25 July 2019

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

David Seymour MP

By email: david.seymour@parliament.govt.nz

Dear Mr Seymour

End of Life Choice Bill – Draft SOP (PCO 1930 v 6.0)

Thank you for giving me the opportunity to provide feedback on your draft Supplementary Order Paper (draft SOP) on the End of Life Choice Bill (Bill). I note that this draft SOP proposes to make a number of amendments to the Bill, some of which concern the Health and Disability Commissioner Act 1994 (HDC Act), the Code of Health and Disability Services Consumers' Rights (the Code) and the functions of this Office.

While the draft SOP has addressed some of my concerns about the workability of the Bill, there remain a number of clauses which are problematic. My focus is to uphold the rights of vulnerable consumers. Please note that HDC's views may change if there are further amendments. However, I trust the below comments, which I make further to my letter of 21 May 2019, are of assistance.

For ease of reference I have also included a copy of the amendments I have suggested below as an appendix to this letter.

1. Amendments to the HDC Act & Code

I note that the draft SOP is proposing to amend the definition of "health services" in section 2 of the HDC Act, after paragraph (a)(vii), to include the following definition:

> "(viii) services provided to a person who has requested assisted dying under the End of Life Choice Act 2017; and"

In my view, this is the right place to insert this definition into the HDC Act. I also consider the wording of the definition to be appropriate as it will help to ensure that the process as set out in the Bill is captured following a request for assisted dying.

I also note that the draft SOP deletes the proposed change the Bill was seeking to make to the section 2(1) definition of "health consumer" and the Code's definition of "services". In my view, these deletions are appropriate.

2. The importance of informed consent and Right 6 and 7 of the Code

It is noted that the draft SOP amends clauses 4(1)(f), 4A, 10(2)(c), 11(3)(c) and 12(3)(c) of the Bill to require that a person seeking assisted dying is medically assessed to be competent to make an informed decision about assisted dying. These amendments will help to ensure that a person seeking assisted dying under the Bill is able to provide informed consent. As some people will have deteriorating conditions it is important to ensure that competency is retained throughout the assisted dying process.

However, the manner in which clause 24C overrides the entirety of Right 6 (the right to be fully informed) and Right 7 (the right to make an informed choice and give informed consent) of the Code is very concerning. As stated in my letter dated 21 May 2019, informed consent is a fundamental pillar of the legal framework applying to the provision of health and disability services in New Zealand.

Application of Right 7 – the right to make an informed choice and give informed consent

It is appropriate that Right 7(2)-(5) are overridden by the Bill, because they relate to instances where services can be provided to a consumer who has either diminished or no capacity to consent, or to advance directives. My understanding is that the draft SOP/Bill is not intending to allow persons with diminished or no capacity to access assisted dying services or to permit people to make advance directives for assisted dying. Rather, as evidenced by clause 4A, the draft SOP/Bill seems to intend that only persons who are competent to make informed decisions about assisted dying should be able to access assisted dying services.

Thus it is unclear why the draft SOP would wish to override Right 7(1) or Right 7(6)-(10) of the Code. Right 7(1) is consistent with clause 4A and provides that:

> "Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise"

Right 7(6) is concerned with ensuring that informed consent to the procedure is written in certain circumstances, including when there is a significant risk of adverse effects on the consumer. This would seem consistent with clauses 14(2)(d) and 14A of the draft SOP which require an eligible person to receive and complete a form which records the time and date they wish to receive the administration of the lethal medication.

Right 7(7) states that every consumer has the right to refuse services and to withdraw consent to services. Again, this right would seem particularly commensurate with the Bill/draft SOP which requires the attending medical/nurse practitioner to advise an eligible person that they can decide not to receive assisted dying services.[1] Right 7(8) provides a right for a consumer to express a preference as to who will provide services and have that preference met where practicable. It is unclear why the draft SOP would wish to deny a consumer the right to express this preference. Right 7(9) and 7(10) are concerned with body parts/bodily substances removed or obtained in the course of a health care procedure. Whilst rights 7(9) and (10) may not be particularly relevant to assisted dying, though there may be instances where they are,[2] it seems unnecessary to override them.

