 1995 (jerseylaw.je)

required to notify the Chief Coroner after each assisted death, for an administrative review. As set out in paras 324-328, it is intended that the assisted dying review committee undertake a post-death administrative review, as opposed to the Viscount.

311. All deaths in Jersey must be registered by law. The Superintendent Registrar holds the register of deaths which is publicly available. Details of the cause of death of a person are transcribed into that register from the MCFCD.

312. In some jurisdictions, for example Western Australia, the death certification process does not record the death as an assisted death; the cause of death is instead recorded as the underlying illness which the person had which made them eligible for an assisted death. This is intended to protect the privacy of the person. In other jurisdictions, however, the law and associated guidance strives for transparency and acceptance around the assisted dying process, for example, in New Zealand and Canada, where the death is recorded as an assisted death with the underlying illness also being noted as a factor.

313. Assisted deaths are not recorded as suicides in jurisdictions where assisted dying is legal. This is because assisted dying is not suicide.

314. It is proposed that in Jersey, an assisted death is recorded in the same way as other deaths i.e., the MCFCD would record:

    a. the disease or condition leading to the death

    b. any antecedent causes

    c. any morbid conditions underlying last conditions

    d. any other significant conditions that contributed to the death but not related to the disease or condition causing the death.

315. In the case of an assisted death:

    a. the ‘disease or condition leading to death’ would, for example, be multi-organ failure i.e., failure caused by the assisted dying substance

    b. the antecedent cause would be the ingestion / administration of the assisted dying substance

    c. the morbid conditions, plus any other significant conditions contributing to the death i.e., the disease and / or conditions that made the person eligible for an assisted death.

316. The causes of death recorded on the MCFCD would then be recorded in the death register which is a public document.

317. The process for burial or cremation of a person who has had an assisted death would be the same as other deaths in Jersey. For cremations only, this includes an additional independent examination of the body of the deceased which is a requirement for all cremations under the Cremation (Jersey) Law 1953 ("the 1953 Law") and Cremation (Jersey) Regulations 1961 ("the 1961 Regulations").

Note: Organ donation

Post-assisted death organ donation is permitted in some jurisdictions where assisted dying is legal albeit some of the diseases and conditions that make a person eligible for an assisted death, such as cancer, rule out the possibility of donation as the organs are no longer viable - although this would not apply to neurodegenerative diseases.

Organ donation may also not be possible where the place of death is not in a hospital, although some jurisdictions, for example, the Netherlands will transfer the deceased to hospital to allow for donation[28]

It is envisaged that the law will not prohibit post-assisted death organ donation in Jersey but detailed guidance will need to be developed as there are complex ethical considerations, for example, to what extent is it appropriate for a doctor to raise the issue of organ donation with a person who has requested / is considering requesting an assisted death.

Support for family and loved ones

318. Following the assisted death families and loved ones may access existing bereavement support services. In addition, they may wish to meet together to share their experiences. The Assisted Dying Services will look to facilitate this.

[28] Organ donation after medical assistance in dying at home - PMC (nih.gov)

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 self-administer 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 self-administer the substance?

Yes ☐

No ☐

Don't know ☐

Please tell us the reasons for your response…….

Key questions on Section 6 – continued

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…….

Section 7: regulation and oversight

319. The Jersey Assisted Dying service:

    a. must operate within the law and be seen to do so

    b. must be safe, and
        - protect and safeguard people who may be vulnerable to coercion and control
        - accord with the highest standards of clinical safety

    c. must meet the needs of care receivers and their families (be patient centred)

    d. must be of high quality, and

    e. must be well-organised and easy to navigate.

320. Appropriate structures / systems will be put in place to ensure the safety, quality and effective delivery of the service, and to provide public assurance of these matters. These structures will 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.

Service provision and assurance

321. As set out in **Section 4** the law will provide that an HCS Service Delivery and Assurance Board will be established to:

    a. oversee the establishment of the Jersey Assisted Dying Service, including the development of a training programme, plus service and clinical protocols

    b. ensure robust clinical governance

    c. ensure ongoing oversight of service safety and quality through continuous monitoring of the service

    d. oversee the management and response to complaints and / or potential patient safety concerns related to the service

e. provide assurance to the Minister and the public about patient experience, clinical safety and service quality.

