Review of Assisted Dying

Assisted Dying Review Panel

14th May 2024

S.R.3/2024

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Chair's Foreword

Assisted Dying is one of the most important areas of policy and legislation that any States Assembly will ever be asked to consider. Whilst we all prefer to focus on areas that can bring positive change to the lives of the people we represent and bring happiness and fulfilment to our community – we cannot deny that suffering and death is a universal and inevitable human experience. How we deal with death and dying in our community, is just as important as the way we deal with life and living. We must not shy away from this. A 'good death' is just as important as a good life.

It was with this in mind that I accepted the Scrutiny Liaison Committee's request to Chair the Review Panel into Assisted Dying. I am grateful that Deputy Catherine Curtis and Deputy Philip Bailhache agreed to form the Panel Membership – between us we hold a diversity of viewpoints on the issue and a willingness to engage in constructive debate.

We have not taken on this task lightly. The Minister's decision to shorten the lodging period from 12 to 9 weeks has meant that as a Panel, we have worked within an extremely tight timeframe. I am proud of the way we have given full and robust consideration to the weighty issues at hand, leaving our own personal viewpoints aside, in order to present Members and the public with this evidence-based report.

Due to the shortened timescale for the review, and the volume of consultation already undertaken, the Panel elected not to call for submissions. We instead took time to carefully examine the existing body of evidence.

Our report focuses in on the key issues and decision points including safeguards, patient dignity, eligibility criteria, training and guidance (including detection and prevention of coercion), ability to object/opt out of participation, the importance of palliative care, and others. I hope that this report, along with our amendment (which can be found on the States Assembly website), will aid the public in their understanding of the issues, and Members in their deliberations on the day of the debate (and beyond).

The Panel was supported by States Greffe Officers whose dedication and hard work cannot be underestimated – for this we are grateful.

Deputy Louise Doublet

Chair, Assisted Dying Review Panel

Executive Summary

The final proposals for assisted dying ('P.18/2024') were lodged by the Minister for Health and Social Services on 22nd March 2024. They are a significant step towards the provision of assisted dying in Jersey, which set out much of the detail that will inform the development of legislation.

However, despite the significant quantity of detail and existing evidence about the development of the final proposals, the timeframe for undertaking its Review of Assisted Dying has been a key challenge for the Panel. As such, it was important that the Panel determined the key items of evidence to be considered at the outset of the review and maintained its focus on the review terms of reference (please see Appendix 1).

The Panel decided to undertake analysis of the extensive body of existing evidence and stakeholder contributions collated by Government throughout its development of the final proposals for assisted dying in Jersey, with particular focus on the Government's Phase 2 Consultation on Assisted Dying and the Ethical Review of the assisted dying proposals. The Panel scrutinised the decisions taken in relation to the final proposals, that resulted from the existing evidence considered by the Panel, as well as the rationale behind any developments and changes made to the final proposals.

Through its analysis of the existing body of evidence, the Panel identified themes and areas of follow-up questioning that it addressed in a Public Hearing with the Minister for Health and Social Services, as well as in written correspondence.

Assisted Dying in Jersey

This section focuses on the need to ensure Ministerial accountability and transparency regarding the development and provision of the assisted dying proposals. The Panel highlights its concern in this section, which is expressed through a number of Findings and Recommendations throughout the Report, that some answers it received did not address its questions sufficiently, and that the Panel is thus unclear about aspects of the final proposals. Furthermore, this section addresses the provision of palliative and end of life care in Jersey, and the need for evidence of the quality and availability of palliative and end of life care services, to provide States Members with assurances about the provision of these services.

Eligibility Criteria

A key focus of the review has been the proposed patient eligibility criteria for assisted dying, that included addressing the existing evidence about Route 1: Terminal Illness and Route 2: Unbearable Suffering. The Panel identified developments to Route 1: Terminal Illness following the in-principle States Assembly decision of P.95/2021 to permit assisted dying in Jersey, that reflect the quality-of-life challenges faced by people with neurodegenerative conditions. However, the Panel is unclear whether the recommendations of the Ethical Review were considered in the development of the eligibility criteria, and whether respondents to the Phase 2 Consultation on Assisted Dying supported Route 2: Unbearable Suffering.

The Panel also considered the minimum age requirement for an assisted death and that children were not consulted on the final proposals due to the distressing nature of assisted dying, however, the Panel recommends that any future consideration given to including children in consultations on assisted dying should involve the Children's Commissioner. Furthermore, the Panel addressed the "slippery slope" effect on assisted dying criteria and

found that all future changes to future assisted dying eligibility criteria, will require changes to Primary Law.

Processes and Safeguards

A core element of the Panel's review, and the final proposals for assisted dying, are the safeguards built into the provision of assisted dying in Jersey. The Panel did not address all aspects of the proposed safeguards but addressed specific safeguarding areas as well as evidence considered by the Panel throughout its review.

The Panel considered the proposed multi-agency approach to patient requests for assisted dying through the establishment of a Multi-Disciplinary Team and Assisted Dying Tribunals, the decision to retain the presumption of capacity for patients requesting an assisted death and the Waiver of Final Confirmation of Consent. The Panel addressed the proposed experience requirements for doctors and registered nurses as assisted dying 'Administering Practitioners' and potential locations that could be approved for an assisted death to take place.

The Panel also addressed the final proposals in relation to discussions about assisted dying between healthcare professionals and patients and participation in assisted dying and the right of staff and service providers to refuse to participate and lodged an Amendment to give more clarity and flexibility when interpreting the word "participation" in assisted dying. The Panel also considered the publication of an annual report on assisted dying, and its implications for patient privacy and wider transparency about assisted dying.

Training and Guidance

The Panel addresses specific items of training and guidance throughout this report; however, this section specifically addresses the development and timelines for the establishment of the assisted dying training and guidance. The final proposals refer to a significant number of items of training and guidance, however, the Panel found that the detail about how this would be delivered in relation to assisted dying was limited, and that the work to develop this would commence following the States Assembly debate on the final proposals in May 2024.

Funding and Resourcing

During its review, the Panel highlighted that funding for the Jersey Assisted Dying Service would be made available through submission to the Government Plan. The Panel learned that amendments or reductions in the level of funding made available to the provision of assisted dying in Jersey would need to be assessed and could impact on service delivery if funding was not adequate. Furthermore, the Panel considered the staffing and recruitment challenges faced by the Health and Community Services Department and their potential implications for the provision of assisted dying in Jersey.

Finally, the proposals set out in P.18/2024 have been developed after an extensive period of consultation with the public and key stakeholders in relation to assisted dying, following the original decision of the Citizens Jury to adopt assisted dying in Jersey. Whilst the final proposals establish a greater level of detail about the provision of assisted dying in Jersey, the Panel has highlighted throughout its report, in recommendations and findings, areas where more information and assurance are needed prior to a future States Assembly debate on assisted dying legislation.

Findings and Recommendations

Key Recommendations

Following its review of assisted dying, the Panel decided to prioritise the following Key Recommendations. The Panel's Key Recommendations relate to palliative and end of life care services, training requirements relating to the identification of and prevention of coercion, prioritisation of patient wishes about locations for assisted dying and that the Minister for Health and Social Services should support the Panel's Amendment to the final proposals:

Key Recommendation 1: The Minister for Health and Social Services should publish a plan to evidence the quality and availability of palliative and end of life care in Jersey, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Key Recommendation 2: The Minister for Health and Social Services should publish an appendix to the final proposals for assisted dying, setting out the training requirements, that comprehensively cover the identification of and prevention of coercion by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Key Recommendation 3: The Minister for Health and Social Services must ensure sufficient planning is in place to prioritise patient wishes about possible locations for assisted dying, including within the home, and that the Jersey General Hospital is only used for assisted dying as a last resort.

Key Recommendation 4: The Minister for Health and Social Services should support the Panel's Amendment to the final proposals for assisted dying.

Palliative and End of Life Care Services

Finding 1: There are three 'Success Criteria' within the Action Plan accompanying the Palliative and End of Life Care Strategy for Adults in Jersey, marked as 'Current / Ongoing' and three marked as 'Not Started'.

Recommendation 1: The Minister for Health and Social Services should publish information about the progress of the actions marked as 'Current / Ongoing' and 'Not Started' within the Action Plan accompanying the Palliative and End of Life Care Strategy for Adults in Jersey, by no later than Tuesday 21st May 2024.

Finding 2: The evidence provided about the quality and the availability of the palliative and end of life care provision in Jersey, through long-term objectives and underpinning metrics within the Palliative and End of Life Care Strategy for Adults in Jersey, is key to providing

States Members with necessary assurances prior to making their decision to support future assisted dying legislation.

Recommendation 2: The Minister for Health and Social Services should confirm the timeline for the development of a Palliative and End of Life Care Strategy beyond 2026, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Eligibility Criteria – Route 1: Terminal Illness

Finding 3: The inclusion of a 12-month life expectancy for Islanders with neurodegenerative conditions under Route 1: Terminal illness:

- Is a development beyond the original, in-principle, decision taken by the States Assembly in November 2021 to permit assisted dying.
- Reflects the particular quality of life challenges faced by people with neurodegenerative conditions.

Eligibility Criteria – Route 2: Unbearable Suffering

Finding 4: It is unclear whether the concerns raised by the Ethical Review, particularly in relation to Route 2: Unbearable suffering, have been considered in detail prior to lodging the final proposals for debate by the States Assembly.

Recommendation 3: The Minister for Health and Social Services should publish details about how the concerns raised by the Ethical Review in relation to Route 2: Unbearable suffering, were considered as part of the development of the final proposals for assisted dying, by no later than Tuesday 21st May 2024.

Finding 5: Details about the level of concern amongst respondents about the inclusion of Route 2: Unbearable suffering, as a percentage breakdown of the 1,300 respondents to the Phase 2 Consultation Feedback Report, were not provided.

Eligibility Criteria – Minimum age requirement

Finding 6: On the advice of the Children's Commissioner, children were not consulted on the final proposals due to the distressing nature of assisted dying, however, the provision of assisted dying for Islanders with mental illness and those under the age of 18 may be subject to future consideration.

Recommendation 4: The Minister for Health and Social Services should not undertake any consultation with children on assisted dying without engaging first with the Children's Commissioner.

Eligibility Criteria – Future changes to eligibility criteria

Finding 7: Any future proposed changes to the assisted dying eligibility criteria will first require approval by the States Assembly.

Finding 8: The European Convention on Human Rights, which extends to Jersey and is incorporated into domestic Law by the Human Rights (Jersey) Law 2000, does not provide a person with the right to die.

Processes and Safeguards - Multi-Disciplinary Team and Assisted Dying Tribunal

Finding 9: The final proposals for assisted dying do not specify the training requirements in relation to the identification and prevention of coercion.

Finding 10: The requirements of members of the assisted dying tribunals will be determined by The Tribunal Service.

Recommendation 5: The Minister for Health and Social Services should publish details of any previous or ongoing consultation with the Tribunal Service about the required skillset of Assisted Dying Tribunal Members, by no later than Tuesday 21st May 2024.

Processes and Safeguards - Decision-making capacity, the Waiver of Final Confirmation of Consent and Guidance about Route 1 and Route 2

Finding 11: The presumption of decision-making capacity within the final proposals is in line with the general law governing capacity, however, it is unclear whether the removal of the presumption of decision-making capacity was considered as part of the development of the final proposals, as recommended by the Ethical Review.

Finding 12: Assisted dying capacity training will focus on how professionals undertake capacity assessments and make determinations that relate to the specific capacity test for assisted dying.

Finding 13: The capacity test for assisted dying will be more extensive than that required under the Capacity and Self Determination (Jersey) Law 2016, however, it is unclear what the specific capacity test for assisted dying will be and what the additional requirements will be.

Finding 14: The Administering Practitioner will be trained to recognise verbal and non-verbal cues associated with refusal or resistance to an assisted death.

Recommendation 6: The Minister for Health and Social Services should publish the full details and processes for establishing refusal or resistance to an assisted death for a person who has lost decision-making capacity, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Processes and Safeguards - Administering Practitioner experience

Finding 15: Some respondents with a healthcare background that responded to the Phase 2 Consultation on Assisted Dying believed at least five years' or 10 years' experience is required for doctors and registered nurses assigned to the Administering Practitioner role.

Processes and Safeguards - Locations for assisted dying

Finding 16: Further work to clarify the types of premises where a right to refuse to participate could apply will be undertaken as part of the development of assisted dying legislative drafting instructions.

Finding 17: Discussions are underway about appropriate places within the Jersey General Hospital for assisted dying.

Recommendation 7: The Minister for Health and Social Services must provide details about the timeline and stakeholders involved in discussions regarding appropriate places within the Jersey General Hospital for assisted dying, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Recommendation 8: The Panel is keen to ensure that assisted dying is only carried out within the Jersey General Hospital as a last resort, and the Minister for Health and Social Services must ensure that the Jersey Assisted Dying Service is not headquartered within the Jersey General Hospital.

Finding 18: The final proposals for assisted dying require appropriate planning for other patients and residents in Government of Jersey owned and / or managed care facilities.

Recommendation 9: The Minister for Health and Social Services must ensure robust planning is in place to mitigate the potential impact of assisted dying on any other residents or patients of Government of Jersey owned and / or managed care and nursing facilities, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Processes and Safeguards - Discussions with patients about assisted dying

Finding 19: The assisted dying legislation will remain silent regarding discussions about assisted dying between healthcare professionals and patients, however, the Minister for Health and Social Services will bring forward 'Appropriate Conversations Guidance' to clarify the circumstances where raising the issue of assisted dying may be appropriate.

Processes and Safeguards - Conscientious objection and direct participation

Finding 20: The Panel's Amendment to the final proposals is intended to give more clarity and flexibility when interpreting the word "participation" in assisted dying.

Processes and Safeguards - Assisted Dying Assurance and Delivery Committee Reporting

Finding 21: The publication of an Assisted Dying Annual Report is intended to balance the need for transparency and destigmatisation of assisted dying against respect for patient privacy.

Training and Guidance

Finding 22: The work to develop the assisted dying training programme and guidance will commence following the States Assembly debate on the final proposals on 21st May 2024.

Finding 23: It is unclear what items of guidance will be developed and prioritised for consideration prior to the States Assembly debate on assisted dying legislation.

Finding 24: The details about all of the guidance to be produced will be finalised during Quarter 1 and Quarter 2 of 2026, after the States Assembly has made a decision on the draft assisted dying legislation.

Finding 25: The draft assisted dying law will be published with an accompanying detailed summary of the assisted dying training programme.

Recommendation 10: The Minister for Health and Social Services should publish details and plans about assisted dying training and guidance that include:

- A detailed summary outlining all items of assisted dying guidance to be developed and produced.
- The items of guidance to be prioritised, shared and presented to States Members.
- Details and plans about the development of the assisted dying training programme.

This information should be provided no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Funding and Resourcing

Finding 26: The Minister for Health and Social Services would be required to suspend the provision of assisted dying in Jersey, in the event that adequate funding was not available or adequate staffing was not available for the service to be delivered safely and in accordance with law.

Finding 27: The Panel is unclear about how broader staffing and recruitment challenges will be addressed in relation to the additional resource implications associated with the provision of assisted dying in Jersey.

Recommendation 11: The Minister for Health and Social Services should provide details about how general recruitment and staffing challenges across the Health and Community Services Department will be addressed in relation to the additional resource implications

associated with the Jersey Assisted Dying Service, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Finding 28: The potential risks associated with suspension of assisted dying in Jersey will be described in a full risk assessment of the assisted dying provisions and presented to the States Assembly alongside the draft assisted dying law.

Recommendation 12: The Minister for Health and Social Services should provide details and plans to mitigate and respond to the risk of Health and Community Services not being able to recruit sufficient staff to the Jersey Assisted Dying Service, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Introduction

The Panel's Review

On 25th March 2024 the Assisted Dying Review Panel (the 'Panel') began its Review of Assisted Dying. The establishment of the Panel and the review followed the publication and lodging of detailed final proposals for an assisted dying service in Jersey, on 22nd March 2024.