Application of Right 6 - the right to be fully informed

[1] For example clause 14(2)(e)(i) requires the attending medical practitioner to advise an eligible person who has completed a form stating the date and time they wish to receive the lethal medication, that they "may decide not to receive the medication". Other examples include clauses 15(3)(d) and 16(2) which similarly require the attending medical practitioner/nurse to advise a person that they can decide not to receive the lethal medication.

[2] For example if bodily tissue is required to assist the medical practitioners in making a determination as to a person's eligibility for assisted dying (e.g. blood tests or a biopsy to help confirm a terminal prognosis).

Right 6 is also commensurate with the clauses of the draft SOP/Bill (with the exception of clause 7). For example, Right 6(1)(a) requires consumers to receive an explanation of their conditions. Clause 8(2)(a)(i) requires the attending medical practitioner to give an eligible person information on the prognosis of the person's terminal illness. Similarly, Right 6(3) is consistent with clause 7(2) of the draft SOP, as it requires a provider to provide "honest and accurate answers to questions relating to services". That is, a provider has to provide a consumer with information upon the consumer's request.

However, it is acknowledged that Right 6(1)(b),(c) and Right 6(2) should be overridden in order to allow for the effective operation of clause 7 of the draft SOP. This is because clause 7 prohibits the attending medical practitioner from initiating any discussion, or making any suggestion, about assisted dying unless a person makes a request for assisted dying. This prohibition in clause 7 may run contrary Right 6(1)(b) which requires providers to provide information to a consumer that a reasonable consumer, in the consumer's circumstances, would expect to receive including an explanation of the options available, one of which could be assisted dying. Right 6(2) similarly provides that before a consumer makes a choice or gives consent, they have the right to information that a reasonable consumer, in the consumer's circumstances, would need in order to make an informed choice or give informed consent.

However, the need for operational clarity between clause 7 and Right 6 does not mean that Right 6 should be overridden with respect to the other clauses of the Bill/draft SOP. It is **recommended** that:

1. Clause 24C is amended to override only Right 7(2) – 7(5) of the Code.
2. Clause 7 is amended to include a new subsection which overrides Right 6(1) and Right 6(2) insofar as the operation of that clause is concerned.

3. Clause 7 & inappropriate breach findings of the Code

Clause 7(3) provides that any health practitioner who initiates or makes a suggestion to a person about assisted dying (per cl 7(1)) "is to be treated as having acted in breach of [the Code]". Clause 7(3) is not clear and is inappropriate. Specifically, the clause is unclear regarding which of the rights contained within the Code would be breached. It is also unclear regarding which person or body is responsible for "treating" the health practitioner as if they have breached the Code, and what the consequences of that breach might be.

Clause 7(3) is also inappropriate because it interferes with, and infringes upon, the jurisdiction of HDC. At present only HDC has the jurisdiction to make findings as to whether the Code has been breached. This is because Parliament intended HDC to be the specialist decision making authority regarding whether a provider's actions are in breach of the Code.

It is **recommended** that clause 7(3) be deleted. Should a provider fail to comply with the requirements of clause 7 it would be open to HDC to consider a breach under Right 4(2) of the Code because the provider has failed to comply with legal standards. If the sub clause remains, it is **recommended** that that clause 7(3) could state the principle that a health practitioner who contravenes subsection (1) will have acted contrary to the legal standards applicable to that health practitioner.

4. Level of competence required during the eligibility assessments

The draft SOP inserts clause 4A which sets out the meaning of "competent to make informed decision about assisted dying". It is noted that clause 4A significantly clarifies the competency standard the Bill intends to apply to various clauses and closely mirrors section 9 of the Substance Addiction (Compulsory Assessment and Treatment) Act 2017 (NZ) section 4 of the Voluntary Assisted Dying Act 2017 (Victoria, Australia). The competency standard medical practitioners are required to consider when reaching the first, second and, if necessary, third opinion regarding whether a person is eligible for assisted dying in clauses 10 - 12, is now clear.

However, it is inconsistent that whilst medical practitioners are required to examine a person seeking assisted dying and read their medical files during the second and third opinion assessments, there is no such requirement for the first assessment. It is **recommended** that clause 10 be amended to include the requirement that medical practitioners forming the first opinion examine the person seeking assisted dying and read their medical notes.