Review committee

321. The law will require that an administrative review of each assisted death is carried out immediately after the death. This will be undertaken by an assisted dying review committee, commissioned by the HCS Service Delivery and Assurance Board.

322. The committee will review the relevant documentation from Steps 1 to 9 of the assisted dying process (see Sections 5 and 6). Assisted dying review boards have been established in several jurisdictions including New Zealand, Western Australia and the Netherlands. Once completed, the review committee will provide a copy of the review to the JCC. The purpose of the administrative review is to ensure that, in each case, there was proper adherence to the legislation and guidance. The committee will also immediately take any action that may be required, if it is found that legislation and guidance has not be adhered to for example:

    a. recommending potential safety and quality improvements to the Minister and the HCS service delivery and assurance Board

    b. referring any matter identified by the committee to the relevant person, for example, the Coroner, the States of Jersey Police, the Superintendent Registrar, the relevant professional lead (for example, the Chief Pharmacist or Chief Nurse; Safeguarding Partnership Board)

    c. suspending the assisted dying practitioner from the opt-in register (or recommending suspension from the register) and informing the JCC or any relevant UK professional registration body of the suspension / recommended suspension or alerting the Assurance and Delivery Board of the need to so.

323. The establishment of the review committee will negate the requirement for all assisted deaths to be reported to the Viscount (see para 311).

324. For the purposes of clarity, the duties of the assisted dying review committee will not detract from any duties or powers of the Coroner with regard to an assisted death.

325. Committee members may be experts in end-of-life care, in medical ethics, in social care (including care for older people and people with disabilities), in the types of terminal and non-terminal physical medical conditions that give rise to assisted dying requests.

Independent regulation and inspection

326. Regulations will be brought forward under the Regulation of Care Law[29] to provide for the Jersey Care Commission (JCC) to regulate and inspect the Jersey Assisted Dying service. There will be a separate consultation on those regulations.

327. The JCC:

a. will act as a key consultee

b. will develop the standards against which the assisted dying service will be inspected

c. will register both the manager and provider of the assisted dying service which must happen before the service begins (it is usually the case that services have to apply to register with the JCC within six months of starting to operate). In doing so, the JCC will require HCS to submit all the information the JCC deems necessary to register the service. This may include the JCC undertaking pre-registration visits (for example, to HCS pharmacy department to look at dispensing arrangements)

d. must have the power to undertake announced or unannounced inspections post-registration which may, include, for example, interviewing involved professionals; people who are using the service as well as their family and friends where appropriate, and other third parties as deemed relevant by the JCC

e. will inspect the assisted dying service at least once a year. The JCC may inspect all, or parts of the service, more than once a year if the JCC deems it appropriate (whether announced or unannounced). The JCC will publish its inspection reports

f. will retain all relevant information documentation provided by the assisted dying service in relation to assisted dying assessments, in line with the JCC retention schedule for regulatory, oversight and reporting purposes

g. will publish an annual report on assisted dying which will support regulatory oversight, including in relation to safety, monitoring, and research purposes. The data included in such a report may, for example, support identification of groups of people with similar characteristics who may be more inclined to request assisted dying and may indicate requirements for changes to existing support or treatment services. It will set out for, example,
   - numbers of Route 1 (terminal illness) and Route 2 (unbearable suffering) assisted dying requests, approvals (plus appeals) and assisted deaths (including as % of overall deaths in Jersey)
   - profile of persons requesting an assisted death, plus profile of those approved and those who had an assisted death (age, gender, physical

[29] REGULATION OF CARE (JERSEY) LAW 2014 (jerseylaw.je)

medical condition, use of palliative and end of life care, nature of suffering reported)
- matters relating to approval (for example, making of advanced directives, consent to proceed, and waiver of final consent)
- matters relating to assisted deaths (mode of assisted death plus any associated intervention, time between approval granted and assisted death, location, professional of administrating practitioner)
- matters relating to assessment process (routes for determining voluntary nature, number of supporting assessments by different professional groups etc)
- uptake of support services for professionals plus family and friends (where known).