The Panel initially focused its work on any changes within the final proposals that differed to the original in-principle decision of the States Assembly, to permit assisted dying in Jersey set out in P.95/2021. The Panel also considered the existing consultation undertaken by Government to date and the submissions provided to Government by key stakeholders. It identified the following key issues to address in relation to assisted dying:

- Final proposals for assisted dying: To consider and examine any changes made to the original proposals P.95/2021, and the processes and safeguards for all individuals involved in assisted dying, and whether these uphold patients' dignity and wishes.
- Eligibility criteria: To examine the proposed eligibility criteria for assisted dying services in Jersey, regarding the findings and recommendations of the Ethical Review, in relation to Route 1 (terminal illness) and Route 2 (unbearable suffering) of the eligibility criteria.
- Stakeholder consultation and views: To determine whether adequate consideration was given to the views of stakeholders that contributed to Phase 2 of the Government's consultation on assisted dying.

As the review progressed, the Panel expanded on the areas and themes it considered throughout the final proposals, which included the processes and safeguards, training and guidance and the funding and resourcing requirements for the provision of assisted dying in Jersey.

Methodology

Due to the highly sensitive nature of the review topic and the timeframe of less than 9 weeks for undertaking its review, the Panel identified a number of key risks and constraints in relation to the scope and nature of the review, particularly in relation to evidence gathering.

To help inform its review within the proposed timeframe, the Panel decided to focus its evidence gathering on the extensive consultation already undertaken by Government, with particular focus on the Phase 2 Government consultation on assisted dying and the Ethical Review, and undertook a comparative analysis of this evidence against the final proposals for assisted dying in Jersey. The Panel scrutinised the decisions taken in relation to the final proposals, that resulted from the existing evidence considered by the Panel, as well as the rationale behind any developments and changes made to the final proposals.

The Panel then received the Minister for Health and Social Services to discuss the evidence it had considered during a Public Hearing on Wednesday 3rd April 2024. This included themes related to the provision of palliative and end of life care in relation to the Palliative Care and End of Life Care Strategy for Adults in Jersey 2023-2026', the eligibility criteria for assisted dying and the proposed processes and safeguards and training and guidance outlined in the final proposals.

The Panel also followed up in written correspondence with additional questions about the eligibility criteria, processes and safeguards, training and guidance and funding and resources.

Throughout its review, the Panel also received a number of written submissions from members of the public and organisations that submitted their views and concerns about the final proposals for assisted dying in Jersey. Whilst the Panel considered the submissions received, these have not informed this work, as the Panel was unable to undertake a general call for evidence and request submissions from all key stakeholders within the timeframe for undertaking its review. However, the Panel wishes to reflect the views of members of the public and key stakeholders in its review, and a number of submissions received have been included and set out in Appendix 3 of this report.

Assisted Dying in Jersey

Background and context

On 25th November 2021, 36 elected Members of the States Assembly voted, in-principle to agree with the Jersey Assisted Dying Citizens' Jury, that assisted dying should be permitted in Jersey [P.95/2021] as Amended [P.95/2021: Amendment]. The debate was informed by recommendations of the Jersey Assisted Dying Citizens' Jury, of which 78% of Jury members agreed that assisted dying should be permitted in Jersey.[1]

The Amendment to P.95/2021 requested the Government to lodge final proposals that include all processes and safeguards on assisted dying, for debate by the States Assembly prior to the preparation of instructions for the Legislative Drafting Office.

In March and April 2022, Islanders were invited to take part in the first phase of public engagement on the proposals. Phase 1 of the public consultation focused on Islanders views towards assisted dying, including their hopes, thoughts and concerns. A summary report was published in May 2022 that identified the key themes to consider in the development of detailed proposals to focus on during the second phase of consultation.[2]

Following election in June 2022, the Minister for Health and Social Services, determined that the timetable of the Assisted Dying proposals should be revised to allow a 12-week consultation period, which, alongside further delays due to the complexity of the subject, pushed back the debate on assisted dying in the States Assembly.

In October 2022, Islanders were invited to take part in the second consultation period on assisted dying, which took place between October 2022 and January 2023[3]. The second consultation period described the proposals as envisaged at that point in time and how an assisted dying service could work in Jersey, so that members of the public and key professional stakeholders could reflect on what was proposed and submit any concerns. A Consultation Feedback Report was published on 28th April 2023 and it was announced by the Minister for Health and Social Services, that *"…the Council of Ministers has agreed that the proposals considered by the States Assembly later this year should be further informed by specialists with a background in medical ethics and law, who hold a range of views on assisted*

[1] Final Report from Jersey Assisted Dying Citizens' Jury – Involve
[2] Public engagement summary report on assisted dying in Jersey – gov.je
[3] Islanders' views sought on Assisted Dying – gov.je

dying. This external review will seek to identify the ethical and moral considerations around assisted dying, including those raised in the responses to the consultation."[4]

In June 2023, the Council of Ministers considered, amended, and agreed the updated proposal, which then informed an external Ethical Review that took place between July and September 2023. A report was published on 7th November 2023 titled Assisted Dying in Jersey Ethical Review report, and considered key areas related to the eligibility criteria, approval routes, timeframes, conscientious objections and discussions with patients, the mode of assisted dying, appeals and certification of the cause and manner of death.

The final proposals for assisted dying ('P.18/2024') were subsequently lodged by the Minister for Health and Social Services on 22nd March 2024.

Ministerial Responsibility and Accountability

Whilst the final proposals for assisted dying have been lodged by the Council of Ministers, the final proposals request that the Minister for Health and Social Services bring forward the legislation that permits assisted dying in Jersey, and the establishment of an assisted dying service, *"to request the Minister for Health and Social Services to bring forward primary legislation that permits assisted dying in Jersey and that requires the Minister to establish an assisted dying service in accordance with the essential provisions and safeguards outlined in the Appendix accompanying this proposition…"*[5]

Therefore, following consideration of the existing body of key evidence, an important aspect of the Panel's evidence gathering for its review was the Public Hearing with the Minister for Health and Social Services on 3rd April 2024, and subsequent written correspondence. However, throughout this report, summarised in a number of Findings and Recommendations, the Panel has highlighted responses it received that did not provide the information the Panel had requested.

This included information about the decision-making processes that have produced key aspects of the final proposals for assisted dying, including decisions about the inclusion of Route 2: Unbearable Suffering and the presumption of decision-making capacity in the final proposals.

During its Public Hearing with the Minister, the Panel was informed that the Minister had not been involved in the development of the final proposals. However, the Panel wishes to highlight that the current Minister for Health and Social Services has responsibility and accountability for the final proposals as lodged by the Council of Ministers on 22nd March 2024, both to the Panel and the States Assembly:

> **Director of Health Policy, Government of Jersey:**
>
> *"But related to that, I just thought it might be helpful to understand, because it goes back to some of the earlier questions about route 2, the process in terms of making the decisions in the proposals that have been put forward to the States Assembly. Before Deputy Binet was appointed as Minister for Health and Social Services, there was a Ministerial working group on assisted dying, which included the Minister for Home Affairs, the Minister for Health and Social Services and the Minister for Social Security because they have a portfolio interest in assisted dying, for want of a better description. It has just been a matter of timing. It was those Ministers who made some*

[4] Assisted dying consultation report published – gov.je
[5] Assisted Dying in Jersey – P.18/2024

of the detailed decisions around how we progress with capacity and around the inclusion of route 2 on the basis, and only on this basis, that it was in the original report, it was in the original in-principle decision."

Deputy L.M.C. Doublet:

"Thank you for explaining some of the political decision-making behind that. Minister, given your officer has outlined some of the wider political accountability around this, have you significantly varied from any of the decisions of that group in the proposals that you have brought forward?"

The Minister for Health and Social Services:

"No. As you will have gleaned from what has been said, I have not had the benefit of participating in the 18 months of work or 2 years of work of any of those bodies coming up to this point in time. In real terms, I have come to the party very, very late, so my intervention in all of this has been relatively low, simply because I have not got the benefit of having had inclusion in all of those processes."[6]

Palliative and End of Life Care Services

The original in-principle decision of the States Assembly in P.95/2021 in November 2021, set out a key qualification regarding the provision of resources for palliative and end of life care in relation to the introduction of assisted dying and that, *"As set out in Sections A and G of this report it is not intended that the resources currently allocated to palliative care, or associated services, would be re-directed to assisted dying services. It is intended that the Assembly would be asked to make additional financial provision for an assisted dying service."*[7]

The final proposals are underpinned and guided by six 'Principles'.[8] The third principle is that the provision of assisted dying will not replace the provision of palliative and end of life care services in Jersey.[9] The Panel decided to consider the third principle regarding palliative and end of life care because of its potential impact on future assisted dying legislation, as set out in the final proposals, *'…legislation permitting assisted dying should not be brought into force until the Assembly is satisfied that decision taken in the 2023 Government Plan to provide for additional investment in end of life and palliative care is supporting improvements in the quality and availability of those services".* [10]

During its review, the Panel considered the final proposals in relation to the Palliative and End of Life Care Strategy for Adults in Jersey ('Strategy'), published in November 2023. The overall aim of the Strategy is to *"…improve the quantity and quality of palliative and end of life care for adults (over the age of 18) in Jersey irrespective of condition or care setting…"*

The Panel decided to ask for more detail about how future Government Plans and the Strategy would monitor, evidence, and highlight the quality and accessibility of palliative and end of life care services, during its Public Hearing with the Minister for Health and Social Services on 3rd April 2024. The Panel found that the Strategy will set out long-term objectives related to the provision of palliative and end of life care, and that these objectives are underpinned by metrics:

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[6] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[7] Assisted Dying in Jersey – P.95/2021
[8] Assisted Dying in Jersey – P.18/2024, P.23
[9] Ibid, P.23
[10] Ibid

Director of Health Policy, Government of Jersey:

"What that strategy does is that strategy has a number of long-term objectives. Those long-term objectives include elements such as 100 per cent of patients at home will have access to 24/7 model of palliative care. That 100 per cent of health and care professionals working across the community and in the hospital and hospice will have access to educational sessions around palliative care on a monthly basis. It also has other metrics in it, which is about 100 per cent of carers being supported through the palliative care experience of their loved ones. The strategy is underpinned by a number of metrics."

The Panel was informed that the draft legislation on assisted dying, would be brought forward with the proposal that it should not be enacted until States Members had received evidence and assurances about the quality and availability of palliative and end of life care services in Jersey:

Director of Health Policy, Government of Jersey:

"…Those are obviously very long-term objectives. What we are envisaging is at the point at which draft legislation is brought to the Assembly, that draft legislation will propose that the Assembly does not enact legislation until it has seen evidence that there is movement in the right direction against those and potentially other metrics, which we will work on over the next 2-year period. Clearly, because the end-of-life and palliative care strategy is a long-term strategy, they will not have met all those targets by that point in time. But what we would want the States Assembly to be assured of is that there was evidence that there was movement in the right direction to improving those services."

However, the Panel was not provided with specific details about how the Minister would monitor the development of the long-term objectives, and the metrics underpinning those objectives within the Strategy, prior to assisted dying legislation being brought forward for debate by the States Assembly:

Deputy L.M.C. Doublet:

"Is this something that you will be keeping a watching brief on and monitoring as it goes along, given the importance of this to States Members and the public?"

[…]

The Minister for Health and Social Services:

"I will probably be keeping a close eye on it aside of that as well, because, as you know, it is something that is close to my heart anyway, and the job needs to be done properly. It was of great interest to me before I came into the States, and it will remain so thereafter."[11]

The Panel also asked about how States Members would be informed of the evidence about palliative and end of life care, and learned that this would be presented as an addendum to the draft legislation with an explanation of the strategy against delivery, and that any changes in 'strategic direction' or amendments to the Strategy would be provided in the addendum to the draft legislation:

[11] Public Hearing – Minister for Health and Social Services – 3rd April 2024

Deputy L.M.C. Doublet:

"How will States Members be informed about whether the strategy and the future Government Plans … financing around the strategy? How will States Members be informed about whether that support is adequate?"

[…]

Director of Health Policy, Government of Jersey:

"Yes. That is absolutely what we envisage at this point in time, is that when we bring the draft legislation, the draft legislation will have an addendum attached to it, which will explain delivery against that strategy achievements. If it is identified that there needs to be any changes in strategic direction, because of course we are talking about a quite long time period here, and if there are any amendments to that strategy that will all be set out in the addendum to the report and proposition at that time, so that States Members can make an informed decision about palliative care provision."[12]

The Panel learned that the information to be shared with States Members prior to the debate on assisted dying legislation included:

Director of Health Policy, Government of Jersey:

"What we would look at presenting to States Members is actual metrics, which look at what the current status quo is in terms of where people are dying, where people want to die, what their access to care is, and tracking the improvements in those metrics over that 2 to 3-year period."[13]

The evidence provided to States Members about the quality and the availability of the palliative and end of life care provision in Jersey, is therefore key to providing States Members with the necessary assurances prior to making their decision to support future assisted dying legislation. In advance of the debate on assisted dying legislation, States Members will need to be informed about the details of the information that will be used to evidence the development of the long-term objectives and underpinning metrics within the Strategy, as to whether or not, palliative and end of life care services in Jersey are of quality and availability:

Assisted Dying in Jersey Consultation Report:

"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."

Finding 2: The evidence provided about the quality and the availability of the palliative and end of life care provision in Jersey, through long-term objectives and underpinning metrics within the Palliative and End of Life Care Strategy for Adults in Jersey, is key to providing

[12] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[13] Ibid

States Members with necessary assurances prior to making their decision to support future assisted dying legislation.

Key Recommendation 1: The Minister for Health and Social Services should publish a plan to evidence the quality and availability of palliative and end of life care in Jersey, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

As part of its analysis of the palliative care and end of life care principle within the final proposals, the Panel also addressed the Jersey End of Life Care Partnership Group ('Group'), the Strategy 'Action Plan' and the 'Success Criteria' for the Strategy. In written correspondence from the Minister for Health and Social Services dated 11th April 2024, the Panel was informed about how the Strategy and the Action Plan within the Strategy, would be monitored and kept under review by the Group:

Letter – Minister for Health and Social Services – 11th April 2024:

"The roles and responsibilities of the partnership group as set out in its terms of reference are:

- *Review and agree the Strategy action plan.*
- *Advise on the establishment of work streams and working groups to implement the Strategy action plan.*
- *Track progress against the success criteria set out in the Strategy and hold system partners to account in delivering the outcomes.*
- *Be a discussion forum to facilitate partnership working and remove barriers.*
- *Contribute to the design of an overarching model of care and support for people.*
- *Make proposals for service change.*
- *Ensure consistency with other island-wide strategies.*

In addition to the above:

- *A memorandum of understanding has been signed by the partner organisations, committing to work together to drive and oversee the implementation of the Palliative and End of Life Care Strategy for Adults in Jersey 2023-2026.*
- *Implementation of the strategy will be monitored through achievement of the action plan.*
- *The action plan will be updated by the HCS Commissioning Team.*
- *The Partnership will meet every 2 months or more often as necessary.*
- *Timescales will be added to the action plan. If any actions are not on track, this will be escalated to HCS executive leadership team and the Boards of partner organisations.*
- *Workstreams linked to the action plan have been set up, consisting of representatives from the partner organisations."*

However, whilst the Terms of Reference provided by the Minister set out the broad objectives for the Group in relation to the Strategy, the Action Plan appendix to the Strategy does not provide detail about the progress of the actions marked 'Current / Ongoing' within the Action Plan. In its letter to the Minister dated 8th April 2024, the Panel asked for more information about the progress of the criteria marked 'Current / Ongoing' but did not receive a response

to this question. In response to the Panel's request for more information about the timeframe for commencing the actions marked 'Not Started', the Minister informed the Panel that:

> **Letter – Minister for Health and Social Services – 11th April 2024:**
>
> *"The action plan continues to be updated, so I can provide the Panel with further information on progress following the Partnership meeting on 18 April."*

The Panel was not given sufficient time to consider this further information (including the progress of the actions marked 'Current / Ongoing' and 'Not Started' within the Action Plan accompanying the Strategy) before finalising the review.

Finding 1: There are three 'Success Criteria' within the Action Plan accompanying the Palliative and End of Life Care Strategy for Adults in Jersey, marked as 'Current / Ongoing' and three marked as 'Not Started'.

Recommendation 1: The Minister for Health and Social Services should publish information about the progress of the actions marked as 'Current / Ongoing' and 'Not Started' within the Action Plan accompanying the Palliative and End of Life Care Strategy for Adults in Jersey, by no later than Tuesday 21st May 2024.