5. When is capacity assessed in the assisted dying process?

Whilst the draft SOP has clarified that a person's competency is to be assessed in clauses 10 -12, there are still a number of clauses where it is unclear if a competency assessment is required. It is crucially important that medical practitioners are clear about when they are required to assess a person's competency and what the competency standard is for the following clauses.

Clause 8(2)(c),(d)

After being informed by a person that they wish to exercise their option for assisted dying, clause 8(2)(c) requires the attending medical practitioner to "ensure the person understands their other options for end-of-life care". Clause 8(2)(d) requires the attending medical practitioner to also "ensure that the person knows that they can decide any time before the administration of medication not to receive the medication".

It is unclear if the attending medical practitioner is required to complete a competency assessment in order to be satisfied that they have ensured the person "understands their other options" per clause 8(2)(c) or "knows that they can decide" per clause 8(2)(d).
It is **recommended** that clause 8(2)(c) and 8(2)(d) be amended in accordance with the following principle:

The attending medical practitioner must obtain the eligible person's informed consent for assisted dying, including informing the eligible person of their other options for end of life care and informing the eligible person of their rights to decide not to receive assisted dying and to withdraw their consent at any time.

Clauses 14(2)(d),(e) and 15(3)(b),(d)

The draft SOP deletes clause 15(3)(c) and amends clause 14 to include 14(2)(d) and (e). Clause 14(2)(d) requires the attending medical practitioner to give the eligible person a form so that they can record their choice of the date and time for the administration of medication. Clause 14(2)(e) requires the attending medical practitioner to advise the eligible person after they have completed

the form that they may decide not to receive the medication; or to receive the medication at a time on a later date that is not more than 6 months after the date initially chosen.

The draft SOP under clause 15(3)(b) requires that, before the chosen date, the attending medical practitioner must ask the eligible person to "choose one of the methods" of administration of the lethal medication. After the eligible person chooses the method, clause 15(3)(d) requires the attending medical practitioner to "ensure" that the eligible person "knows that they can decide" at any time before the administration of the lethal medication, not to receive the medication, or to receive the medication at a time on a later date that is not more than 6 months after the date initially chosen.

It is unclear but arguable that an attending medical practitioner is required to conduct a number of implicit competency assessments when:

- They ask the eligible person to fill in a form so that they can chose a date and time for the administration of medication pursuant to clause 14(2)(d) and advise the person that they can choose not to receive the medication, or receive it at a later time pursuant to clause 14(2)(e). If an eligible person is unable to choose a date and time for the administration of the lethal medication, or appears not to understand that they can choose not to receive the medication, or can choose to receive it at a later date, it is unclear what should occur. Would the attending medical practitioner be required to reassess the person's competency?
- Similarly, what should occur if an eligible person is unable to or declines to choose a method of administration pursuant to clause 15(3)(b)? Would the attending medical practitioner be required to assess the person's competency?
- Further, is the attending medical practitioner required to complete a competency assessment in order to be satisfied that they have ensured an eligible person "knows they can decide" not to receive the medication, or receive it at a later date under clause 15(3)(d)?

It is **recommended** that the draft SOP clarify if competency assessments are required in the steps specified in clauses 14(2)(d),(e) and 15(3)(b),(d). If competency assessments are required then it is **recommended** that the clauses be amended to require that the attending medical practitioner be satisfied that the eligible person is competent to make an informed decision about assisted dying (per clause 4A).

Clause 16(2)

The draft SOP amends clause 16(2) to require an attending medical or nurse practitioner at the chosen time of administration to ask the eligible person if they "wish" to either receive the medication, to receive it at a different time not more than six months from the date initially chosen, or not to receive the medication and rescind their request.

The draft SOP removes the word "choose" and replaces it with "wish". Arguably expressing a wish requires less capacity then making a choice.[3] Even if the word "choose" is preferred, it remains unclear if clause 16(2) requires an attending medical or nurse practitioner to assess a person's competency immediately before the lethal medication is administered. Please also note the discussion below concerning the ambiguity clause 16(2) creates with respect to advance directives.