328. The annual report will be suitably anonymised and steps will be taken to ensure that people cannot be identified. It must be appreciated, however, that a combination of small population size plus the recording of the facts and cause of death in the public domain may, in some cases, allow for identification by family and friends.

329. In the event there are no assisted deaths in Jersey in any given year, the JCC will not publish a separate report but will include a statement to that effect in the JCC annual report.

Acting on findings arising from inspections or the review committee

330. In the event the JCC finds alleged or confirm breaches of the law or its standards, whether it finds those breaches / alleged breaches during an inspection (or is informed of breaches by the review committee), the JCC will take action in accordance with its existing escalation and enforcement policy[30]. This action may include, for example, development of an improvement plan, issuing of an improvement notices or suspension or cancellation of registration which would, in effect, shut down the assisted dying service.

331. 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). It is proposed that the Regulation of Care Law is amended in such a way as 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 it may, in effect, be shut down by the JCC.

[30] https://carecommission.je/wp-content/uploads/2022/03/Escalation-and-Enforcement-Policy-002.pdf

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…….

Key questions on Section 7 – continued

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 ☐

No– I disagree, it should be considered an essential service ☐

Don't know ☐

Please tell us the reasons for your response…….

Section 8: next steps

Consultation and law drafting process

332. The comments provided in response to this consultation document will be given full consideration and, where appropriate, reflected in the report and proposition to be lodged for debate by the States Assembly in early 2023.

333. A consultation feedback report will be published alongside the report and proposition detailing the feedback received.

334. Law drafting instructions will be developed after the Assembly debate and will reflect any amendments to the proposals agreed by the States Assembly. Depending on the complexity of the final proposals it is likely that it may take up to 12 months to draft the law.

335. Existing legislation will also need to be amended to provide for:

    a. regulation and inspection by the Jersey Care Commission (see Section 7)

    b. certification and registration of assisted deaths (see Section 6).

336. The Law Officers will need to undertake a detailed human rights assessment to ensure the draft law complies with Jersey's human rights obligations. The Minister will also undertake and publish Children's Rights Impact Assessment to ensure matters relating to the rights of children under the UNCRC have been considered.

337. As the Assisted Dying Law will be new primary legislation it will require approval by the UK Privy Council. Subject to approval by the Assembly, it is proposed that the law will include a regulation making power enabling the Assembly to amend any aspect of the law at a future date. Consideration has been given to building a statutory 5-year review period into the law (as, for example, in Canada) requiring the Assembly to review within five years to determine if the law should be amended. There are concerns however, that a five-year review period may be counter effective on the basis that if it is found that the law:

    a. does not operate effectively or does not include sufficient statutory safeguards this should be addressed in the immediate term

    b. is too restrictive to achieve the Assembly's policy intent this may need to be addressed in a shorter timeframe, or a longer timeframe as a larger body of data and evidence may be required.

338. The Assembly will need to debate and adopt the proposed law which will need to be brought into force, by an Appointed Day Act, once the implementation phase has been completed. As set out in Section 1, it is envisaged that the report and proposition will ask Members to agree, in principle, that legislation permitting assisted dying should not

be brought into force until the Assembly is satisfied that all Islanders can access good quality palliative and end-of-life care services.

Implementation phase

339. Prior to the law coming into force the following actions will need to be undertaken:

a. HCS will need to recruit / contract the assisted dying practitioners and Care Navigators who will deliver the service

b. the assisted dying training package will need be developed and undertaken by assisted dying practitioners

c. the opt-in register will need to have set up and professionals who wish to do so will need to have opted in

d. the Minister will need to have published the necessary guidance and all the necessary forms by Order

e. the Delivery and Assurance Board will need to have developed and will publish all relevant clinical practice protocols

f. Delivery and Assurance Board will need to have established the assisted dying review committee and developed its working protocols

g. the Judicial Greffe will need to have made the necessary arrangements for the assisted dying tribunal

h. Rules of Court will need to be developed in relation to appeals

i. a dedicated assisted death certification process will need to have been implemented with associated changes to supporting electronic recording systems

j. bespoke webpage and public-facing information developed and made available in accessible formats.

