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Deputy Doublet Chair, Assisted Dying Review Panel BY EMAIL

10 April 2024

Dear Chair,

Re: Further Questions on the Assisted Dying Report & Proposition

In response to your letter dated 8 April, please see below a response to your additional questions on the proposals for Assisted Dying in Jersey.

More time is required to respond to the questions outlined on palliative and end of life care, which I will share with the Panel as soon as possible.

Eligibility Criteria

5. The Panel notes that the Phase 2 consultation on assisted dying received a "...number of written responses from stakeholders focused on the inclusion of unbearable suffering in the eligibility criteria". Please can you provide a percentage breakdown of the responses from the Phase 2 consultation, both in favour and against the inclusion of Route 2?

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.")

That said, "NOTE: Route 2 – unbearable suffering" (Appendix 1. Para 3 of the report and proposition) notes that a "significant number of respondents did express specific reservations about 'Route 2 – unbearable suffering', and it was for this reason that the Ethical Review Panel was asked to give specific consideration to the inclusion of Route 2.



a. How was stakeholder feedback from the Phase 2 consultation on assisted dying regarding the inclusion of Route 2, considered during the development of the final proposals?

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.

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.

6. The Panel also notes that the Ethical Review recommended against the inclusion of Route 2. Please can you describe how the recommendation of the Ethical Review, against the inclusion of Route 2, was considered during the development of the final proposals?

In November 2021 the States Assembly agreed, in principle, that assisted dying should be permitted in Jersey (P.<u>95/2021</u>) 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.

a. 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.

7. The Panel was informed during the Public Hearing that if Route 2 is approved, the Government would look at "how to support additional awareness of ableist views being imposed on people with a disability and their quality of life". Please can you provide more details about how you would support additional awareness regarding ableist views of people with disabilities and their quality of life?

In the event the Route 2 is approved, Government will work with disability and community groups to determine how best this may be achieved, and the details of this



work would be made available to the Panel. Planning has not commenced ahead of an Assembly decision.

a. Would this work be in addition to existing assisted dying training or guidance to be developed in relation to ableism?

Yes. The assisted dying training and guidance, which would include consideration of matters related to ableism, would be for all assisted dying practitioners. What is envisaged is wider worker with health and care professionals and wider community about addressing ableist views. This would be linked to existing Government activity around disability.

It should be noted that the costs of this additional activity are not yet included in the indicative services costs set out in the report and proposition but would be included in the costs presented alongside the draft law, if the Assembly were to proceed with Route 2.

Safeguards

8. The Panel note that the Proposition asks States Members to request the Minister to bring forward legislation and establish an assisted dying service in accordance with the essential provisions and safeguards, outlined in the appendix. Please can you clarify the use of the term 'essential'?

The term 'essential' is used to indicate the provisions and safeguards which, it is proposed, 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. Many others are described in the report. See Question 8a below.

a. Please can you clarify whether the essential provisions include all of the safeguards?

'Essential provisions and safeguards' refers to the matters set out in the Appendix A to the proposition, sub-paragraphs (i) to (xxvi). There are other safeguards set out paragraphs (a) to (e) of the proposition. These include, for example:

 the eligibility criteria as set out in para (a) which include, for example, the requirements that a person must have a voluntary, clear, settled and informed



wish to end their own life (which means, amongst other matters, that their wish must be free from coercion). As the proposition is construction the Assembly cannot agree to permit assisted dying without adopting the safeguards set out in para (a) and in the Appendix, unless the proposition is subject to amendment.

• the provision of minimum timeframes as set out in paragraph (e), with the detail of those timeframes include in the Appendix.

The proposition captures the essential safeguards but does include all the safeguards as described in the accompanying report, simply because of the extent of the detail required, for example:

- sub-paragraph (viii) sets out that person may withdraw their request at any point but does not detail the requirement to complete a Step Transition Form (see para 161 of the report) to confirm the person's wish to proceed to the next step in the process and to safeguard against the risk of the person losing control of the process
- sub-paragraph (xviii) makes reference to the establishment of the Assisted Dying Assurance and Delivery Committee but does not detail the requirement for that Committee to be chaired by an independent person to safeguard against conflict (see paragraph 82 of the report).
- 9. The final proposals also set out that mandatory training in assessing capacity regarding assisted dying will be developed for assisted dying practitioners. Please can you confirm how this training will be tailored to assisted dying?

As per paragraphs 288 and 289 of the proposition (p89), the law will:

- a. provide that as person can only be assessed as eligible for assisted dying if they have capacity to make an assisted dying decision, which includes a decision to request an assisted death and a decision to have an assisted death.
- b. provide a specific capacity test for assisted dying decision-making.

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.

a. Please can you confirm whether existing guidance on capacity and consent will be used to inform this training?

It will be used to inform the training, but there will be additional requirements driven by the assisted dying capacity test.

10. The Panel understands that Administering Practitioners with direct involvement in assisted dying will be Level 1 doctors or registered nurses. Please can you



confirm the level of experience (in years) required of doctors and registered nurses to undertake the Administering Practitioner role?

The Administering Practitioner will be:

- a doctor, or
- a registered nurse (level 1).

As described in paragraph 150a of the report, they must:

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

As described in paragraph 141 of the report, the competency frameworks will be developed by the Assurance and Delivery Committee in consultation with the relevant stakeholders, for example the UK professional regulatory bodies and professional membership organisations.

Training and Guidance

11. The Panel understands that there are some "big policy questions that need to be asked and answered" regarding training and guidance. Please can you provide an overview of these areas of policy?