In its letter to the Minister dated 8th April 2024, the Panel also asked about how the provision of palliative, and end of life care would be prioritised and demonstrated beyond the Strategy, and was advised that:

> **Letter – Minister for Health and Social Services – 11th April 2024:**
>
> *"The current Palliative and End of Life Care Strategy expires in 2026. A further strategy will be developed in due course, which will outline actions to be taken throughout 2027-2030."*

However, in the absence of a timeframe for developing a further Strategy beyond the current Strategy, it is not clear when the work to demonstrate how palliative and end of life care will be prioritised in future years, will commence.

Recommendation 2: The Minister for Health and Social Services should confirm the timeline for the development of a Palliative and End of Life Care Strategy beyond 2026, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

During its Public Hearing with the Minister on 3rd April 2024, the Panel learned that *"…because the end-of-life and palliative care strategy is a long-term strategy, they will not have met all those targets by that point in time* [by the time legislation is brought to the States Assembly]."[14] The Panel decided to follow up on this in written correspondence to the Minister dated 8th April 2024 and was informed that:

> **Letter – Minister for Health and Social Services – 11th April 2024:**

[14] Public Hearing – Minister for Health and Social Services – 3rd April 2024

"The success criteria for the Strategy, which are on page 53 of the Strategy, performance against these criteria will be used to help evidence improvements to the quality and accessibility of palliative and end of life care services."

However, this response does not address whether, and if so which, of the specific targets or 'Success Criteria' within the Strategy will be prioritised ahead of the States Assembly debate on assisted dying legislation.

Eligibility Criteria

The eligibility criteria are a core aspect of the final proposals for assisted dying, that mean that an assisted death will only be lawful where a person meets all the criteria. The five criteria that all persons must meet to be eligible for an assisted death are:

(i) *"the person must meet the conditions set out in either paragraphs (b) or (c);* [15]
(ii) *the person must be aged 18 or over at the point at which they make a first formal request for an assisted death;*
(iii) *the person must be ordinarily resident in Jersey;*
(iv) *the person must have a voluntary, clear, settled and informed wish to end their own life; and*
(v) *the person must have capacity to make the decision to end their own life;"*[16]

During its review, the Panel also sought to understand how the Minister for Health and Social Services intended to make the Proposition ('P.18/2024') on assisted dying to the States Assembly. In written correspondence dated 17th April 2024, the Minister confirmed that States Members would be asked to vote on each paragraph within the Proposition element of P.18/2024 separately, *"For the purposes of complete clarity, paragraphs (a) to (l) will be voted on separately, but the sub-paragraphs in the Appendix will not be voted on separately."* [17] Therefore, the Panel understands that States Members will be provided with a separate vote on the inclusion of, Route 1: Terminal Illness and Route 2: Unbearable Suffering, during the States Assembly debate on the final proposals.

The original in-principle, decision of the States Assembly to permit assisted dying in Jersey through P.95/2021 in November 2021, proposed that assisted dying be made available for people with both a terminal illness (Route 1) and unbearable suffering (Route 2). In line with the Terms of Reference for its review, the focus of this section is an examination of the proposed eligibility criteria against the previous body of evidence received from experts and key stakeholders, as well as the Panel's Public Hearing with the Minister for Health and Social Services on 3rd April 2024.

This section does not address all the eligibility criteria detailed in the final proposals but considers specific themes and key areas that have emerged from existing evidence that the Panel has considered. In particular, it will look at specific evidence about the routes available for an assisted death, with focus on the life expectancy requirements and current suffering under Route 1: Terminal illness, and how the evidence presented in relation to Route 2:

[15] This is reference to Reference to Route 1: Terminal Illness and Route 2: Unbearable suffering.
[16] Assisted Dying Proposition – P.2 - P.18/2024
[17] Letter – Minister for Health and Social Services re Construction of Assisted Dying Proposition – 17th April 2024

Unbearable suffering, has been considered and informed the development of the final proposals.

During its analysis of the evidence about assisted dying, the Panel learned that two different approval routes for assisted dying had been proposed, *"In light of the initial public engagement feedback and the findings of further research…"* and that the rationale for the inclusion of both Route 1: Terminal Illness and Route 2: Unbearable Suffering included:

> *"a. parallels with current practice / decision making, and*
>
> *b. differences between objectivity and subjectivity in decision making."*[18]

This section will also analyse evidence the Panel has received about the eligibility criteria relating to age and potential future changes to the eligibility criteria, based on concerns and themes emerging from evidence the Panel has considered during its review.

Route 1: Terminal illness

For a person to be eligible for Route 1: Terminal illness as a means of obtaining an assisted death under the final proposals, they must be diagnosed with a medical condition that meets four qualification criteria that include: a terminal physical medical condition; that is giving rise to, or is expected to give rise to unbearable suffering; that cannot be alleviated in a manner the person deems to be tolerable, and that is reasonably expected to cause the person's death within the timeframe specified.[19]

The minimum timeframe for Route 1, "…*between a person's first formal request for an assisted death and the administration of the assisted dying substance will be 14 days, except for when the person's life expectancy is less than 14 days when there will be no minimum timeframe."*[20] During its Public Hearing with the Minister for Health and Social Services, the Panel learned that the decision to remove the 14-day minimum timeframe between a person's first formal request and the administration of the assisted dying substance, in circumstances where a person's life expectancy is less than 14 days, was the one outstanding decision that had been made following the appointment of the current Minister in February 2024:

> **Director of Health Policy, Government of Jersey:**
>
> *"…It was clarified to say unless your life expectancy is less than 14 days when there is no minimum timeframe. That was a live issue that had not been resolved before Deputy Binet became Minister, and that is the one policy issue that has been resolved by Deputy Binet since he was appointed Minister for Health and Social Services."*

During its review, the Panel analysed evidence the Government had received from experts and key stakeholders about the inclusion of Route 1: Terminal illness ('Route 1') in the final proposals for assisted dying. The Governments Phase 2 Consultation Report ('Consultation') highlighted the challenges perceived by respondents to the Consultation in relation to predicting life expectancy for persons with a terminal illness, *"There was some consensus amongst supporters and opponents as to the difficulties associated with predicting life expectancy, particularly for those with neurological conditions or non-malignant disease such as cardiac or respiratory failure."*[21]

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[18] Assisted Dying Consultation Report
[19] Ibid
[20] Assisted Dying Proposition – P.2 - P.18/2024
[21] Phase 2 Consultation Feedback Report – gov.je

However, the Ethical Review was on balance, supportive of the life expectancy requirements specified for Route 1, *"…diagnoses and prognoses may not be entirely precise but are reassured that these become more accurate the closer the person is to death. (2.18). We similarly believe that the proposed timeframes are defensible, as these provide a safeguard by being more objective and measurable, and they align with laws elsewhere (2.19)."*[22]

The Panel found that the final proposals specified a different life expectancy requirement of 12 months for patients suffering from neurodegenerative conditions, compared with a six-month life expectancy requirement for other conditions. During its Public Hearing with the Minister, the Panel questioned the rationale to specify neurodegenerative conditions within the proposals:

> **Deputy L.M.C. Doublet:**
>
> *"In terms of the different routes within the proposals - there is the route one, which is for terminal illness, could you provide some more information about the decision to specify neurodegenerative diseases in the proposals above any other diseases and conditions?"*
>
> **Director of Health Policy, Government of Jersey:**
>
> *"Under the proposals, life expectancy is 6 months for someone who has got a terminal illness, but 12 months for someone with a neurodegenerative disease. That is a development from the original proposals that the States voted for in principle. There are a number of clarifications and amendments to that original in-principle decision, and this is one of them."*[23]

The Panel also learned that the decision to specify a 12-month life expectancy for patients with neurodegenerative conditions followed research about the operation of assisted dying in other jurisdictions, including discussions with assisted dying practitioners, and particular quality of life challenges for certain categories of neurodegenerative conditions:

> **Director of Health Policy, Government of Jersey:**
>
> […]
>
> *The reason why we introduced that is we have done a lot of research about the realities of how assisted dying works in other jurisdictions. We have spoken to practitioners in other jurisdictions and most other jurisdictions, or many other jurisdictions, have some kind of life expectancy. One of the things that was quite clear in those conversations is the practitioners were raising with us the particular risks of a 6-month life expectancy for people with neurodegenerative conditions. That is because of the disease trajectory. If you have something like muscular dystrophy*[24]*, it is regrettably the case that your quality of life is going to diminish many, many months before you actually die. Hence, as a result, the proposal that for those categories of neurodegenerative diseases only that have those particular challenges around quality of life, there should be special provision of 12 months made."*[25]

During its analysis of the evidence produced by the Consultation, the Panel also considered feedback from respondents about 'current suffering' in relation to Route 1, in relation to

[22] Assisted Dying in Jersey Ethical Review Report
[23] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[24] The reference to muscular dystrophy should have been a reference to motor neurone disease
[25] Public Hearing – Minister for Health and Social Services – 3rd April 2024

ambiguity about whether Islanders with 'current suffering' would be included in the final proposals, *"Responses received from two stakeholder organisations commented on the wording in paragraph 13 of the consultation report – 'has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months'*

Noting that it was ambiguous and did not appear to explicitly allow for those with a terminal illness who are currently suffering:".[26]

However, the final proposals highlighted that the definition of Route 1 had been updated to clarify that, *"…those eligible under Route 1 may either be experiencing current suffering OR expected to experience suffering in the future".*

Finding 3: The inclusion of a 12-month life expectancy for Islanders with neurodegenerative conditions under Route 1: Terminal illness:

- Is a development beyond the original, in-principle, decision taken by the States Assembly in November 2021 to permit assisted dying.
- Reflects the particular quality of life challenges faced by people with neurodegenerative conditions.

Overall, whilst the Panel identified some disagreement about the minimum timeframes for Route 1 and some ambiguity about the provision for 'current suffering' under the Route 1 proposals within the Consultation, the Panel noted consensus amongst respondents and stakeholders, that the process for assisted dying should be no longer than necessary, *"…in order to balance safeguards with a system that does not prolong suffering. They also supported that proposal that Route 1 approvals did not require approval by a Court or Tribunal."*[27]

Furthermore, the Panel found that the Ethical Review was supportive of the proposals for Route 1: Terminal illness, that struck a balance between self-determination and protection, more accurate diagnoses, prognoses and predictions nearer to death and that the associated timeframes were more objective and measurable, *"Assuming that AD will be legalised in some form, on balance we believe that the proposals regarding Route 1 (terminal illness) are ethically appropriate, for the various reasons given in favour above."*[28]

Route 2: Unbearable Suffering

For a person to be eligible for Route 2: Unbearable suffering as a means of obtaining an assisted death under the final proposals, they must meet three qualification criteria that include: an incurable physical medical condition, that is giving rise to unbearable suffering and that cannot be alleviated in a manner the person deems to be tolerable.

The second qualification criteria highlight within the proposals that a key distinction from Route 1 is that a person will only be eligible if they are *"…currently experiencing unbearable suffering (i.e., not an expectation of future unbearable suffering)."*

During its review, the Panel considered evidence from the Phase 2 Government Consultation on Assisted Dying ('Consultation') and the Ethical Review in relation to Route 2. The Panel found mixed responses to the Consultation about the inclusion of 'unbearable suffering' in the

[26] Phase 2 Assisted Dying Consultation Feedback Report
[27] Assisted Dying Phase 2 Consultation Report
[28] Assisted Dying in Jersey – Ethical Review

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

However, the Panel also considered the recommendation of the Ethical Review, which takes a position against the inclusion of Route 2 in the proposals for assisted dying:

> **Ethical Review:**
>
> *"…we have serious reservations about allowing AD in such circumstances and on balance we believe that the proposals regarding Route 2 are not ethically appropriate. Aside from linguistic quibbles about the accuracy of describing assistance in such cases as instances of assisted dying, Route 2 raises significant concerns because it: makes (and reinforces) an "ableist" judgment about the negative value of the lives of people with disabilities; relies on perceptions of the tolerability of suffering, which may change over time and be influenced by social and psychological factors; rests on a concept – "suffering" – which is too vague, multifaceted and subjective to be a reliable eligibility criterion; and, given its inherent subjectivity, may lead to the expansion of AD in terms of numbers and scope."*

During its Public Hearing with the Minister for Health and Social Services, the Panel questioned the Minister about some of the concerns expressed in the Ethical Review, such as the concern about Route 2 making and reinforcing an *"…ableist judgement about the negative value of the lives people with disabilities"*:

> **The Minister for Health and Social Services:**
>
> *"This is a matter of personal choice for an individual. So long as there are sufficient safeguards everywhere for everybody concerned, I do not really see this as being an issue. I have to say, with regard to the ethical review, and I will make my feelings a little bit better known, I read the biography of the 3 people concerned and, before I started reading their outcome, I guessed straight away what the outcome would be. When I read it through, it was the outcome I expected. I have gone public on saying that I think an ethical review was not perhaps the wisest of things to do because you could have chosen any combination of 3 ethicists and perhaps had a different outcome. It is the opinion of 3 people, and that is what their ethical opinion happens to be. How useful that is, as I say, this is a free vote, a democracy. If people want to take note of that and that informs them to the extent that they feel obliged to follow the ethical advice that has been given by these 3 people, that is a matter for them."*

Furthermore, the Panel decided to ask additional questions about how the Ethical Review was considered and factored into the development of the final proposals in relation to Route 2:

> **Deputy L.M.C. Doublet:**
>
> *"Not getting to the debate just yet, so focusing on the period of time between the ethical review and the proposals that have been lodged, in terms of the decision making between then, what regard did you give to the ethical review before you lodged these proposals?"*
>
> **The Minister for Health and Social Services:**

"…I looked at the ethical review and I thought, there we are. We have had the opinion of 3 ethicists, and I think it is appropriate that that should be included in the proposals that go forward for the States Members to decide for themselves what they make of it."[29]

However, the responses the Panel received do not indicate whether the concerns raised by the Ethical Review about Route 2 have been considered in detail prior to lodging the final proposals for debate by the States Assembly. Nor do the responses address whether the evidence submitted by the Ethical Review, has informed the development of the final proposals in relation to Route 2. For example, the Panel identified two pieces of evidence cited by the Ethical Review about its concerns over Route 2 in relation to the concept of "ableism":

Ethical Review:

"…[Route 2] *reflects an "ableist" presumption that persons with a illness, disease, or disability, whether it is in the context of end-of-life or not, are better off dead than alive (see 2.23).*[30]

[…]

"Allowing AD as a response to unbearable suffering makes (and reinforces) an "ableist" judgment about the negative value of the lives of people with disabilities. According to a broad definition of disability, all persons applying for AD on the basis of an incurable physical condition can be defined as disabled."

"40 Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) provides: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". [31]

Finding 4: It is unclear whether the concerns raised by the Ethical Review, particularly in relation to Route 2: Unbearable suffering, have been considered in detail prior to lodging the final proposals for debate by the States Assembly.

Recommendation 3: The Minister for Health and Social Services should publish details about how the concerns raised by the Ethical Review in relation to Route 2: Unbearable suffering, were considered as part of the development of the final proposals for assisted dying, by no later than Tuesday 21st May 2024

Following the Public Hearing, the Panel decided to follow up in written correspondence with questions about Route 2 and asked for a breakdown of respondents to the Phase 2 Government Consultation on Assisted Dying about support for and against Route 2 and was informed that the Consultation was not necessarily representative of wider public opinion. This question was not asked during the Phase 2 Consultation however, the following response was provided:

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[29] Public Hearing – Minister for Health and Social Services – 3rd April 2024

[30] See, e.g., H Braswell, R Garland-Thomson. When antidiscrimination Discriminates. The American Journal of Bioethics 2023; 9: 35-38.

[31] *https://www.ohchr.org/en/instrumentsmechanisms/instruments/convention-rights-persons-disabilities* and https://www.ohrc.on.ca/en/policy-ableism-and-discrimination-based-disability/2-what-disability#_edn17"

"As set out in "NOTE: Route 2 – unbearable suffering" (Appendix 1. Para 3 of the report and proposition) the Phase 2 consultation survey did not include a specific question on whether Route 2 should be permitted, as the States Assembly had already decided 'in principle' that it should be permitted. As such it is not possible to provide a percentage breakdown of responses that supported or did not support Route 2."