340. It is anticipated that the implementation phase will take approximately 18 months from the point at which the States Assembly adopt the legislation.

Section 9: financial and resource implications

341. The financial and resource implications cannot be fully scoped until the full proposals have been decided by the Assembly, but the key areas of cost are described in the paras 343-355, below. The costs include one-off costs to establish the service plus ongoing service costs.

342. In addition to costs directly associated with the development of an assisted dying service outlined below, additional funding will be sought via the 2023 Government Plan to allow for investment in palliative care and end-of-life services.

343. Development of legislation (one-off cost)
    a. funded from within existing departmental heads of expenditure unless the Assembly requires escalation of work which may require additional law drafting capacity.

344. Assurance and Delivery Board
    a. recruitment of independent members (one-off cost)
    b. renumeration of independent members (recurrent cost) and cost of HSC staff members (funded from withing existing department heads of expenditure)
    c. recruitment to assisted dying review committee (one-off cost) plus renumeration of members and staffing capacity required to support the committee (recurrent cost)

345. Care Navigators – c. 1.5 FTE
    a. recruitment (one-off cost)
    b. salary and overhead costs.

346. Assessing Doctors / supporting assessment costs / Administering Practitioners / service delivery costs
    a. contract development costs (one-off cost)
    b. salary / contract payment (recurrent cost). For budgeting purposes allow for 50 hours work per patient
    c. medicines management, pharmaceutical and supplies costs (recurrent).

347. Assisted dying practitioners training package
    a. content development (one-off cost) plus ongoing maintenance costs
    b. development of on-line platform (one-off cost) plus ongoing maintenance costs
    c. backfill / contract payment costs for those undergoing training.

348. All providers education on assisted dying process and materials to 'support conversations'
    a. development of training (one-off) and educational materials (recurrent cost as supplies given to providers)
    b. delivery of training (recurrent cost).

349. Clinical protocols, medicines management protocols and service / practice guidance
    a. development (one-off) plus ongoing maintenance costs
    b. development of on-line platform (one-off cost) plus ongoing maintenance costs.

350. Support systems
    a. access to psychological support for involved professional (recurrent)
    b. debriefing and collegial support / networking sessions for other attending practitioners and carers (recurrent)
    c. family and friends' access to bereavement support / peer support (recurrent).

351. Front door access to Assisted Dying Service / public information
    a. development website (one-off cost) plus ongoing maintenance costs
    b. development of public information literature (recurrent cost)
    c. Care Navigator office space / patient and family meeting room (recurrent cost).

352. Opt-in register costs
    a. development of opt-in registration platform (one-off cost) plus administration of registration (recurrent cost).

353. Jersey Care Commission costs
    a. development of assisted dying service standards under Regulation of Care Law (one-off cost) plus ongoing inspection and regulation costs (recurrent)
    b. production of annual report (recurrent cost).

354. Tribunal
    a. establishment of tribunal, recruitment of members, development of operating protocols (one-off cost)
    b. renumeration of members (recurrent cost).

355. Certification of death processes
    a. contract development costs (one-off cost)
    b. salary / contract payment (recurrent cost)
    c. development of web-enabled certification (one-off cost).

Appendix 1: assessment of eligibility criteria

1. The factors to be considered when assessing whether a person meets the eligibility criteria are described below.

Aged 18 years or over

2. The person must be aged 18 years or over at the time they make their first request for an assisted death. This will require production of documentary evidence such as a passport or drivers' licence as part of the first assessment.

Jersey resident

3. The law will provide that the person must have been ordinarily resident in Jersey for at least 12 months at the time they make their first request.