It is essential that the person exercising their option to receive assisted dying at the point immediately prior to the administration of the medication is competent in order to make an informed choice and give informed consent. Accordingly, it is **recommended** that clause 16 be amended to require that the attending medical or nurse practitioner must be satisfied that the eligible person is competent to make an informed decision about assisted dying (per clause 4A).

6. Advance Directives

Clause 24A(a) makes it clear that no person may make an advance directive, will, contract, or other agreement to exercise the option to receive assisted dying under the Act. However, it is questioned whether clause 14(e)(ii), 15(3)(d), and 16(2)(b) (which are concerned with informing/permitting an eligible person to choose a time not more than six months after the date initially chosen to receive assisted dying), provide for de facto advance directive agreements.

For example, an eligible person may meet the competency criteria of the Bill/draft SOP from the time of their request up until the date initially chosen to receive the lethal medication, however their capacity may well decline in the subsequent six months should they exercise their option to extend the date. Clause 16(2) in the draft SOP still requires the attending medical/nurse practitioner to ask the eligible person if they "wish" to receive the lethal medication before it is administered. However it is unclear if the eligible person needs to be competent enough to provide legally effective informed consent in accordance with the requirements of clause 4A, or have just enough capacity to express a "wish". If the latter is the standard, then the decision made at the date initially chosen would in effect be an advance directive.

This reinforces the point above that the person must be competent at all material times.

7. Attending nurse practitioner to take no further action if pressure suspected

The draft SOP deletes clause 22A of the Bill and replaces it with clause 18B. Clause 18B clarifies that the threshold for an attending medical practitioner to take no further action is if they have reasonable grounds to suspect a person is not expressing their wish free from pressure from any other person. However it makes no reference to an attending nurse practitioner. It is noted that the draft SOP amends clause 16 to also allow a nurse practitioner to administer lethal medication. Accordingly, it is **recommended** that clause 18B be amended to require an attending nurse practitioner to similarly take no further action if pressure is suspected.

In light of the issues discussed above, I consider the Bill as amended by the draft SOP, remains problematic.

[3] The Oxford Dictionary defines "wish" as a 'desire or hope for something to happen'. It defines "choose" as follows: to 'pick out (someone or something) as being the best or most appropriate of two or more alternatives.

Thank you for the opportunity to comment on the draft SOP.

Yours sincerely,

Anthony Hill
Health and Disability Commissioner

Cc: Hon Dr David Clark, Minister of Health
Dr Ashley Bloomfield, Director-General of Health, Ministry of Health

Appendix

Summary of amendments to End of Life Choices draft SOP (PCO 1930 v 6.0) recommended by HDC

Clause 7

Amend Clause 7 to include a new subsection which overrides Right 6(1) and Right 6(2) insofar as the operation of that clause is concerned.

Delete Clause 7(3). Alternatively reword Clause 7(3) to state the principle that a health practitioner who contravenes subsection (1) will have acted contrary to the legal standards applicable to that health practitioner.

Clause 8

Amend Clauses 8(2)(c) and 8(2)(d) in accordance with the following principle:

The attending medical practitioner must obtain the eligible person's informed consent for assisted dying, including informing the eligible person of their other options for end of life care and informing the eligible person of their rights to decide not to receive assisted dying and to withdraw their consent at any time.

Clause 10

Amend Clause 10 to include the requirement that medical practitioners forming the first opinion examine the person seeking assisted dying and read their medical notes.

Clause 14

Clause 14 be amended to require that the attending medical practitioner be satisfied that the eligible person is competent to make an informed decision about assisted dying.

Clause 15

Clause 15 be amended to require that the attending medical practitioner be satisfied that the eligible person is competent to make an informed decision about assisted dying.

Clause 16

Clause 16 be amended to require that the attending medical or nurse practitioner must be satisfied that the eligible person is competent to make an informed decision about assisted dying

Clause 18

Clause 18B be amended to require an attending nurse practitioner to similarly take no further action if pressure is suspected

Clause 24C

Clause 24C is amended to override only Right 7(2) – 7(5) of the Code.