Furthermore, as noted in page 12 of the Phase 2 consultation report, the people who responded to the consultation did so because of their interest in assisted dying and it must not be assumed that their responses are representative of wider public opinion ("A consultation is not an opinion poll; it is a tool to allow those who want to express an opinion to have their say. Consultations are not carried out among representative samples of those in a target audience… [and] should not, therefore, be taken as a comprehensive statement of public, business or stakeholder opinion – it simply harvests a wide range of views and opinions among interested parties on given proposals").[32]

However, the Consultation exercise was highlighted as a key piece of information used by Government to help inform the development of the final proposals, "*During the P95/2021 debate, the Assembly noted the need for further consultation with both the public and professional stakeholders, in order to inform the development of the detailed proposals outlined in this report. That was undertaken in two phases."*[33] Furthermore, the Consultation received a significant number of responses *"Phase 2 of the public consultation focussed on detailed proposals for assisted dying in Jersey and took place over a 12-week period between October 2022 and January 2023.7 Approximately 1,300 people and organisations responded to this second phase of consultation."* [34]

In written correspondence to the Minister, the Panel also asked about how the Consultation feedback had been considered during the development of the final proposals, and noted in the Ministers response dated 10th April 2024 that the feedback indicated 'levels of concern':

Letter – Minister for Health and Social Services – 10th April 2024:

As set out above, the feedback in the Phase 2 consultation informed the decision to ask the Ethical Review Panel to consider Route 2 because the feedback received indicated levels of concern amongst respondents.

However, details about the level of concern amongst respondents cited in the Minister's response were not provided, and the Panel was unable to consider whether respondents expressed concerns about the inclusion of Route 2 as a percentage breakdown of the 1,300 responses received.

Finding 5: Details about the level of concern amongst respondents about the inclusion of Route 2: Unbearable suffering, as a percentage breakdown of the 1,300 respondents to the Phase 2 Consultation Feedback Report, were not provided.

Furthermore, the Minister also advised the Panel that feedback from the Consultation survey responses indicated mixed views about the specific characteristics of Route 2, and that

[32] Letter, Minister for Health and Social Services, 10th April 2024
[33] Assisted Dying Proposition – P.17 - P.18/2024
[34] Assisted Dying Proposition – P.17 - P.18/2024

individual comments received in addition to research had informed the characteristics of Route 2 as set out in the final proposals:

> **Letter – Minister for Health and Social Services – 10th April 2024:**
>
> *"With regard to the specific characteristics of Route 2 (for example, 90-day minimum timeframe; confirmation of approval by Tribunal) feedback from survey respondents was very mixed, with no clear majority views. It was the individual comments received, in addition to research about practice in other jurisdictions, that predominately informed the proposed Route 2 characteristics. For example, the inclusion of a tribunal – which whilst not common to many other jurisdictions that permit assisted dying – was recognised by assisted dying practitioners as a valuable safeguard for non-terminally ill people."*

The Panel also followed up on questioning about the Ethical Review in written correspondence, and asked how the recommendation of the Ethical Review not to include Route 2 was considered as part of the development of the final proposals:

> **Letter – Minister for Health and Social Services – 10th April 2024:**
>
> *In November 2021 the States Assembly agreed, in principle, that assisted dying should be permitted in Jersey (P.95/2021) for Routes 1 and 2 but determined that detailed proposals should be brought back to the Assembly for debate.*
>
> *The inclusion of Route 2 reflects the 2021 decision with the report to the proposition including a more detailed examination of Route 2, including the feedback received in the Phase 2 consultation and the views of the ethical review authors.*
>
> *It is for the Assembly to determine whether to proceed with Route 2. It is not for the Council of Ministers to remove Route 2 based on the feedback received ahead of a decision of the Assembly.*

However, the Panel is concerned about the lack of a robust rationale behind the decision to reject this finding of the Ethical Review. The Panel is also concerned about whether the finding was considered or how it has impacted the decision-making processes used to inform the development of the final proposals. Furthermore, it is unclear whether the evidence supporting the conclusions of the Ethical Review has been addressed or considered by the Minister as part of the development of the final proposals:

> **Letter – Minister for Health and Social Services – 10th April 2024:**
>
> *"How was the evidence provided by the Ethical Review factored into this process?*
>
> *As outlined above, the Ethical Review is evidence to be by considered by the Assembly in determining whether to proceed with Route 2."*

Following its review, the Panel was also provided with the results of the Government's targeted engagement with disabled Islanders about Route 2, published on 7th May 2024 as an addendum to the final proposals. However, the Panel did not have sufficient time to use the results of this engagement to inform this work.[35]

[35] Assisted Dying P.18/2024 – Addendum

Minimum age requirement

The original in-principle, decision of the States Assembly in P.95/2021 in November 2021 was to include research and detailed consultation with the Children's Commissioner, prior to lodging any associated legislation. However, the final proposals preclude children from requesting an assisted death[36]. The decision to restrict assisted dying to Islanders aged 18 and over, followed a process that involved consultation between the Minister for Home Affairs and the Children's Commissioner. The report accompanying the final proposals summarises the concerns of the Children's Commissioner, that *"…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."*[37]

The Panel learned that children were not consulted on the development of the final proposals for assisted dying. The Phase 2 Assisted Dying Consultation highlights that the target audience of the consultation was Islanders aged 18 years and over, and that *"Views of children where not explicitly sought on the advice of the Children's Commissioner".*[38]

During its Public Hearing with the Minister for Health and Social Services on 3rd April 2024, the Panel asked about the views the Government had received on assisted dying in relation to children during the consultation period, and learned that the topic of assisted dying would be too distressing for children to be consulted on:

> **Deputy L.M.C. Doublet:**
>
> *We are going to move on to another aspect that was highlighted in the ethical review and your proposals have been brought forward in line with the ethical review; that is the age of 18 and over. The decision was made to restrict the assisted dying service to people over the age of 18. This proposed eligibility criteria, is it in line with other jurisdictions and did you receive any views during the consultation period that argued the other way to reduce that age?*
>
> **Director of Health Policy, Government of Jersey:**
>
> *"When the States made the original in-principle decision in 2021, they made the in-principle decision for 18 and over because that was recommendations of the citizens' jury. However, within the body of that report, for that report and proposition, we said that we would do additional consultation on this issue. We reached out to the then Children's Commissioner to have a conversation about how we manage the consultation with children and young people on such a sensitive subject, and we got a very clear steer back from the Children's Commissioner that it was the view of the Children's Commissioner that this subject was potentially so distressing to children and young people that the benefits of consulting them were outweighed by the risks of consulting them. What we did not do is bespoke consultation with children and young people. However, we had young people who did attend some of our public hearings, and those young people held different views on whether or not children should be eligible to assisted dying."*[39]

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[36] Assisted Dying Proposition – P.18/2024
[37] Assisted Dying Proposition – P.18/2024
[38] Assisted Dying in Jersey – Phase 2 Consultation Feedback Report – April 2023
[39] Public Hearing – Assisted Dying Review Panel with the Minister for Health and Social Services – 3rd April 2024

Furthermore, the Ethical Review recommended that the provision of assisted dying be restricted to adults, and cited a number of concerns about the extension of assisted dying to children, "*However, in view of concerns about the autonomy and vulnerability of children, the public's ambivalence about extending AD to minors, and the low uptake and controversial status of child euthanasia in those jurisdictions that allow the practice, on balance we believe that, if permitted, AD should be restricted to adults."*[40]

During its Public Hearing, the Panel also asked about the relationship between assisted dying for children and Gillick competency. Gillick competency is often used in *"a wider context to help assess whether a child has the maturity to make their own decisions and to understand the implications of those decisions".*[41] The Panel learned that Jersey had taken a major step forward in the provision of assisted dying and that restriction of assisted dying to adults was a 'sensible starting point':

> **Deputy L.M.C. Doublet:**
>
> *Minister, with this concept in mind, could you outline why proposals were not included for under-18s who could demonstrate this Gillick competency to be able to access assisted dying?*
>
> **The Minister for Health and Social Services:**
>
> *If I am quite honest, I think Jersey has already taken a fairly major step in both (a) and (b). There is certainly not sufficient experience in any of this to be going into an area which is, as you describe it, Director of Health Policy, Government of Jersey], complicated. You used 2 terms that I thought were …*
>
> **Deputy L.M.C. Doublet:**
>
> *Very difficult ethical area.*
>
> **The Minister for Health and Social Services:**
>
> *Absolutely. This really is a very tricky area. I have to say, if I was 16½, 17 and confronting a terminal illness and was in acute pain, I would feel aggrieved that the law did not include me. But I think we have to have a sensible starting point. I think the one that we have is probably as far as it was sensible to go at this stage.*[42]

However, in further questioning about the possibility of assisted dying for children in Jersey in future, the Minister informed the Panel that consultation on assisted dying for Islanders with a mental illness and Islanders under the 18, may be subject to 'further consideration':

> **Deputy L.M.C. Doublet:**
>
> *"Thank you. Is it fair to say, if there are areas that might be revisited down the line, that this might be one of them?"*
>
> **The Minister for Health and Social Services:**

[40] Assisted Dying in Jersey - Ethical Review Report
[41] NSPCC – Gillick competency and Fraser guidelines
[42] Public Hearing – Assisted Dying Review Panel with the Minister for Health and Social Services – 3rd April 2024

"There are 2 key areas that are difficult: mental illness and below 18. Those are 2 very complex areas that may, at some point in time, come back on to the radar for further consideration."[43]

Finding 6: On the advice of the Children's Commissioner, children were not consulted on the final proposals due to the distressing nature of assisted dying, however, the provision of assisted dying for Islanders with mental illness and those under the age of 18 may be subject to future consideration.

Recommendation 4: The Minister for Health and Social Services should not undertake any consultation with children on assisted dying without engaging first with the Children's Commissioner.

Future changes to eligibility criteria

During its review, the Panel noted concerns in evidence about a 'slippery slope' effect on the assisted dying eligibility criteria and the safeguards in place. This concern was expressed in the Report accompanying the Government's Phase 2 Consultation ('Consultation'), that "*Nearly half of the public written responses opposed to assisted dying expressed concern that the eligibility criteria and any safeguards set out in law would 'erode' over time."*[44]

The Consultation also highlighted that some responses had provided examples of other jurisdictions where assisted dying eligibility criteria had widened over time, *"either through political decisions or as a result of Court challenge on the grounds of human rights"*. Furthermore, the Consultation highlighted that, *"Other responses expressed concern that the number of people requesting or receiving an assisted death in some other jurisdictions had risen over time, particularly in Canada and the Netherlands."*[45]

However, the concern about widening the provision of assisted dying was also set out in the Ethical Review of the proposals, in relation to Route 2: Unbearable suffering, which highlighted that allowing assisted dying in response to unbearable suffering *"…may lead to the expansion of AD [assisted dying] in terms of numbers and scope*[46]*"*, and highlighted Belgium, the Netherlands and Canada as examples.

During its Public Hearing with the Minister for Health and Social Services on 3rd April 2024, the Panel asked about the concerns raised in relation to the potential for the expansion of assisted dying, and was informed that Government had not identified a route towards a 'slippery slope' and that the final proposals do not allow for any regulation making powers:

Deputy C.D. Curtis:

"Can you comment on the concerns raised about the potential for the expansion of assisted dying in numbers and scope, and how they specifically will be mitigated?"

The Minister for Health and Social Services:

"I think in all the time that I have had an interest in assisted dying, I have had people mentioning the slippery slope this and the slippery slope that. All I would say is whatever rules and regulations may come about, whatever laws come about as a result

[43] Public Hearing – Assisted Dying Review Panel with the Minister for Health and Social Services – 3rd April 2024
[44] Assisted Dying in Jersey – Phase 2 Consultation Feedback Report – April 2023
[45] Assisted Dying in Jersey – Phase 2 Consultation Feedback Report – April 2023
[46] Assisted Dying in Jersey – Ethical Review

of this process, to have any changes to those laws would require precisely the same degree of care and attention that this has received. Within the provisions that will come through from this, if they do come through, I do not see there is any route for slippage. The only slippage that can occur is if somebody goes back to the Assembly and asks for changes, and those changes would have to go through the same rigorous process as we have already been through. I personally find it something of a false argument."

Director of Health Policy, Government of Jersey:

"Very specifically, the proposals do not allow for any regulation-making power. Every decision must come back to the States Assembly. It might also be helpful for the panel to understand that in some of the jurisdictions where there has been an expansion of the eligibility criteria over a period of time, that has sometimes been driven by the fact that other jurisdictions have hardwired into their legislation a 5-year review period.

It is that review period and the outcome of that review period, which has resulted in an expansion of criteria. This legislation very deliberately does not do that."[47]

Finding 7: Any future proposed changes to the assisted dying eligibility criteria will first require approval by the States Assembly.

Furthermore, the Panel learned that the reasons for the expansion of assisted dying in other jurisdictions, were sometimes related to the decisions taken by parliaments of those jurisdictions, but also sometimes related to the rights afforded to the citizens of those countries, and how the experiences of Canada regarding assisted dying differed from that of jurisdictions protected by the European Convention on Human Rights ('ECHR'). The Panel was informed that a limitation on the expansion of assisted dying in Jersey was that the ECHR does not provide a person with the right to die:

Director of Health Policy, Government of Jersey:

"We have done a lot of thinking around this issue in developing proposals; a lot of thinking around the issue of the slippery slope. We have been very live to the concerns that have been expressed to us by members of the public, and also very live to the fact that in some jurisdictio–s - not all jurisdictio–s - where assisted dying has been introduced, you have seen an incremental expansion of the eligibility criteria. When, as officers, we were set out on this task, one of the guiding principles was you need to address to look at how your proposals address the slippery slope. For that reason, as I said, we have not included regulation-making powers. I think it was in Canada and one other jurisdicti–n - I am sorry, I cannot remember which jurisdicti–n - they included this review period. But the other thing that we have done is we have looked at the reasons why you see an expansion of criteria in other jurisdictions. Sometimes that is because those jurisdictions have made a decision … Parliaments of those decisions, have made a decision looking at the day-to-day working of their assisted dying legislation that needs to be amended. But in some jurisdictions, there is a very different reason. Canada is often cited as the jurisdiction of concern. One of the things that is not necessarily understood about the experience that they have gone through in Canada is that, in Canada, they essentially have a Bill of Rights, which has a right in it, which is a right to die. We do not have that in the European Convention for Human Rights. What has happened is individual members of society have gone to the courts

[47] Public Hearing – Assisted Dying Review Panel with the Minister for Health and Social Services – 3rd April 2024

in Canada and have argued for their right to an assisted death and argued that their legislation in Canada was too restrictive because it provided an assisted death for some people and not other people. Because of their Bill of Rights, their court has agreed with them. Also in Canada, the way that their legislative system is set up is very different. Essentially, their Supreme Court can now instruct their Parliament to amend its legislation. It is a very, very different set up."

Director of Health Policy, Government of Jersey:

"They just do not exist. The European Convention on Human Rights is absolutely silent on the right to die. There is no right to die. There is no point at which a person can argue under the European Convention on Human Rights, that they have a right to assisted death. They do not. They have a right not to be discriminated against, but they do not have a right to die for an assisted death."

Finding 8: The European Convention on Human Rights, which extends to Jersey and is incorporated into domestic Law by the Human Rights (Jersey) Law 2000, does not provide a person with the right to die.