4. The checks will be undertaken by the HCS team that currently deals with eligibility matters but the Coordinating Doctor must confirm they are satisfied these checks have been undertaken. To assist, the person will be asked to consent to the HCS team contacting any relevant GOJ department in order that the department may provide supporting information. The law will also provide that the relevant department may share information surrounding age or proof of residential status with the Assisted Dying Service.

The person's wish must be voluntary, clear, settled and informed

5. Only people with a voluntary, clear settled wish to end their own life will be eligible for assisted dying. The Assessing Doctors must be satisfied that these conditions are met as part of their assessments.

6. The Delivery and Assurance Board will provide detailed guidance to help the Assessing Doctors determine whether the request meets the specified conditions. The guidance will set out that assessments must include:
    - time to discuss and understand the reasons why a person is requesting an assisted dying
    - questions that explore how the person reached their decision, including what or who may have influenced them
    - talking with the person on their own
    - talking with, or gathering information from, family, friends or other people who have a close connection with the person (for example, other attending practitioners and carers). This may include observation and assessment of family dynamics. The person must consent to the Assessing Doctors talking to others. If the person declines to provide that consent, the assisting doctor must advice the person that this may impact on their ability to determine whether their wish for an assisted death meets the specified conditions.

Voluntary

7. The person must freely choose to request an assisted death and must do so free of coercion. Indicators of possible coercion may include:

    a. excessive deferment by the patient to carers, family or friends for answers, reassurance or explanation
    b. carers, family or friends talking over the patient / answering on their behalf
    c. inconsistencies in the person's answers to questions about their suffering, experience of illness experience or assisted dying in general.

8. If the Assessing Doctors are unable to determine whether the person is acting voluntarily (or if they concerned that the person is experiencing, for example, family or domestic violence, financial abuse or elder abuse) they must refer them to a person with appropriate skills and training to support their determination. This may include, for example, an experienced registered health practitioner (e.g., a psychologist) or another appropriate professional (e.g., a social worker). Other professionals who are familiar with the person may also be called on to aid this determination (e.g., community workers or police officers). This cannot include any individual who:

    a. is a family member of the person;

    b. knows or believes that they are a beneficiary under a will of the person; or may otherwise benefit financially or in any other material way from the death of the person.

9. If either Assessing Doctors is not satisfied that the person's decision is voluntary, they will be ineligible for an assisted death.

Clear and settled

10. The assisted dying process has built in controls to ensure the person's wish is both clear and settled.

11. Each step of the process can only be initiated by the person expressing a wish to proceed to that Step (the Assessing Doctors must ask them to confirm). Plus, the person may withdraw their request at any point in the process (see paras 137-140; withdrawal of request).

12. It is understood that a person's wish for an assisted death may fluctuate. They may be very determined on some days, but less sure on other days. The Assessing Doctors must be sensitive to these fluctuations which may require a more detailed consideration of the nature of the request. The Coordinating Doctor must not, however, approve the request unless both Assessing Doctors are satisfied that the wish is no longer fluctuating (i.e., it is settled).

Informed

13. The law will provide that the person requesting the assisted death must be fully informed about:
    a. their diagnosis, prognosis and all available care and treatment options
    b. all aspects of the assisted dying process.

14. Information may be provided in writing but must also form part of the discussions with the person (i.e., it needs to be actively discussed; not passively provided).

15. The Assessing Doctors must both be satisfied the person is able to understand the information provided to them. The person must be considered ineligible for an assisted death if they are unable to understand the information as they will be deemed unable to make an informed wish.

16. The law will provide that the Assessing Doctors must, as part of the first and second assessment, inform the person and talk to the person about:
    a. their diagnosis and prognosis, including:
        - treatment options available to them and the likely outcomes of that treatment (and refer on, where requested)
        - care options available to them (and refer on, where requested)
        - options /support for managing suffering (for example, lifestyle /environmental changes beyond medical and therapeutic treatment, for example housing options)