The 'big policy questions' I referred to at the public hearing on 3 April relate directly to those set out in the proposition, for example, 'will the Assembly agree that an assisted dying service should be established?' or 'will the eligibility criteria include both Routes 1 and 2?'

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.

12. The Panel was informed that "some very preliminary conversations with some of the professional oversight bodies in the UK who develop clinical training" had taken place. Please can you confirm the planning that has taken place to develop a training programme and guidance regarding assisted dying?

As the stated at the Panel meetings, there have been some very preliminary conversations but to date, there has been no detailed planning for the training programme.



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.

a. When will the development of the detail of the training programme and guidance commence?

More detailed work will commence after 21 May debate, alongside the development of law drafting instructions.

13. The Panel notes that in addition to the draft Law on assisted dying, "a very detailed summary of what the training programme would look like, how it would work, what the modules would be", would be included. Please can you specify the items of training and guidance that will be provided as part of this summary?

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.

As already stated, the detailed summary of the content of the training programme and guidance will be provided alongside the draft law, but these elements cannot be finalised until the law has been adopted on the basis that:

- up until that point, the proposed assisted dying process and eligibility criteria may be subject to amendment, which will have an impact on the content of the training module and guidance.
- specialist support will be required to develop the training package and GoJ
 cannot invest public monies in the process until the law has been adopted. As
 set out in the report and proposition, it is estimated that around £340,000 will be
 required for training, which includes up to £185,000 for the development of the
 training package.
- a. How will the development of the items of training and guidance be prioritised?



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.

b. The Panel notes that the draft Law "might not have all the detail of guidance". When do you anticipate that the detail all the training and guidance will be made available?

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.

Funding and Resourcing

14. Minister, the Panel understands that Government Plan will need to provide additional funding for the Jersey Assisted Dying Service. If the full funding request is not approved or is reduced, how will impacts on service delivery be mitigated?

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.

a. How will impacts on service delivery be mitigated if funding is reduced in future Government Plans?

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)



15. Please can you provide more information about the 'one off' costs of £363,607 associated with the item called 'Implementation'?

£363,607 includes the follows indicative costs:

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

16. Please can you provide more information about the 'one off' implementation costs of £155,000 associated with the item called 'Jersey Assisted Dying Service'?

£155,000 includes the follows indicative costs:

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

17. Please can you provide more information about the 'one off' implementation costs of £112,192 associated with the item called 'Regulation, oversight, approval'?

£112,192 includes the follows indicative costs:

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



18. Minister, please can you describe how you intend to focus the implementation period on recruitment and training of on-Island opt-in professionals?

Appendix 1, Section 4 b (p181) sets out that the Ethical Review recommended that once the assisted dying proposals have been confirmed [i.e. *after* the Assembly debate the report and proposition], further work is undertaken to survey local health and care professionals regarding their willingness to participate in the assisted dying service. It is envisaged this survey work will be undertaken in late 2024 / early 2025 to ensure that, at the point at which the Assembly debate the draft law (Q4 2025), there is a better understanding of the likely participation of on-island professionals and / or the need to recruit off-island professionals.

During this period, more detailed work will also commence on scoping the training requirement in full and identifying potential providers / developers of the training programme so that, in the event the law is adopted in late 2025, work can commence on development of that training package. Clearly detailed plans cannot be developed until the Assembly has determined the key features of the law (as this will have training and recruitment implications) but it is broadly anticipated that activity will include:

• Training programme and guidance development finalised: Q1 to Q2 2026

• Job specification development: Q1 2026

Recruitment: Q2 to Q3 2026Training roll out: Q1 to Q2 2027

19. If UK-based staff are contracted to work for the Jersey Assisted Dying Service, what impact will this have on the staff costs, including training and salaries?

As set out above, the indictive budget allows for £60,000 for the recruitment of staff (this would include on-island and off-island staff).

Paragraph 577 of the report and proposition (p158) provides indicative annual costs of running the services (which vary depending on the numbers of assisted deaths per year). The calculations that underpin these estimates are based on the current hourly rates incurred when off-island professionals are engaged in the delivery of HCS services.

Clearly if UK based staff are required to deliver the Assisted Dying Service, HCS may also incur expenses associated with travel and accommodation depending on the contractual arrangements.

More precise costs cannot be provided until the requirement for off-island professionals is better understood (see answer to Q18 above). This information will be available to the Assembly when they debate the draft law.

The costs associated with training would be the same for on-island and off-island professionals, except if additional travel and accommodation costs are incurred.



20. The Panel notes recent recruitment and staffing challenges across the Health and Community Services Department. Minister, please can you explain how you intend to respond to these challenges in relation to the provision of the Jersey Assisted Dying Service?

Professionals working for the Jersey Assisted Dying Service may be Government employees, bank staff or professionals on special contracts. This may include both onisland 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.

21. Minister, if no assisted dying service is available due to a lack of necessary staff. Please can you describe the process that would be followed if an assisted dying service was not possible due to staffing issues?

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.

22. Please can you clarify why the potential risk of the assisted dying service not being operational is not also present on the currently identified list of risks?

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.

In the interim, Risk no.19 on the table of risks clearly sets out that there are known risks associated with staffing.



23. Please can you confirm whether funding will be made available for counselling services for bereaved family members?

Approximately £40,000 has been provided in the indicative budget for family support during the assisted dying assessment process and for post-death bereavement support.

a. Which organisation will be responsible for delivering the counselling services?

This decision has not yet been taken but it is envisaged that a local organisation will be contracted to provide the service.

I trust that the above is of assistance to the Panel.

Yours sincerely,

Deputy Tom Binet

Minister for Health and Social Services

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