Processes and Safeguards

The safeguarding of adults is *"…about preventing and responding to the abuse or neglect of adults with care and support needs".*[48] A core aspect of the final proposals, and a key consideration for the Panel during its review, has been the safeguards built into the provision of assisted dying in Jersey. The original in-principal decision of the States Assembly to permit assisted dying in Jersey through P.95/2021 in November 2021, set out the following safeguards:

"(iii) an assisted dying service in Jersey should be subject to the following safeguards:

(1) assisted dying should be permitted with the direct assistance of registered medical practitioners and registered nurses only;

(2) 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;

(3) assisted dying should be subject to a mandatory period of reflection;

(4) a withdrawal of request should be permitted at any time; and

(5) assisted dying should only be permitted at pre-approved locations."[49]

The final proposals ask States Members to *"…request the Minister for Health and Social Services to bring forward primary legislation that permits assisted dying in Jersey and that requires the Minister to establish an assisted dying service in accordance with the essential provisions and safeguards outlined in the Appendix accompanying this proposition…"*[50]

[48] Safeguarding Adults – Safeguarding Partnership Board
[49] Assisted Dying in Jersey – P.95/2021
[50] Assisted Dying in Jersey – P.18/2024

During its review the Panel decided to ask for clarification about the meaning of 'essential provisions', in relation to the assisted dying safeguards. The Minister informed the Panel that use of the term 'essential' was to indicate safeguards and provisions that are:

- *"essential to providing a service which supports the needs and wishes of people who have requested an assisted death, for example sub-paragraph (x) provides for the assisted dying substance to be self-administered or administered by the Administering Practitioner*

- *essential to safeguarding people, for example sub-paragraph (v) requiring assessment by two doctors in order to protect people from the potential risks associated with a single assessment process The essential provisions and safeguards have been identified through the consultation and research phase but, for purposes of clarity, they are not the only safeguards."*[51]

The final proposals have established five overarching safeguarding objectives, under which 76 safeguarding provisions are set out. These safeguarding objectives include compliance with the proposed eligibility criteria, protection and support for all Islanders, practitioners acting within the law, support for practitioners when acting in accordance with guidance and law, and the delivery of a high quality and safe service[52].

This section will not address all the safeguarding provisions set out within the final proposals but will address specific safeguarding areas and evidence considered by the Panel throughout its review. These include the establishment of an assisted dying Multi-Disciplinary Team and Assisted Dying Tribunal, patient decision-making capacity and the Waiver of Final Confirmation of Consent, the professional experience required of Administering Practitioners, locations for assisted dying, discussions with patients about assisted dying, conscientious objection and direct participation and the reporting on assisted dying by the Assisted Dying Assurance and Delivery Committee.

Safeguards: Multi-Disciplinary Team and Assisted Dying Tribunal

As part of its analysis of the assisted dying safeguards set out within the final proposals, the Panel identified that assisted dying in Jersey would include the establishment of a *"…multi-disciplinary team* ('MDT') *and additional assessments / additional clinical opinions are required where an assessing doctor is not able to reach a determination about elements of the eligibility criteria".*[53]

During its review, the Panel found evidence that is supportive of a multi-agency approach to patient requests for an assisted death. The Phase 2 Government Consultation on assisted dying ('Consultation') set out that: "…*some health professionals offered the view that making a determination on eligibility for an assisted death would be better suited to a multi-agency decision-making approach."*[54]

The final proposals reiterated the feedback received from the Consultation that supported the establishment of an MDT, *"During the Phase 2 consultation process, multiple stakeholders expressed the view that the assisted dying assessment process could be more robust if it included the involvement of other professionals, in addition to the assessing doctors. This*

[51] Letter – Minister for Health and Social Services – 11th April 2024.
[52] Assisted Dying in Jersey – P.18/2024
[53] Assisted Dying in Jersey – P.18/2024
[54] Assisted Dying in Jersey – Phase 2 Consultation Feedback Report

included feedback during the in-person public sessions and the dedicated health care professionals' sessions."[55]

The purpose of the MDT was summarised in the final proposals as being established to *"…provide check and challenge for the assessing doctors and a multidisciplinary perspective to discussions of eligibility."*[56]

However, the Panel found within the final proposals that, "*The requirement for an MDT, and the practice of the MDT will not be provided for in law"*[57]*.* The Panel decided to ask about the MDT during its Public Hearing with the Minister for Health and Social Services on 3rd April 2024, and why the requirement and practice of the MDT would not be provided for in law. The Panel learned that the reasons for not making an MDT a legal requirement was because the MDT depended on the needs of the person requesting an assisted death:

> **Deputy L.M.C. Doublet:**
>
> *"*[…] *I would like to ask about the multidisciplinary teams and the associated assessment guidance. The multidisciplinary teams will be formed but the requirement in practice of those teams will not be provided for within the actual legislation. Could you just provide information to us about why that will not be in the legislation given that a team will be formed for each of the assisted dying requests?"*
>
> **Director of Health Policy, Government of Jersey:**
>
> *"Yes, the law said there would be a multidisciplinary team that will place a duty on the Minister to ensure that there is a multidisciplinary team available. The reasons why the actual work and activities will not be described in detail in the legislation is because it will be entirely dependent on the person who has made a request for an assisted dying. For example, if there are concerns about potential coercion, you will need to engage different members of the multidisciplinary team with different skills, for example more social workers who have more understanding and training in family dynamics to look at the coercion issue. If the person who has made a request has a communication difficulty, you would need to engage the members of the multidisciplinary team who have speech and language therapy support. It is not defined because the activities of that team will be entirely dependent on the needs of the person who has made the request and on the requirements of both the co-ordinating doctor and the independent assessment doctor in terms of what extra skills, knowledge, et cetera, they need to be able to make a full assessment of that person and that person's situation."*[58]

The Panel then asked about the resourcing of the MDTs and whether the expertise was available on-Island for these to be established. However, the responses the Panel received did not confirm whether the MDTs could be resourced from the on-Island expertise available at present, but that the final proposals are clear that non-resident professionals could be contracted to undertake the work if necessary:

> **Deputy L.M.C. Doublet:**
>
> *"Thank you. Minister, are you satisfied that we have the necessary expertise on-Island to form these teams to make good, robust decisions?"*[59]

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55 Assisted Dying in Jersey – P.18/2024
56 Assisted Dying in Jersey – P.18/2024
57 Assisted Dying in Jersey – P.18/2024
58 Public Hearing – Minister for Health and Social Services – 3rd April 2024
59 Public Hearing – Minister for Health and Social Services – 3rd April 2024

The Minister for Health and Social Services:

"In general, to the extent that I know I would say yes, and I would have thought that if we really needed expertise from elsewhere, then we would seek that expertise from somewhere else, would we not?"

[…]

Director of Health Policy, Government of Jersey:

"Yes, the proposals are very clear, and it is not just related to the multidisciplinary team. It is related to everybody who works in the assisted dying service because there is a right to refuse to participate. People need to opt in to work for the service, and that would include the members of the multidisciplinary team. It may be that we either cannot engage individuals with the right skills who are currently on-Island, or we cannot engage enough of the right people with the right skills on-Island. The proposals are very clear that in order to be able to stand up this service the Health Department may need to contract non-resident professionals to come to Jersey on a contract basis to support an assisted dying request, but it is really important to note that if we do that the proposals are very clear that that person must be registered with the Jersey assisted dying service. They must have undergone the mandatory training, and they must meet the competency requirements for that particular post."[60]

The Panel questioned whether the MDTs would be capable of spotting patient coercion and was informed that a dedicated training module on coercion would be delivered. However, the Panel found that the final proposals do not specify the training requirements regarding the identification of and prevention of coercion, and asked the Minister to ensure that sufficient detail is included about this:

Deputy L.M.C. Doublet:

"[…] *How can you be certain, Minister, that the multidisciplinary team will be equipped to spot coercion where it does take place?"*

[…]

Director of Health Policy, Government of Jersey:

There would be a dedicated module around coercion within training, which everybody would undergo. I think the ..

Deputy L.M.C. Doublet:

"Given that it does not seem to be highlighted as a specific area of the training, Minister, would you agree to take a look at the format of that training to ensure that it is included in sufficient detail?"

The Minister for Health and Social Services:

"I will certainly take a look at it, but I will make the point again that in any of these proposals one has to eventually exercise some common sense and make a judgment as to looking at those proposals, 32 looking at the safeguards and saying on balance,

[60] Public Hearing – Minister for Health and Social Services – 3rd April 2024

is that a sensible way to proceed. I am comfortable at this point in time that it is, but I will take up your point."[61]

Finding 9: The final proposals for assisted dying do not specify the training requirements in relation to the identification and prevention of coercion.

Key Recommendation 2: The Minister for Health and Social Services should publish an appendix to the final proposals for assisted dying, setting out the training requirements, that comprehensively cover the identification of and prevention of coercion by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

The Panel also considered the requirement for assisted dying tribunals for patients requesting an assisted death via Route 2: Unbearable suffering. The tribunal process is an additional step, that will be required by the assisted dying legislation, for patients requesting an assisted death via Route 2, whereby *"…a person has an incurable physical condition, and is eligible under 'Route 2 – unbearable suffering', the Coordinating Doctor's approval must also be subject to confirmation by a Tribunal".*[62]

During its Public Hearing with the Minister, the Panel asked questions about the level of experience required of assisted dying tribunal members. The Panel was informed that the experience required of tribunal members would be determined by The Tribunal Service:

Deputy C.D. Curtis:

"The panel notes that each assisted dying tribunal will be appointed by the Bailiff and consist of one legal member, one medical member and one lay member. Please can you provide more information about the level of experience required of the medical member of the tribunal?"

[…]

Director of Health Policy, Government of Jersey:

"The tribunal would be stood up through the Royal Court, and that would be a decision for the Royal Court to stand up as part of the tribunal service. Clearly there have been active and live conversations about the skillset that is required but it would be a determination of the tribunal service as to the level of experience that they would require. I have no doubt that they would seek advice on that."[63]

However, whilst the response indicates that conversations are underway regarding the skillset required of Assisted Dying Tribunal Members, the details about how these requirements are being determined have not been shared with the Panel. This information is important as each Assisted Dying Tribunal will be constituted with *"1 x legal member (the Chair) – advocate or solicitor of Royal Court for 5- years minimum, 1 x medical member - medical practitioner with relevant experience and 1 x lay member".*[64]

[61] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[62] Assisted Dying in Jersey – P.18/2024
[63] Public Hearing – Assisted Dying Review Panel with the Minister for Health and Social Services – 3rd April 2024
[64] Assisted Dying in Jersey – P.18/2024

Finding 10: The requirements of members of the assisted dying tribunals will be determined by The Tribunal Service.

Recommendation 5: The Minister for Health and Social Services should publish details of any previous or ongoing consultation with the Tribunal Service about the required skillset of Assisted Dying Tribunal Members, by no later than Tuesday 21st May 2024.

Safeguards: Decision-making capacity, the Waiver of Final Confirmation of Consent and Guidance about Route 1 and Route 2

The Panel identified capacity as a key consideration for its review of the final proposals. This is because a person having decision making capacity means *"…the ability to use and understand information to make a decision, and communicate any decision made*[65]*."* The final proposals stipulate that an assisted death will only be lawful if, among other eligibility criteria, *"…the person must have capacity to make the decision to end their own life".*[66]

The final proposals also set out that future assisted dying legislation, "*In line with existing capacity legislation, the law will state that the person is assumed to have decision-making capacity in relation to assisted dying unless it is shown that they lack capacity."*

Furthermore, the final proposals state that assisted dying legislation will *"…set out a legal test that assessing doctors must use to determine whether a person has the capacity to decide to request an assisted death (assisted death decision-making capacity)."*[67]

During its analysis of the evidence, the Panel found that whilst the Ethical Review was supportive of the proposal to establish a specific test for patient capacity, it raised concerns about the proposal to retain the presumption of capacity, *"AD presents risks and there is evidence from other jurisdictions which raise concerns about capacity assessments (2.49). We welcome the proposal to set out a specific capacity test and provide tools and guidance, but we suggest that, for AD, the presumption of capacity could be removed, and training also provided, in order to safeguard patients and best ensure compliance and consistency (2.50)."*[68]

Furthermore, the Ethical Review cited evidence from the Netherlands and Canada, as examples of jurisdictions where concerns had been reported about the determination of patient capacity in relation to assisted dying:

> *"There is evidence, particularly in the context of euthanasia for mental illness, that physicians' judgments about patients' capacity to opt for AD often differ and that they often consist of only global judgments. This raises concerns about reliance on general (and potentially diverse) approaches to determining capacity and ensuring consent, which have not been specifically tailored to AD.*
>
> Supporting footnote: *102 SN Doernberg, JR Peteet, SYH Kim. Capacity Evaluations of Psychiatric Patients Requesting Assisted Death in the Netherlands. Psychosomatics 2016; 57(6): 556-565.*

[65] NHS – Assessing capacity
[66] Assisted Dying in Jersey – P.18/2024
[67] Ibid
[68] Assisted Dying in Jersey – Ethical Review

"There is evidence from Canada that clinicians assessing requests for AD have mostly done so without undertaking a formal capacity assessment or, when this has taken place, by using clinical tools that have been developed for other settings. The evidence also suggests that they have rarely assessed applicants for the presence of mental illness."[69]

Supporting footnote: "*E Wiebe et al. Assessment of capacity to give informed consent for medical assistance in dying: A qualitative study of clinicians' experience. CMAJ Open 2021; 9(2): E358-E363."*[70]

The final proposals address the concerns raised by the Ethical Review, and the suggestion that the presumption of capacity be removed, *"Consideration has been given to removing the presumption of capacity, but it is proposed that it is retained, as presumed capacity is widely perceived as an important legal principle which ensures proper respect for personal autonomy by requiring any decision as to a lack of capacity to be based on evidence."*[71]

During its Public Hearing with the Minister for Health and Social Services, the Panel decided to ask about the consideration that had given to the removal of the presumption of capacity:

Deputy C.D. Curtis:

"Now a question about capacity. Minister, the panel notes that the ethical review recommended removing presumed capacity but that the final proposals include presumed capacity, so no capacity test when someone is applying. Please can you describe the consideration that was given to removing the presumption of capacity and why the decision was taken not to?"

[…]

Director of Health Policy, Government of Jersey:

"It is a bit more complex than that. What the proposals say is that there will be a presumption of capacity but if there are any concerns about capacity that capacity must be tested, and that is absolutely standard with every other single piece of legislation. For example, our mental health and capacity law works on the premise that there is an assumption of capacity. What is set out in the proposals is entirely in accordance with Jersey legislation and is entirely in accordance with legislation within the U.K. (United Kingdom) about presumptions of capacity. There is nothing unusual about it, but even though there is a presumption that a person has capacity, there is a very clear legal duty placed on the co-ordinating doctor and the independent assessing doctor if there are any concerns, fleeting, glimpsing concerns, about capacity and if they are not fully qualified themselves, because some of those doctors will be qualified to make capacity assumptions, they must - and it is a requirement of the law - go and seek a specialist who can undertake a capacity assumption. In addition to that, as set out in the proposals, it is envisaged that what the law will provide for is a capacity test against which a person's capacity will be tested, which is very specific to assisted dying and goes beyond the capacity test which is currently set out in the capacity law. There is a belt and braces approach within that."[72]

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[69] Ibid
[70] Assisted Dying in Jersey – Ethical Review
[71] Assisted Dying in Jersey – P.18/2024
[72] Public Hearing – Minister for Health and Social Services – 3rd April 2024

However, whilst the response indicates that the decision to include the presumption of capacity in the final proposals is in line with existing Jersey and UK legislation, it does not explain how consideration was given to the removal of the presumption of capacity, as set out in the final proposals. The Panel then followed up on its questioning about the consideration that had been given to the removal of the presumption of capacity, and was informed that consideration had not been given to a 'compulsory capacity test':

> **Deputy L.M.C. Doublet:**
>
> *Minister, did you consider a compulsory capacity test as part of the proposals?*
>
> **The Minister for Health and Social Services:**
>
> *No*. [73]

The Panel asked why the recommendation of the Ethical Review about capacity had not been considered, and was informed that a response could not be provided:

> **Deputy L.M.C. Doublet:**
>
> *"Why did you not give consideration to that element, given it was advised by the ethical review?"*
>
> **The Minister for Health and Social Services:**
>
> *"I am sorry, I just simply cannot answer that. Once again, it is a very specific question and bearing in mind I have had a relatively limited amount of time to apply myself to this, I trust a lot to what* Director of Health Policy, Government of Jersey *does. I think* Director of Health Policy, Government of Jersey *has given a very adequate explanation of the situation in any event, which hopefully you are happy with."*[74]

The Panel then questioned how the Minister understood decision-making capacity to be assessed in other jurisdictions:

> **Deputy C.D. Curtis:**
>
> *"Can I ask as well then, in other jurisdictions is there no capacity test done in the same way as what is done for Jersey?"*
>
> **Director of Health Policy, Government of Jersey:**
>
> *"A few things within that. In terms of other jurisdictions, every other jurisdiction that permits assisted dying requires capacity. The law in those other jurisdictions takes a different approach to whether or not they have a specific capacity test or not, and this is often the case with assisted dying. In other jurisdictions there are very different approaches to it, but the presumption of capacity is a common feature in lots of other assisted dying laws. This particular recommendation of the ethical committee was, I think, of all the recommendations that they made the one that we found to be slightly unusual, one of the reasons being that it is a basic human right to assume that a person has capacity until it is proved that they have not, akin potentially to it is a basic human right to assume a person is innocent."*[75]

[73] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[74] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[75] Public Hearing – Minister for Health and Social Services – 3rd April 2024

However, whilst the response the Panel received highlighted that different jurisdictions have different approaches regarding assessments of capacity, it did not address or counterevidence how the recommendation of the Ethical Review was 'unusual' specifically within the context of assisted dying, or why this rationale was not included within the final proposals.