    b. assisted dying and the associated process including:
        - the potential risks of self-administering or being administered the assisted dying substance (and confirm the person's understanding that the outcome of self-administering or being administered those substance is death)
        - the method by which the substance is likely to be self-administered or administered, including a discussion of the person's preferred method
        - the request and assessment process, including the requirement for a written second declaration signed in the presence of a witnesses
        - ability to withdraw their request at any point in the process
        - the person's wishes for their assisted death including the place where they wish to die. Where this place is the person's home, they must explain the need for the Administering Practitioner to approval it as a safe and suitable location. Where it is somewhere they cannot be supported to have an assisted death this will include a discussion about alternative locations

    c. involvement of others, including associated consents to share information with others including:
        - family and friends and other professionals involved in the person's care and treatment
        - implications of not giving consent (for example, rendering the doctor unable to determine there is no coercion etc).

The person must have the capacity to make the decision to end their life

17. In debating P95/2021 the Assembly determined that a person must have the capacity to make a decision to have an assisted death, but that further consideration should be given to whether advanced decisions should be permitted.

18. As set out in paras 147-156, it not proposed that the law provides for advanced directives but that it does provide for a 'waiver of final consent'. This means a person must have capacity to make the decision to end their life throughout the whole process, except in the very limited circumstances where they have a Route 1 (terminal illness) and loose capacity after their request for an assisted death have been approved but before the day on which they die.

19. The Delivery and Assurance Board will develop detailed guidance to help the Assessing Doctors determine decision-making capacity in the context of a request for an assisted death, with a clear process for additional assessments, where required.

20. The law will set out a legal test that the Assessing Doctors (& Administering Practitioner) must use to assess whether a patient has decision-making capacity, specifically in relation to assisted dying.

21. In line with existing capacity legislation[31], the person is presumed to have decision-making capacity in relation to assisted dying unless the person is shown not to have that capacity.

22. Tools and guidance will be developed by the Delivery and Assurance Board to support the determination of decision-making capacity.

23. If the Assessing Doctor is unable to determine whether the patient has decision-making capacity in relation to assisted dying, they must refer the patient to a health practitioner with appropriate skills and training for a determination. In doing so:

    a. copies of any reports provided to the Assessing Doctor must be included in the First Assessment Report Form or Independent Assessment Report Form
    b. depending on the patient's medical condition and any comorbid mental illness, suitable registered health practitioners may include a psychiatrist, geriatrician, psychologist or specialist social worker
    c. once the Assessing Doctor has received the referral report, they may adopt the determination of the other health practitioner, or they may choose to rely on their own determination
    d. If they decide not to adopt the determination of the health practitioner, they should have clear and robust reasons for their decision that are well documented.

[31] CAPACITY AND SELF-DETERMINATION (JERSEY) LAW 2016 (jerseylaw.je)

24. The law will provide that a person has decision-making capacity in relation to assisted dying if they have the capacity to:

    a. understand any information or advice about an assisted dying decision that is required under the law to be provided to them
    b. understand the matters involved in an assisted dying decision
    c. understand the effect of an assisted dying decision
    d. weigh up the factors referred to above for the purposes of making an assisted dying decision
    e. communicate an assisted dying decision in some way (including verbally, using gestures or by other means).

Appendix 2: jurisdictions where assisted dying is permitted

Assisted dying (either self-administered, practitioner administered or both) is currently legislated for in the following jurisdictions:

Country	Date legislation came into effect	For those with terminal illness only?
11 US states	1994 (Oregon)	Yes
Netherlands	2002	No
Belgium	2002	No
Luxembourg	2009	No
Colombia	2015	No
Canada	2016	No
Australia	2019 (Victoria)	Yes
New Zealand	2021	Yes
Spain	2021	No
Austria	2022	No

Appendix 3: List of consultation questions

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 ☐

Q.3 If yes, do you think assisted dying:

should be permitted ☐

should not be permitted ☐

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 12 months or less.

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?

Yes ☐

No ☐

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 ☐

No, it should be paid for ☐

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 ☐

No, they should not have the right to refuse ☐

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 ☐

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 ☐

Don't know ☐

Please tell us the reasons for your response……..

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 minimum 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 should not prohibit professionals for raising the subject of assisted dying?

Yes – I agree ☐

No – I do not agree ☐

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…….

<u>Second opinion (see paras 116-122)</u>
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…….

<u>Confirmation of consent to proceed (see para 143-146)</u>
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 ☐

No – the law should not allow for a waiver of final consent ☐

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) ☐

No – all approvals by the Coordinating Doctor should be confirmation by a Tribunal (ie. a Tribunal involved in all cases ☐
Don't know ☐

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 ☐

Please tell us the reasons for your response…….

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?

Yes ☐

No ☐
Don't know ☐

Please 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 ☐

No– I do not agree, there should be a time period longer than 48-hours ☐

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 ☐

No - I disagree, I think there should be an expiry date ☐

Other, please state ☐.....

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 self-administer 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 self-administer the substance?

Yes ☐

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:

d. an HCS Service Delivery and Assurance Board

e. an assisted dying review committee to undertake a post-death administrative review of each individual assisted death

f. 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 ☐

No– I disagree, it should be considered an essential service ☐

Don’t know ☐

Please tell us the reasons for your response…….

Appendix 4: Privacy notice

Assisted Dying Consultation Privacy Notice

This privacy notice covers the consultation on assisted dying in Jersey, which is delivered by the public policy directorate which sits within the Strategic Policy, Planning and Performance department.

The Strategic Policy, Planning and Performance department is registered as a 'Controller' under the Data Protection (Jersey) Law 2018 (the "Data Protection Law"), as we determine the purpose and means of the processing of the personal information collected about you for this service.

As a Government Department, we generally process and hold your information in order to provide public services and meet our statutory obligations. This notice explains in more detail how we use and share your information in order to provide the service described above.

For information on how the Department uses you personal data for other services, please see the Government's webpage here.

We will continually review and update this privacy notice to reflect changes in our services and feedback from service users, as well as to comply with changes in the law.

1. How we collect information about you

Information about you will, in most cases, be collected directly from you. This may be done in any of the following ways:

- By you emailing assisteddying@gov.je
- By you responding to the consultation by mail
- By you sharing your views at an in-person consultation event

In some cases, we may collect information about you from another Government of Jersey department or from the following third parties with which we interact in order to deliver our duties:

- Responses to the consultation questions via Smart Survey
- Information collected via Eventbrite when booking for the in-person events

2. Types of information we collect

The types of personal data collected will vary depending on what information you volunteer and the information we need in each circumstance. However, we have listed below the most common categories of information we may collect about you:

- ***Contact Details*** *– e.g. Name, Address, Email address;*
- ***Organisation Details*** *– e.g. Name of your organisation, and the organisation's view on assisted dying*
- ***Your views on assisted dying*** *– e.g. you response to the consultation questions, or whether or not your support the assisted dying proposals*
- ***Voluntary Information*** *– e.g. unsolicited information you may provide to us when you engage with us.*

3. How we will use the information about you

We need to collect and hold information about you, in order to carry out the public functions of the Strategic Policy, Planning and Performance department. Our legal basis for processing personal data in most cases is that it is necessary for the exercise of Strategic Policy, Planning and Performance department function of the States or any public authority (Schedule 2 para 4(c) of the Data Protection Law).

We have set out in further detail below why we use your personal data in each instance.

Data Collected:	Used for:	Legal Basis
Contact Details; Organisation Details; Voluntary Information	*So that data can be collected for the public consultation report, and views attributed to individuals or organisations, if permission is given to do so.*	*Consent: The data subject has consented to the processing of his or her data for one or more specific purposes. (Data Protection (Jersey) Law 2018, Schedule 2, paragraph 1)*
Views on assisted dying proposals	*To contribute to consultation on policy proposals.*	*Public functions: The processing is necessary for the exercise of any function of Crown, the States or any public authority (Data Protection (Jersey) Law 2018, Schedule 2, paragraph 4b)*

4. Who we may share your Personal Information with?

4.1. Other Data Controllers

We may need to pass your information to other Government of Jersey Departments or the Scrutiny office within the States Greffe for the purposes stated above:

We may also disclose information to other public authorities where it is necessary, either to comply with a legal obligation, or where required under other legislation. Examples of this include, but are not limited to: where the disclosure is necessary for the purposes of the prevention and/or detection of crime; for national security purposes; for the purposes of meeting statutory obligations; or to prevent risk of harm to an individual, etc.