Finding 11: The presumption of decision-making capacity within the final proposals is in line with the general law governing capacity, however, it is unclear whether the removal of the presumption of decision-making capacity was considered as part of the development of the final proposals, as recommended by the Ethical Review.

The Panel also considered the provision of training in relation to capacity and found that this would be included as part of the training set out within the final proposals, *"…As detailed in Appendix 4: Outline of mandatory training, training in assessing capacity in relation to assisted dying will be developed as part of the assisted dying training for assisted dying practitioners."*[76]

The Panel decided to follow-up in written correspondence with a question about the mandatory capacity training referenced in the final proposals, asked how the capacity training would be tailored to the topic of assisted dying and received the following response:

> **Letter – Minister for Health and Social Services – 10th April 2024:**
>
> *"The training provided will focus on how professionals undertake capacity assessments and make determinations that relate to this specific capacity test, which is more extensive that the provided for under the Capacity and Self Determination (Jersey) Law 2016."*

Furthermore, the Panel questioned whether existing guidance about capacity and consent would be used to inform the capacity training and was informed that *"It will be used to inform the training, but there will be additional requirements driven by the assisted dying capacity test".* However, the Panel were not provided with further details about the 'additional requirements' in relation to the assisted dying capacity test.

Finding 12: Assisted dying capacity training will focus on how professionals undertake capacity assessments and make determinations that relate to the specific capacity test for assisted dying.

Finding 13: The capacity test for assisted dying will be more extensive than that required under the Capacity and Self Determination (Jersey) Law 2016, however, it is unclear what the specific capacity test for assisted dying will be and what the additional requirements will be.

The Panel also considered the provisions in place under the final proposals for patients that lose decision making capacity. The final proposals make provision for a Waiver of Final Confirmation of Consent ('Waiver'), *"…a person who is eligible under Route 1 may make a 'Waiver of Final Confirmation of Consent'. This allows 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 confirm their consent during the 'final review' (at Step 7), the assisted death can still take place."*[77]

[76] Assisted Dying in Jersey – P.18/2024
[77] Assisted Dying in Jersey – P.18/2024

In addition, the final proposals set out that even if a Waiver is in place, an assisted death would not proceed if signs of refusal or resistance were shown by the person, *"Even if the person has in place a Waiver of Final Confirmation of 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)."*[78]

During its analysis of the evidence about assisted dying, the Panel found that the Phase 2 Government Consultation ('Consultation') did not indicate a, *"…strong preference for the law to allow 'waiver of final consent'."*[79] However, the Panel also found that the most common reason Consultation respondents supported a Waiver was respect for patient wishes, and the most common disagreement with the provision of a Waiver was about safeguards if a person subsequently changed their mind.[80]

During its Public Hearing with the Minister, the Panel decided to ask questions about the Waiver in relation to signs of refusal or resistance to assisted dying. The Panel was given examples of refusals or resistance, and was informed that the Administering Practitioner would be trained to recognise the signs of refusal or resistance:

> **Deputy L.M.C. Doublet:**
>
> *"Minister, I would like to ask you about the concept of the waiver of final confirmation of consent. How will signs of refusal or resistance be established if a person has been deemed to have lost their decision-making capacity?"*
>
> **Director of Health Policy, Government of Jersey:**
>
> *"We have had conversations with healthcare providers about this. If a person was not consenting, the signs of consenting would be things like them turning their head away or shaking their head or saying no or holding up their hands. There are both verbal and non-verbal cues that the administering practitioner would be trained to recognise."*[81]

Finding 14: The Administering Practitioner will be trained to recognise verbal and non-verbal cues associated with refusal or resistance to an assisted death.

Recommendation 6: The Minister for Health and Social Services should publish the full details and processes for establishing refusal or resistance to an assisted death for a person who has lost decision-making capacity, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

The Panel also considered the development of guidance to ensure that assisted dying is a last resort, and that there is no confusion about Route 1: Terminal Illness and Route 2: Unbearable Suffering. During its analysis of the evidence about assisted dying, the Panel noted a recommendation of the Ethical Review to ensure the provision of guidance about, *"Whichever route(s) is ultimately allowed, professional guidance will be needed to ensure that AD is a last*

[78] Assisted Dying in Jersey – P.18/2024
[79] Assisted Dying – Phase 2 Consultation Feedback Report
[80] Assisted Dying – Phase 2 Consultation Feedback Report
[81] Public Hearing – Minister for Health and Social Services – 3rd April 2024

resort (4.12) and, if both routes are to be allowed, to minimise possible confusion about which process to follow (4.13).”[82]

The Panel questioned the Minister during its Public Hearing about whether the development of professional guidance would ensure assisted dying was a last resort:

> **Deputy C.D. Curtis:**
>
> *“The ethical review recommended that professional guidance is developed to ensure that adequate efforts are made to ensure that assisted dying is a last resort. Please can you confirm whether the guidance developed in relation to assisted dying covers this aspect?”*
>
> **Director of Health Policy, Government of Jersey:**
>
> *“It absolutely does. Within the assessment process, both for the co-ordinating doctor and the independent assessing doctor, it is very clear that any decision to have an assisted death must be informed. Informed includes placing a duty on those doctors to make sure the person knows about and is informed about alternative care and provision treatments for them so that there is absolutely no presumption that an assisted death is the right way forward for the person.”*[83]

The Panel clarified that a person requesting an assisted death would be informed of the available treatments if they were not already receiving it. The Panel also learned that the guidance ensuring assisted dying as a last resort would be available following a ‘full development process’:

> **Deputy C.D. Curtis:**
>
> *“They see what treatment is available in case they are not getting it at the moment?”*
>
> **Director of Health Policy, Government of Jersey:**
>
> *“Yes.”*
>
> **Deputy C.D. Curtis:**
>
> *“We could not see it in the forms and guidance section.*
>
> **Director of Health Policy, Government of Jersey:**
>
> *Apologies if it is not clear in that or if it is an oversight. That is all it will be. They are quite dense at this stage, as I am sure you will appreciate. As we come to the full development process, if there are any oversights or gaps, those will be picked up.”*[84]

The Panel then asked about guidance to mitigate against the risk of confusion about Route 1: Terminal Illness and Route 2: Unbearable suffering. The Panel learned that this guidance would be developed, and that it would make the distinction between Route 1 and Route 2:

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[82] Assisted Dying – Ethical Review
[83] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[84] Public Hearing – Minister for Health and Social Services – 3rd April 2024

Deputy L.M.C. Doublet:

"In terms of that list of guidance, the ethical review recommended that some guidance was produced to mitigate against confusion between the 2 routes. Can you confirm whether that guidance has been developed, because we could not spot that in the list?"

Director of Health Policy, Government of Jersey:

"It has not been developed but it will be developed. There will be very clear guidance on what route 1 and what route 2 is."[85]

Safeguarding: Administering Practitioner experience

The final proposals set out that the Administering Practitioner must be, *"the doctor or registered nurse (level 1) who will directly administer the substance used in assisted dying or support the person to self-administer the substance. Works within the Jersey Assisted Dying Service."*[86]

During its analysis of the evidence supporting the final proposals, the Panel found that 'many respondents' with a health background, that responded to the Government's Phase 2 Consultation on Assisted Dying ('Consultation'), did not believe the role of 'assisted dying practitioner' would be suitable for newly qualified doctors, *"Many stakeholders with a health background stated that the assisted dying practitioner role would not be suitable for newly qualified doctors. Some felt that 5 years minimum experience was a suitable threshold, others cited the Australian model where the minimum requirement is consultant level or 10 years post-qualification. The submission from the Nursing and Midwifery Council (NMC) questioned limiting the role of carrying out assessments to doctors only, suggesting nurses may also be suitable for such a role".*

The Panel decided to ask for more information about the level of experience required of doctors and nurses assigned the role of Administering Practitioner under the final proposals, in written correspondence dated 8th April 2024. The Panel found that doctors and registered nurses would be required to have 12 months post General Medical Council ('GMC') and National Midwifery Council ('NMC') registration experience:

Letter – Minister for Health and Social Services – 10th April 2024:

"…they must: a. be registered with the JCC to work in Jersey, and more than 12 months post full GMC/NMC registration;"

However, following the Consultation where some respondents stated that they believed at least five years' or 10 years' experience should be required to undertake the Administering Practitioner role, the rationale in the final proposals for at least 12 months post-GMC/NMC registration experience for doctors and registered nurses is not provided.

Finding 15: Some respondents with a healthcare background that responded to the Phase 2 Consultation on Assisted Dying believed at least five years' or 10 years' experience is required for doctors and registered nurses assigned to the Administering Practitioner role.

[85] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[86] Assisted Dying in Jersey – P.18/2024

Safeguarding: Locations for assisted dying

During its review, the Panel considered the potential locations for assisted dying and how decisions about location would factor in the wishes of patients. The final proposals stipulate that the future assisted dying law will provide that possible locations for an assisted death must be approved by the Administering Practitioner and could include private homes, care and nursing facilities owned by the Government of Jersey or managed by the Government of Jersey, care and nursing facilities not owned by Government of Jersey (these may be privately owned, parish-owned or owned by a charity or community organisation) and hospital facilities.[87]

During its analysis of the Government's Phase 2 Consultation on Assisted Dying ('Consultation'), the Panel identified support for premise owner and operators having the right to refuse an assisted death on their premises. The Consultation survey responses provided that 59% of respondents believed premise owner and operators had the right to refuse an assisted death on their premises, *"Overall survey respondents agreed that premise owners / operators should have the right to refuse an assisted death on their premises…".* [88]Furthermore, the Consultation highlighted that, *"The stakeholder feedback echoed the range of survey responses – i.e. balancing a premises owner's right to act according to their beliefs vs. a person's right to die in a place they consider to be their home".*[89]

Furthermore, the Panel found that the Ethical Review supported the position of allowing organisations to 'opt out' of permitting assisted dying on their premises, *"There are compelling arguments both for and against allowing caring facilities, and those who own or manage these, to conscientiously object to AD on their premises. On balance, we suggest that the arguments in favour of allowing organisations to opt out of allowing AD are more powerful, and we note that the public consultation supports this".*[90]

However, the final proposals do not extend the right of premise owners and operators to conscientiously object to an assisted death, *"to any Government of Jersey premises or private landlords".*[91]

During its Public Hearing with the Minister for Health and Social Services on 3rd April 2024, the Panel decided to ask about the provision of assisted dying in relation to shared accommodation:

> **Deputy L.M.C. Doublet:**
>
> […] "*One of the principles within the proposals is the right to object to the provision of an assisted death. In terms of private landlords, can you provide some more information about the processes that might be followed by an administering practitioner if the patient is in shared accommodation and the owner of that accommodation objects to them having an assisted death?"*
>
> **Director of Health Policy, Government of Jersey:**
>
> *"Yes. It is proposed that the right not to participate is extended to premises owners. In most cases we would envisage that being a care home provider, so where a person is in a care home as a resident in care and has requested an assisted death, that care*

[87] Assisted Dying in Jersey – P.18/2024
[88] Phase 2 Consultation on Assisted Dying
[89] Ibid
[90] Assisted Dying in Jersey – Ethical Review
[91] Assisted Dying in Jersey – P.18/2024

home provider may object for a whole range of reasons about the impact on other residents, et cetera. Clearly it is the case that where people live in some form of shared accommodation, for example a lodging house, it may be that the owner of that accommodation objects but obviously if it was a private rented accommodation with a front door, we would not envisage extending the right to refuse, to object to a person having an assisted death within the privacy of their own home."

The Panel then asked for clarification about the application of the right of premise owners and operators to object, regarding lodging house settings where no care is provided:

Deputy L.M.C. Doublet:

"Can you just clarify whether it applies to a lodging house which is a private residence where no care is provided but there might be multiple smaller residences within a house? Does it apply to that situation?"

Director of Health Policy, Government of Jersey:

"In terms of the law drafting instructions, we need to put some extra thought and clarity into the different forms of places where premises owners could object. If the States decide that people should be allowed to have an assisted death, of course it is desirable that people are allowed to die in their own home and where they live, and that will be the preliminary principle when bringing forward the legislation, but in respecting that preliminary principle it has to be understood that there are collective living situations where it might not be appropriate. What we need to do is we need to do more work to define what those collective living situations would be. Also, an administrating practitioner must make sure that the place is safe. For example, if it was a shared home and everybody in that shared home violently objected to that person having an assisted death, it might be that the administering practitioner determines it is not safe for that assisted death to go on there."

Whilst the proposals state that any landlords of private residences cannot conscientiously object to an assisted death on their premises, the response the Panel received during the Public Hearing indicates that Government needs to undertake further work to clarify the different types of premises where a right to refuse to participate could apply.

Finding 16: Further work to clarify the types of premises where a right to refuse to participate could apply will be undertaken as part of the development of assisted dying legislative drafting instructions.

Following further questioning about conscientious objection in relation to the premise owners and operators of care homes and nursing homes, the Panel learned that further discussions would be taking place about appropriate alternative locations for assisted dying if a patient could not die at their chosen location, and that options for assisted dying to take place within the Jersey General Hospital were being considered:

Director of Health Policy, Government of Jersey:

"Absolutely. If a person was in a care home and the care home objected, then there would be a conversation with that person about an alternative [...] location. The most likely place for that would be Jersey General Hospital and there will be active and live conversations about an appropriate place in the hospital for assisted deaths to take place, so not on a general ward."

The confirmation of details about the alternative locations for assisted dying, and the possible options for assisted dying to take place within the Jersey General Hospital, is an important detail for States Members to consider prior to a future debate on assisted dying legislation.

Furthermore, the Panel is concerned about the use of the Jersey General Hospital for assisted dying, including its potential impact on other hospital patients. Its therefore important that the Minister for Health and Social Services considers the range of other, "*care and nursing facilities owned by GoJ* [Government of Jersey] *or managed by GoJ"* [92]which are in scope within the final proposals for assisted dying. However, the Minister should also ensure that robust planning is in place to mitigate the potential impact of assisted dying on any other residents or patients, "*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."*[93]

Finding 17: Discussions are underway about appropriate places within the Jersey General Hospital for assisted dying.

Finding 18: The final proposals for assisted dying require appropriate planning for other patients and residents in Government of Jersey owned and / or managed care facilities.

Key Recommendation 3: The Minister for Health and Social Services must ensure sufficient planning is in place to prioritise patient wishes about possible locations for assisted dying, including within the home, and that the Jersey General Hospital is only used for assisted dying as a last resort.

Recommendation 7: The Minister for Health and Social Services must provide details about the timeline and stakeholders involved in discussions regarding appropriate places within the Jersey General Hospital for assisted dying, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Recommendation 8: The Panel is keen to ensure that assisted dying is only carried out within the Jersey General Hospital as a last resort, and the Minister for Health and Social Services must ensure that the Jersey Assisted Dying Service is not headquartered within the Jersey General Hospital.

Recommendation 9: The Minister for Health and Social Services must ensure robust planning is in place to mitigate the potential impact of assisted dying on any other residents or patients of Government of Jersey owned and / or managed care and nursing facilities, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

[92] Assisted Dying in Jersey – P.18/2024
[93] Assisted Dying in Jersey – P.18/2024

Safeguarding: Discussions with patients about assisted dying

The final proposals require the Jersey Assisted Dying Service to provide *"…clear written information to Islanders (including healthcare professionals) on assisted dying, including online and printed information materials".* This objective also highlights the role of the Assisted Dying Assurance and Delivery Committee, among other objectives, is to provide *"approval of guidance and protocols"*.

During its review of the final proposals for assisted dying, the Panel considered the format and means of providing information to patients about assisted dying, including discussions with patients. The final proposals summarise that the Government's Phase 2 Consultation on Assisted Dying ('Consultation') was supportive of any future assisted dying legislation remaining silent on the topic of assisted dying:

> *"The Phase 2 consultation report posed two questions on the matter of professionals discussing assisted dying with patients. These are summarised below:*
>
> *Do you agree the law should not prohibit professionals from raising the subject of assisted dying?*
>
> - *Yes, I agree – 48%*
> - *No, I do not agree 44.2%*
>
> *Do you agree the law should not place an explicit requirement on professionals to tell people about the assisted dying service?*
>
> - *Yes, I agree – 70.2%*
> - *No, I do not agree 21.2%*
>
> *The combined responses indicate support for the law to remain 'silent' on professionals discussing assisted dying with patients (i.e., professionals are neither compelled to raise the subject or prohibited from doing so)."*[94]

The Ethical Review also considered this area and recommended that the law remain silent on discussions about assisted dying with patients, *"…the ethical value of open and honest information-sharing, to empower patients to make informed decisions about their care, supports the position of legal silence outlined in the proposal".* [95]However, the Ethical Review also highlighted a need for professional guidance and training to be developed in relation to discussions about assisted dying with patients, *"We agree with the GMC and NMC that this requires professional guidance. We also suggest that the mandatory training for HCPs expecting to participate in AD should cover this issue to minimise any risk that raising the option of AD might be interpreted by a patient as encouraging or recommending it."*[96]

The final proposals adopted this approach and highlight that, *"…the law will remain 'silent' on the discussion of assisted dying with patients, but that the Minister will bring forward 'Appropriate Conversations Guidance' which will clarify the circumstances where raising the issue of assisted dying may be appropriate".*

During its Public Hearing with the Minister for Health and Social Services on 3rd April 2024, the Panel asked about the 'silent' position that future legislation will take regarding discussions

[94] Assisted Dying in Jersey – P.18/2024
[95] Assisted Dying in Jersey – Ethical Review
[96] Assisted Dying in Jersey – Ethical Review

with patients about assisted dying. The Panel learned that the assisted dying law would not place any requirement on healthcare professionals to discuss or to not discuss the topic:

> **Deputy L.M.C. Doublet:**
>
> *"The law is intended to be silent regarding discussions with patients about assisted dying. Can you just clarify where a healthcare professional can choose not to provide any information about assisted dying if the patient has not asked for it?"*
>
> **Director of Health Policy, Government of Jersey:**
>
> *"The law is silent on it. The law neither places a duty on a healthcare professional to provide information nor does it prevent a healthcare professional providing information even if the person has not asked."*

Furthermore, the Panel was informed that if a person asked about assisted dying, but the healthcare professional had a conscientious objection to it, they would be referred to another healthcare professional that could speak about it:

> **Deputy L.M.C. Doublet:**
>
> *"If the person asks, what is the duty there?"*
>
> **Director of Health Policy, Government of Jersey:**
>
> *"If the person asks, if the healthcare professional has a conscientious objection to assisted dying - and this is not a matter for law, this is a matter for the professional guidance of the N.M.C. (Nursing and Midwifery Council) and the G.M.C. (General Medical Council) and other professional bodies who produce extensive guidance on conscientious objection - what the healthcare professional needs to do ... it works for termination of pregnancy as well. A healthcare professional has to say: "I have a conscientious objection to assisted dying, termination of pregnancy, whatever it may be, so I cannot provide you advice and support and I suggest that you go and speak to X about it." We will produce leaflets that healthcare professionals can just hand out for the assisted dying service."*

Finding 19: The assisted dying legislation will remain silent regarding discussions about assisted dying between healthcare professionals and patients, however, the Minister for Health and Social Services will bring forward 'Appropriate Conversations Guidance' to clarify the circumstances where raising the issue of assisted dying may be appropriate.

Safeguarding: Conscientious objection and direct participation

During its review of the final proposals, the Panel considered paragraph (d) of the main proposition to P.18/2024, which sets out, *"to agree that no person should be under a legal duty to participate directly in the provision of assisted dying and any such person will have a right to refuse direct participation;"*[97]

However, the Panel is concerned that the inclusion of the words "directly" and "direct" in the context of participation in assisted dying in P.18/2024, is unclear and may unduly restrict the right to refuse participation in assisted dying. The Panel believes it is important that all persons within the purview of assisted dying have the right to refuse to participate and that the meaning

[97] Assisted Dying in Jersey – P.18/2024

of “participate”, defined by the Oxford English Dictionary as *“To take part; to have a part or share with a person, in a thing”*, is sufficient wording on its own.

The Panel decided to bring an Amendment to the final proposals, which removes references to “direct” and “directly” in relation to participation in assisted dying, from P.18/2024. Furthermore, the Amendment is intended to give more clarity and flexibility when interpreting the word “participation” in assisted dying, and to ensure that the definition of these words is not narrowed within the final proposals.

The Panel’s Amendment was lodged for debate during the States Assembly sitting in May 2024, and the Amendment and report accompanying the Amendment can be found here.

Finding 20: The Panel’s Amendment to the final proposals is intended to give more clarity and flexibility when interpreting the word “participation” in assisted dying.

Key Recommendation 4: The Minister for Health and Social Services should support the Panel’s Amendment to the final proposals for assisted dying.

Safeguarding: Assisted Dying Assurance and Delivery Committee Reporting

As previously stated in this report, the final proposals set out that an Assisted Dying Assurance and Delivery Committee (‘Committee’) must be established by the Minister for Health and Social Services. The Panel found that one of the key roles of the Committee once established will be providing “*oversight of the Jersey Assisted Dying Service”*, and that this would include *“producing and publishing an annual report on assisted dying in Jersey”.*[98]

The final proposals further state that the ‘annual report’ on assisted dying in Jersey will set out, *“…matters related to the numbers of requests, names of assisted death etc. This will include information related to demographic details, types of health condition etc. All data will be published anonymously. The Medical Officer for Health will act as an independent adviser to agree the data to be presented in that annual report and to agree the methodology for compiling the data.”*

During its Public Hearing with the Minister for Health and Social Services, the Panel decided to ask about how patient anonymity would be protected regarding the publication of an assisted dying annual report. This is because the final proposals highlighted that in some circumstances the annual report, *“…may, in some cases, result in the identification of an individual”*. The Panel was informed that it was important to recognise that there was a ‘tension’ between transparency and the need to destigmatise assisted dying, and the respect for patient privacy:

> **Deputy L.M.C. Doublet:**
>
> *“Thank you. In terms of the assurance and delivery committee, the panel notes that this committee would publish an annual assisted dying report. One of the concerns flagged was that in some cases that could result in the identification of an individual, given the small size of our Island, and that a decision in that case may be made not to publish some demographic details to protect that anonymity. Please could you provide some more information about how the decision would be made of whether to publish or not to publish?”*

[98] Assisted Dying in Jersey – P.18/2024

[…]

Director of Health Policy, Government of Jersey:

"…It is also important to recognise that there is a tension. To be transparent about the tension that exists with regard to information being in the public domain about an assisted death, part of that is that we would not, through that annual report, want to disclose information that may reveal the identity of a person or reveal too much about the identity of a person, because that is about respecting privacy. At the same time, it is really important to recognise that the death registration process for someone who has an assisted death will in fact put into the public domain the fact that that person has had an assisted death."

[…]

"…Different jurisdictions take different approaches to it. In some jurisdictions they just put the fact that the person had cancer. They do not put any information into the public domain that talks about an assisted death. There are genuine concerns about transparency and openness around that in what is a service that rightly should have a great deal of public scrutiny but also there is concern that if Jersey, like some other jurisdictions, is going to permit assisted deaths, you need to destigmatise that choice that people make. It needs to be a genuine choice that people do not feel fear or feel that they are going to be ridiculed or dismissed making. One of the ways in which you destigmatise things is you talk about it, and you are open about it. So, there is a tension between those 2 things."

Finding 21: The publication of an Assisted Dying Annual Report is intended to balance the need for transparency and destigmatisation of assisted dying against respect for patient privacy.

Training and Guidance

The provision of training and guidance is an important aspect of the final proposals for assisted dying, as such it is provided within the final proposals that, *"…All assisted dying practitioners (i.e., professionals who are registered with the Jersey Assisted Dying Service) must have successfully completed the bespoke training programme prior to registration".*[99] The importance of training and guidance about assisted dying was also set out in the original in-principle decision of the States Assembly in P.95/2021, "*Given the significance and complexity of any assisted dying legislation a comprehensive training and information programme would be developed. As well as training on new legislation, this may require additional training in related areas such as capacity and self-determination legislation."*[100]

There are a significant number of references to training and guidance throughout the final proposals, covering learning aspects that include understanding assisted dying, legality and ethics, drugs, assisted dying practices, death, dying and loss, assisted dying simulations and

[99] Assisted Dying in Jersey – P.18/2024
[100] Assisted Dying in Jersey – P.95/2021

personal and professional resilience.[101] However, much of the detail of the proposed training and guidance is not yet available. In written correspondence from the Minister for Health and Social Services dated 10th April 2024, the Panel was informed that *"I now understand that work cannot commence on developing the training programme and guidance until those policy decisions have been taken by the Assembly on 21 May 2024".*[102]

However, the Panel understands that the Assisted Dying Assurance and Delivery Committee ('Committee') will be responsible for establishing the training programme and guidance. Furthermore, the final proposals set out that, *"The training programme will be developed by the Committee. In developing the training, the Committee will look to work with other jurisdictions who have experience in developing mandatory assisted dying training".*[103]

The proposed training and guidance is summarised in Appendix 3 and Appendix 4 to the main report accompanying the final proposals. Whilst references are made to specific items of training and guidance across various sections of the final proposals and highlighted in relevant sections of the Panel's report, the Panel decided to seek more information about the overall plans and timelines regarding the development of an assisted dying training programme and guidance.

This section will analyse Appendix 3 and Appendix 4 in relation to the development and timelines for the establishment of assisted dying training and guidance.

Finding 22: The work to develop the assisted dying training programme and guidance will commence following States Assembly debate on the final proposals on 21st May 2024.

Guidance

The summary of the assisted dying guidance within the final proposals is set out in Appendix 3: Forms and Guidance ('Appendix 3'), which highlights 15 items of guidance that the assisted dying law will require the Minister for Health and Social Services to publish. Additionally, Appendix 3 sets out 12 items of guidance that the Assisted Dying Assurance and Delivery Committee ('Committee') will be required to bring forward and develop in consultation with relevant stakeholders. [104]

The final proposals refer readers to Appendix 3 for a *"full list of guidance and protocols to be developed by the Committee".*[105] However, during its Public Hearing with the Minister for Health and Social Services on 3rd April 2024, the Panel was informed that it was likely that additional guidance would be added to the items set out in Appendix 3:

> **Deputy L.M.C. Doublet:**
>
> *"In terms of that appendix 3, the forms and guidance, are there likely to be additional forms and additional guidance documents that would be added to that?"*
>
> **Director of Health Policy, Government of Jersey:**
>
> *Absolutely. As a policy office, it has been quite difficult for us. We have tried as much as possible to bring forward as much detail as possible but to a certain extent, until the*

[101] Ibid
[102] Letter – Minister for Health and Social Services – 10th April 2024
[103] Assisted Dying in Jersey – P.18/2024
[104] Assisted Dying in Jersey – P.18/2024
[105] Ibid

States Assembly have made decisions as to how they want to progress, it is a bit of a moving target."[106]

The Panel then asked about the timeframe for bringing all of the proposed guidance to the States Assembly for consideration by States Members. The Panel was informed that the assisted dying law could be delayed, if States Members request all the guidance to be provided at the same time as the draft assisted dying legislation is lodged for debate by the States Assembly:

Deputy C.D. Curtis:

"Will this be in place before it comes back to the Assembly then, so we are able to see it?"

Director of Health Policy, Government of Jersey:

"What will come back to the Assembly is the draft law. I think that if the Assembly was to want all the guidance in place at the same point that the draft law is in place, that will potentially create some delays in getting the draft law forward to the Assembly. Also, there are very real practical difficulties in writing guidance against the draft law. It needs to be in approval because if the Assembly were to make any amendments to the draft law, that would negate the guidance."[107]

Deputy L.M.C. Doublet:

"How will you manage that, Minister, in terms of giving States Members enough information as to what the guidance will be in terms of what Director of Health Policy, Government of Jersey *has said?"*

The Minister for Health and Social Services:

"I have to say I will simply trust Director of Health Policy, Government of Jersey *as somebody I know who has put in an enormous amount and, as you can see, has a huge amount of detailed knowledge of this. There does come a point from a Ministerial point of view where you have to be reliant on your officers. I have to say I have a great deal of faith in what* Director of Health Policy, Government of Jersey *is telling us, so I am very comfortable with that."*[108]

However, the guidance to be produced and brought forward by the Minister is an important consideration, with a legal requirement to consult professional bodies in the development of the guidance, *"In developing the training programme, professional guidance and the service and clinical protocols, the Committee will have a legal duty to consult with relevant professional bodies…"*[109]. The details and plans to develop the assisted dying guidance, following the States Assembly debate on the final proposals, should be formalised, and published. Furthermore, the response the Panel received during the Public Hearing did not provide details about how the Minister would manage the process of developing guidance to ensure that States Members were informed about what will be produced and brought forward.

[106] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[107] Ibid
[108] Public Hearing – Minister for Health and Social Services – 3rd April 2024
[109] Assisted Dying in Jersey – P.18/2024

The Panel decided to follow up with questioning about the assisted dying guidance in written correspondence dated 8th April 2024. The Panel asked how the development of the items of guidance would be prioritised:

> **Letter – Minister for Health and Social Services – 10th April 2024:**
>
> *"As above, monies have been provided in the indicative budget for development of the training package, plus a further £38,000 is provided for development of the guidance."*

However, the response does not indicate what items of guidance will be developed and prioritised or a process for how this will be completed. The Panel also asked about the timeframe for the development of the detail of all the guidance to be brought forward by the Minister, and when this would be made available:

> **Letter – Minister for Health and Social Services – 10th April 2024:**
>
> *"Training programmes and the guidance will be finalised during Q1 to Q2 2026 (after the adoption of the draft law) to ensure that it ready for training roll out in Q1 to Q2 2027."*

Finding 23: It is unclear what items of guidance will be developed and prioritised for consideration prior to the States Assembly debate on assisted dying legislation.

Finding 24: The details about all of the guidance to be produced will be finalised during Quarter 1 and Quarter 2 of 2026, after the States Assembly has made a decision on the draft assisted dying legislation.

Training

The provision of mandatory training will be a requirement of Assisted Dying Practitioners and Care Navigators and is, *"…expected to take the form of a ten-day face-to-face modular programme. This will be followed by ongoing clinical supervision and case management. There will be a requirement for assisted dying practitioners to complete mandatory refresher training every three years."*[110]

The proposed ten-day face-to-face training programme is set out with a total of 44 items of learning within a 'Training Matrix' in Appendix 4. The Panel decided to seek more information about the development of the Training Matrix and the timeline for development of the assisted dying training programme. During its Public Hearing with the Minister for Health and Social Services, the Panel asked about when details about the training programme would be made available to States Members:

> **Deputy L.M.C. Doublet:**
>
> *"In terms of the training programme, we have asked some questions about that, and I think it is quite critical in terms of giving reassurance to States Members. Can you clarify when the detail on that training programme will be available to States Members, please?"*

[110] Assisted Dying in Jersey – P.18/2024

Director of Health Policy, Government of Jersey:

"Obviously, we have not started to develop it yet because there are some really big policy questions that need to be asked and answered. We have had some very preliminary conversations with some of the professional oversight bodies in the U.K. who develop clinical training about whether or not they would be interested in being commissioned to do this work. We have had some provisional indications that they would be. We would obviously look to lots of other jurisdictions, so New Zealand and Australia have got these really detailed training programmes. We have already got some indication that they would be prepared to share the detail of their training programmes with us. So, we would not necessarily be starting from a blank piece of paper but clearly whatever we are training would have to be Jersey-specific because it would be specific on our law. I would anticipate that if a draft law was brought forward, while it might not have all the detail of guidance, what it would do is it would contain a very detailed summary of what the training programme would look like, how it would work, what the modules would be.[111]"

Following the responses it received during the Public Hearing, the Panel decided to seek more information in written correspondence dated 8th April 2024, about the conversations that had taken place between professional oversight bodies in the UK that develop clinical training, and what planning had taken place to develop a training programme:

Letter – Minister for Health and Social Services – 10th April 2024:

"There has been initial work undertaken on developing the forms (Appendix 3, paragraph 1 (e-n)) which will underpin parts of the training programme and some the guidance to be brought forward by the Committee (Appendix 3, paragraph 2). This initial work was required to enable officers to confirm the overarching assisted dying process and steps, with more work to be undertaken after 21 May debate."