In some instances, this data sharing may require us to transfer your personal data outside Jersey and the EEA, however, we shall only do this with the necessary safeguards in place and where it is lawful because it is necessary and proportionate for the proper discharge of our statutory functions.

4.2. Service Providers

Your personal data may be processed on our behalf by certain third parties who provide service to us, so that they can provide those services. We have strict contracts in place with these service providers to ensure they process your data only on our instructions and with appropriate security in place. The categories of third parties who may receive your personal data in order to provide us with a service are:

- Email and data storage providers such as Microsoft;
- IT support or security service providers such as Prosperity 24/7;
- Event booking platforms such as Eventbrite;
- Online Survey providers such as SmartSurvey.

At no time will your information be passed to organisations for marketing or sales purposes or for any commercial use without your prior express consent.

5. Publication of your information

We may publish your information on gov.je in the public consultation feedback report for the following reasons:

- *in the interests of demonstrating a fair and transparent decision-making process, although your data will be anonymised to protect your identity, unless you have given permission for your response to be quoted and attributed to you*
- *where we are required to provide statistical information about a group of people; although your data will be anonymised to protect your identity*
- *where you have responded to a consultation, although your comments will be anonymised to protect your identity where the contribution is made in a private capacity. If it is from a person on behalf of an organisation views and connection with the organisation may be attributed.*
- *where you have contributed content to the website or Government of Jersey social media channels*.

6. How long do we store the information about you?

We will keep your information accurate and up to date and not keep it for longer than is necessary in order to develop the assisted dying proposals. Please ask to see our retention schedule for more detail about how long we retain your information.

7. Where do we store the information about you?

Government of Jersey systems store data in Jersey, the UK and the European Union. The UK has been granted adequacy status by the European Commission and personal data stored there will be protected to the same standards as personal data held in Jersey and the EU.

Some of our service providers (such as Eventbrite) are based in outside the UK and EU *e.g. the United States*. We ensure that all service providers who process personal data on our behalf outside Europe are subject to contractual restrictions that ensure they will continue to protect the data in accordance with EU requirements (known as ‘Standard Contractual Clauses) or that another mechanism (such as Adequacy) that complies with the international transfer restrictions in the Data Protection Law, is in place.

Cookies and the gov.je website

Cookies are small text files that are placed on your computer by websites that you visit. They are widely used in order to make websites work, or work more efficiently, as well as to provide information to the owners of the site. Please see the gov.je privacy notice for details of the cookies used on gov.je websites.

8. Statutory or contractual obligations to provide personal data

You are not obliged by any law or contract to provide us with your personal data. However, if you choose not to provide certain information when requested, we may not be able to perform the service you have requested, or we may be prevented from complying with our legal obligation.

9. Your rights

Please see the Government of Jersey website here for details of your rights under the Data Protection Law and how to exercise them.

10. Withdrawal of Consent

Where we rely on your consent to process personal data (see section 3 above), you can withdraw your consent by contacting assisteddying@gov.je.

11. Complaints

If you have an enquiry or concern regarding processing your personal data you can contact the Central Data Protection Unit at DPU@gov.je.

If you wish to make a complaint about how your personal data is processed, you can contact the Government's Data Protection Officer at DPO@gov.je

If you believe that [insert name of Department] has contravened the Data Protection Law and the contravention affects your data protection rights, you have the right to make a complaint at any time to the Jersey Office of the Information Commissioner (JOIC), (https://jerseyoic.org/).

We would, however, appreciate the chance to deal with your concerns before you approach the JOIC, so please contact us in the first instance.

12. Changes to this Notice

We may, from time to time, revise this privacy to ensure it remains up to date. It is advisable to check it regularly to keep aware of any changes.

This version was last updated on 14 October 2022.