The Panel also asked for more information about the detailed summary of the training programme referenced in the Public Hearing, including specific items of training and guidance to be provided in the summary accompanying the draft assisted dying legislation:

Letter – Minister for Health and Social Services – 10th April 2024:

"An outline of the mandatory training programme is already set out in Appendix 4 of the report and proposition. It is very high level at this stage and has some recognised omissions (for example, it does not make specific reference to training in coercion / family dynamics).

In short, the detailed summary will set out for States members:

- *the content of the training programme for each of the different assisted dying practitioners (i.e. what the Assessing Doctors will be trained in; what the pharmacy professional will be training in etc).*
- *how the training will be delivered (in person; on-line learning).*
- *how the trainers will be trained and who will provide the training.*
- *how it will be determined if a professional has 'passed' the training."*

However, whilst the response provides an overview of the information that States Members will receive, further details about the specific items of training to be included within the

[111] Public Hearing – Minister for Health and Social Services – 3rd April 2024

summary are yet to be confirmed. As previously stated in this report, the Panel found that this work will commence following the decisions taken by the States Assembly on 21st May 2024.

Finding 25: The draft assisted dying law will be published with an accompanying detailed summary of the assisted dying training programme.

Recommendation 10: The Minister for Health and Social Services should publish details and plans about assisted dying training and guidance that include:

- A detailed summary outlining all items of assisted dying guidance to be developed and produced.
- The items of guidance to be prioritised, shared and presented to States Members.
- Details and plans about the development of the assisted dying training programme.

This information should be provided no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Funding and Resourcing

The provision of an assisted dying service will have resource and financial implications, both in terms of funding and initial set up costs and from staffing and recruiting to an assisted dying service[112]. This was also set out in the original in-principal decision of the States Assembly to permit assisted dying in Jersey in P.95/2021, *"It is anticipated that an assisted dying service would require the provision of additional funding within a future Government Plan."*[113]

This section will analyse the provision of funding for assisted dying through the Government Plan, including potential impacts from reductions or amendments to future Government Plans, and a summary of the breakdown of the implementation and one-off costs provided by Government, in relation to establishing an assisted dying service.

Finally, this section will consider how broader staffing and recruitment challenges faced by the Health and Community Services Department could affect the provision of assisted dying in Jersey.

Funding and implementation costs

Section 12 of the final proposals relate to 'Resource and financial implications, risks and next steps', and highlights how funding for assisted dying will be provided, *"Implementation of assisted dying in Jersey, including the establishment of the Jersey Assisted Dying Service and all regulation and oversight mechanisms, will require the provision of additional funding within a future Government Plan"* [114]. The Government Plan sets out the funding position for the Government, including income and capital and revenue expenditure[115], across the range of Government services and priorities.

During its review, the Panel questioned the impact on the provision of an assisted dying service, if the funding requested in Government Plan was not approved or was reduced, and

[112] Assisted Dying Proposition – P.2 - P.18/2024 – Section 12: Resource and financial implications, risks and next steps
[113] Assisted Dying in Jersey – P.95/2021
[114] Ibid
[115] Government Plan 2023-2026 – gov.je

how impacts on service delivery would be mitigated. The Panel learned that a business case for the provision of assisted dying would be submitted to the 2026 Government Plan, and that any amendments or reductions in funding to assisted dying would need to be assessed in relation to their impact on service delivery:

> **Correspondence – Minister for Health and Social Services to Assisted Dying Review Panel – 10th April 2024:**
>
> *"A Jersey Assisted Dying business case will be submitted to the 2026 Government Plan (to provide for the one-off costs of establishing the service and the ongoing costs). In the event the business case is rejected, it would not be possible to enact the law from a practical perspective, assuming the proposed law was adopted.*
>
> *If the business case was to be amended, thereby reducing the monies available, the impact of the proposed reduction would need to be assessed to determine if it were possible to deliver the service in accordance with the law. It would, for example, be possible to proceed without providing bereavement counselling and support for loved ones, although highly undesirable to do so. Ultimately any reductions in budget would be a decision for the Assembly."*

Furthermore, the Panel learned that the provision of an assisted dying service could be suspended in the event that adequate funding was not available:

> **Correspondence – Minister for Health and Social Services to Assisted Dying Review Panel – 10th April 2024:**
>
> *"If Government funding was reduced to the extent that the Jersey Assisted Dying Service could not be safely delivered or delivered in accordance with the Law, I would be required to suspend the service until such point as the necessary funding was available. Paragraph 68 of the report and proposition notes that the law must recognise that there will be circumstances in which is not possible for the Minister to provide the Service.*
>
> *I would of course notify the Assembly of risks of reduced funding for the Service, but ultimately it would be a decision of the Assembly as to whether the funds were provided.*
>
> *The law would not provide for a 'reduced' Assisted Dying Service to be provided (ie. costs could not be avoided through the provision of one assessment, as opposed to two assessments)."*

The Panel also considered the key costs associated with the implementation and set-up of assisted dying in Jersey, which are summarised as follows under Section 12 of the final proposals, 'Resource and financial implications, risks and next steps':

Category	Cost (£)
Implementation	363,607
Training	340,000
Information management	5,000
Jersey Assisted Dying Service	155,000
Public information	42,360
Regulation, oversight, approval	112,192
TOTAL	**£1,018,159**

The Panel decided to ask for more detailed breakdowns of the most significant costs related to 'Implementation', 'Jersey Assisted Dying Service' and 'Regulation, oversight, approval', and was provided with the following breakdowns in written correspondence from the Minister for Health and Social Services dated 10th April 2024:

Implementation - £363,607:

Additional Law drafting capacity	Development of legislation	£150,000
Project manager to oversee implementation	Implementation - project management	£177,607
Specialist clinical advisor to support development of all forms, guidance and protocols	Development of forms, guidance and protocols	£36,000

Jersey Assisted Dying Service - £155,000:

Cost associated with the recruitment process for assisted dying service staff	Staffing	£60,000
Establishment of Jersey Assisted Dying Service office - equipment & office fitout	Facilities/ equipment/ supplies	£30,000
Recruitment of Independent Members	Assurance and Delivery Committee	£60,000
ADRMP training	Death certification	£5,000

Regulation, oversight, approval - £112,192:

Recruitment to the Assisted Dying Review Panel	Assisted Dying Service Panel	£60,000
Recruitment of Tribunal	Tribunal	£1,500
Training - Tribunal members	Tribunal	£5,000
Development of Standards under Regulation of Care Law	Jersey Care Commission	£45,692

Staffing costs and recruitment

The final proposals set out that the Health and Community Services Department ('HCS') will engage professionals to fulfil roles within the Jersey Assisted Dying Service, that may be on a contract for services or employment basis, and include HCS employees, HCS bank staff and professionals on special contracts such as General Practitioners and registered nurses employed by other organisations or off-Island professionals. [116]

[116] Assisted Dying in Jersey – P.18/2024

However, HCS has faced challenges staffing and recruiting for vacancies. In September 2023, it was reported by ITV News that one in five vacancies across HCS were unfilled, and that there *"…are currently 517 unfilled roles - giving the department an overall vacancy rate of 18%."*[117]

During its review, the Panel decided to ask the Minister for Health and Social Services in written correspondence, about how recruitment and staffing challenges across HCS would be addressed in relation to the provision of the Jersey Assisted Dying Service. Whilst the response describes the 'sessional' nature of the work of the Jersey Assisted Dying Service, it does not specify how broader staffing and recruitment challenges will be addressed in relation to the additional resource implications associated with the provision of assisted dying in Jersey:

> **Correspondence – Minister for Health and Social Services to Assisted Dying Review Panel – 10th April 2024:**
>
> *"Professionals working for the Jersey Assisted Dying Service may be Government employees, bank staff or professionals on special contracts. This may include both on-Island and off-island professionals. The estimated number of assisted deaths (based on experience in other jurisdictions) ranges from 6 to 38 per year. Based on these estimates, it is not necessarily envisaged that staff will be employed / contracted on a full-time basis to work in the Assisted Dying Service. In any event, it is recognised that working in the service on a sessional basis will help protect staff from emotional overload. The employment or contracting of staff on a part-time or sessional basis will help overcome some of the challenges commonly associated with the recruitment of full time staff."*

Furthermore, the Panel learned that if adequate staffing arrangements were not available, this could lead to a suspension of assisted dying in Jersey:

> **Correspondence – Minister for Health and Social Services to Assisted Dying Review Panel – 10th April 2024:**
>
> *"As per the answer to Q14a above, paragraph 68 of the report and proposition (p36) sets out that the law will need to recognise that I may not be able to provide an assisted dying service if the necessary staff are not available to deliver the service safely or in accordance with the law. A service suspension process will be developed as part of the implementation phase, which will commence after the Assembly has debated the draft law. Clearly any service suspension process will need to address actions to be taken with regard to people whose request for an assisted death is already being assessed or has been approved, in addition to new requests for an assisted death."*

Finding 26: The Minister for Health and Social Services would be required to suspend the provision of assisted dying in Jersey, in the event that adequate funding was not available or adequate staffing was not available for the service to be delivered safely and in accordance with law.

However, the final proposals acknowledge current uncertainty about the staffing and recruitment of eligible professionals to the proposed Jersey Assisted Dying Service, and that

[117] One in five jobs in Jersey's health department currently unfilled – ITV News

further work is required to survey local health and care professionals in relation to undertaking this work:

> **Assisted Dying in Jersey – P.18/2024:**
>
> *"It is not known how many professionals currently working in Jersey would be prepared to work for the assisted dying service. During the course of the consultation process, a number of professionals pro-actively stated that they would, in principle, work for the service, whilst a number made it clear that they would not.*
>
> *[…]*
>
> *The Ethical Review authors recommend that once the assisted dying proposals have been confirmed [i.e. after the Assembly debate on this proposition], work is undertaken to survey local health and care professionals regarding their willingness to participate in assisted dying. This would support a better understanding of the potential implementation challenges and the likely requirement for 'off island' practitioners prior to the approval of a draft law. This in-depth survey work cannot be meaningfully undertaken until after the detailed proposals have been developed, as professionals have made clear that they need a full understanding of the proposals to inform their decision."*

The final proposals reference the 'in-depth' survey work that is required with health and care professionals, to better understand the potential implementation challenges and requirements for off-Island practitioners. However, whilst the potential for staffing and recruitment challenges are identified as a risk in the final proposals, the mitigations and responses to this risk do not include specific details or planning about how the recruitment and training activity, capacity and demand and engagement with UK staff will work in practice:

> **Assisted Dying in Jersey – P.18/2024:**
>
> *"It is proposed that there will be an c.18- month implementation period post adoption of any assisted dying law. This will allow for focused recruitment and training activity (costs are accounted for in estimated resource and financial implications). Jersey Assisted Dying Service will work to try to ensure that capacity matches anticipated demand for service. If staffing requirements cannot be met on-Island, HCS will look to engage UK-based staff to work on a contract basis for Assisted Dying Service."*

In response to questioning by the Panel in its written correspondence dated 8th April 2024, the Minister confirmed that the potential risks associated with the suspension of assisted dying in Jersey will be described in a full risk assessment of the assisted dying provisions:

> **Correspondence – Minister for Health and Social Services to Assisted Dying Review Panel – 10th April 2024:**
>
> *"Paragraph 580 of the report and proposition (page 168) states that a full risk assessment will be undertaken as part of the legislation development programme. That full risk assessment will include a more detailed description of risks and assess the potential likelihood of those risks occurring and the associated impact. The potential risk that the service may be suspended on staffing grounds (or other grounds such as lack of funding) will be described in that full risk assessment."*

Furthermore, the final proposals state that *"A full risk assessment will be undertaken as part of the legislation development process and will be presented to the States Assembly alongside the draft law."*

Finding 27: The Panel is unclear about how broader staffing and recruitment challenges will be addressed in relation to the additional resource implications associated with the provision of assisted dying in Jersey.

Recommendation 11: The Minister for Health and Social Services should provide details about how general recruitment and staffing challenges across the Health and Community Services Department will be addressed in relation to the additional resource implications associated with the Jersey Assisted Dying Service, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Finding 28: The potential risks associated with suspension of assisted dying in Jersey will be described in a full risk assessment of the assisted dying provisions and presented to the States Assembly alongside the draft assisted dying law.

Recommendation 12: The Minister for Health and Social Services should provide details and plans to mitigate and respond to the risk of Health and Community Services not being able to recruit sufficient staff to the Jersey Assisted Dying Service, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.

Conclusion

Throughout this review, the Panel has been mindful of the highly sensitive nature of assisted dying, the implications of the final proposals on the future development of assisted dying legislation, and the provision of an assisted dying service in Jersey.

The Panel has assessed the final proposals against the previous, in-principle, decision of the States Assembly (P.95/2021) to permit assisted dying in Jersey and assessed whether changes have been made following this decision, and the extensive body of evidence collected by Government to date through public consultations and stakeholder submissions and addressed key themes and specific areas of focus.

The Panel has highlighted areas where it believes greater clarity and more detail is required about some aspects of the final proposals, in particular regarding the processes and safeguards for all individuals involved in assisted dying and whether these uphold patient wishes, through recommendations in areas such as: the provision of palliative and end of life care; the multi-agency approach to safeguarding; protections for patients that lose decision-making capacity; and alternative locations for assisted dying. Furthermore, the Panel has considered references to training and guidance made throughout the final proposals and recommends that detail and plans about the development of training and guidance be published.

Finally, the Panel has made recommendations within this report which it believes will improve the information available to States Members prior to the future States Assembly debate on assisted dying legislation and the establishment of an assisted dying service in Jersey.

Appendix One

Panel Membership

Deputy Louise Doublet (Chair)

Deputy Catherine Curtis (Vice-Chair)

Deputy Philip Bailhache (Member)

Terms of Reference

1. To examine the final proposals for assisted dying, with particular consideration of the following:

    a. Whether (and if so why) any changes have been made to the original proposals outlined in P.95/2021.
    b. The proposed processes and safeguards for all individuals involved in assisted dying, and whether these uphold patients' dignity and wishes.

2. To examine the previous body of evidence received to date from experts and stakeholders.

Appendix Two

Key Documentation

As previously stated in this report, the Panel has considered a number of key items of documentation throughout its review, as part of the evidence base for undertaking analysis of the final proposals for assisted dying. These have included:

- Assisted Dying (P.95/2021): The original, in-principle, decision of the States Assembly to permit assisted dying in Jersey in November 2021. Throughout its report, the Panel have considered to what extent changes have been proposed within the final proposals for assisted dying following this decision of the States Assembly.
- Assisted Dying in Jersey – Phase 2 Consultation Feedback Report: This consultation report, published in April 2023, provides the results of the Government consultation with the public as well as key stakeholders, about how an assisted dying service could work in Jersey.
- Assisted Dying in Jersey - Ethical Review: The Ethical Review is an evidence-based report, commissioned by the Government, and produced by three ethicists about the final proposals for assisted dying in Jersey in November 2023.

Appendix Three

Submissions

Due to the short timeframe for undertaking the review, the Review Panel was unable to launch a general call for evidence for submissions. However, the Panel did receive a number of submissions from members of the public and these submissions will be retained in the event that that a review of the draft Assisted Dying Legislation is undertaken. Of those who provided submissions to the Panel, three agreed for their submissions to be uploaded to the Assisted Dying Review Panel website and they are linked here below:

Submission 1 - 23 April 2024

Submission 2 - 22 April 2024

Submission 3 - 18 April 2024

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