

Privacy Commissioner's submission to the Justice Committee on the End of Life Choice Bill

Executive summary

1. The End of Life Choice Bill ("the Bill") provides people who have a terminal illness or a grievous and irremediable medical condition with the option to request assistance from a medical practitioner to end their life ('assisted dying').
2. This submission focusses on the provisions in the Bill that concern individuals' health information when they request assisted dying. I support these provisions with regard to protecting personal privacy. I consider they are necessary for practitioners to deliver services, and support appropriate regulatory oversight given the significant consequences of a person receiving or being denied assisted dying.
3. This is the first opportunity I have had to comment on the Bill. Should it be enacted, I anticipate that my Office will assist the Ministry of Health in ensuring the protection of personal information is consistent with the Health Information Privacy Code 1994, which sets specific privacy rules for the health sector.
4. In my submission I make a number of recommendations to identify and clarify the policy intent of the Bill, and how it will deal with individuals' personal information.
5. I **recommend** that the purpose of the assisted dying register is expressed in the statute.
6. I **recommend** the Committee investigates incorporating elements of the existing mortality review committee model into the Bill, particularly:
 - i. A clearly identified purpose for the review committee, which would guide the committee's collection and use of information.
 - ii. Provisions governing the review committee's collection of personal information, and safeguards to protect it, including prohibiting disclosure other than for the purposes of the review committee.
7. I **recommend** subclause 8(h)(ii) is amended to clarify whether it is compulsory or optional for the person requesting assisted dying to authorise their practitioner to talk to at least one family member. If it is intended to be optional, I recommend clause 8(h)(ii) is amended to read as follows:

“...talking with members of the person's family, if the person has approved any for this purpose”.

Individuals' health information under this Bill

8. The Bill provides for medical practitioners and a Registrar (Assisted Dying) within the Ministry of Health to collect, use, disclose and store individuals' health information.
9. A person who seeks assisted dying will need two, and in some circumstances three, medical practitioners to independently agree they are eligible. If the person is eligible a practitioner will provide assisted dying services consistent with the person's chosen timing and method.
10. At each stage of the process the Bill requires practitioners to record information using prescribed forms, including:
 - practitioners' opinions on a person's eligibility to receive assisted dying
 - the person's prescription for lethal medication
 - the provisional arrangements the person makes to receive assisted dying, and
 - details of the person's death as reported by their attending practitioner.

I encourage the Ministry of Health to consult my Office on the development of the regulations that would prescribe the forms required by the Bill.

Privacy and deceased persons' information

11. This Bill deals with information that is about persons who are living and deceased. The principles under the Privacy Act 1993 usually only apply to information about living identifiable persons. The situation is different under the Health Information Privacy Code, which modifies ordinary privacy principles for the health sector. Rule 11 of this Code extends agencies' obligation not to disclose health information to information about deceased individuals for 20 years after they have died.

The assisted dying register should have clear a purpose

12. Clause 21(2) requires the Registrar to maintain an assisted dying register that will hold the prescribed forms. The Bill does not currently identify the purpose of the register or set out its intended use and availability. It is not clear from the Bill whether the register information is intended to be publicly available (although I suspect it is not) or shared with other agencies.
13. The register information is likely to be of interest to the Ministry of Health and others for various purposes outside of administering the assisted dying process. For example, the register will hold information indicating a person's wish to end their life, including when they have been denied assisted dying. Will this individual and their family be of interest to agencies with a concern for the person's safety, such as the New Zealand Police? What information will be available to a family member who alleges a breach of the Act after their loved one has died? Or to a practitioner facing disciplinary proceedings?

14. I encourage further work on the Bill to identify the purpose of the register and provide for access and use necessary for that purpose. Where the policy anticipates information sharing, the Bill should define parameters and a mechanism for ensuring the privacy principles are complied with. While the Bill does not need to prescribe every allowable interaction with the register, it should be apparent why an individual's information is being collected, how it will be used and by whom.
15. I support the Bill's requirement for the Registrar to consult the Privacy Commissioner when establishing this register, and then at regular intervals. I would expect consultation to include, in particular, the Registrar's proposed steps to prevent unauthorised access, use, modification and disclosure, and intentions for retention and disposal of individuals' information.

The Bill should identify the review committee's purpose and provide for it to collect and use information consistent with that purpose

16. Clause 20 of the Bill provides for a review committee. This committee will consist of a medical ethicist and two medical practitioners, one practising in the area of end of life care. The committee's functions include reporting its "satisfaction or otherwise with the cases reported" to the Registrar and recommending actions the Registrar may take to "follow up" cases if the committee is not satisfied.
17. Subclause 17(3) requires the Registrar to disclose reports on assisted dying deaths to the committee. These reports will contain personal information about the person who has died, and conceivably others close to them who share their home or otherwise came to be with them when they died.
18. I encourage further work to clearly identify the purpose of the committee. What will it aim to achieve when it reports on whether it is satisfied with a death? Will the reports under clause 17 provide enough information, or will the committee want to make further enquiries? This exercise is essential for an assessment of what personal information the committee needs and how it will be used.
19. I consider New Zealand's existing mortality review committee model offers a useful starting point for the Committee. The Health Quality and Safety Commission appoints mortality review committees under the New Zealand Public Health and Disability Act 2000 (the NZPHDA). These committees review and report on particular deaths (such as suicide), or the deaths of particular people (such as children) to learn how to prevent them.
20. I **recommend** the Committee investigates incorporating elements of this model into the Bill, particularly:
 - i. A clearly identified purpose for the review committee, which would guide the committee's collection and use of information (mortality review committees work with a view to reduce mortality and morbidity under section 59E of the NZPHDA).

- ii. Provisions governing the review committee's collection of personal information, and safeguards to protect it (schedule 5 to the NZPHDA deals with mortality review committees' obligations, including prohibiting disclosure other than for the purposes of the review committee under clause 4).

The provision for a practitioner to talk to a person's family about their wish should be clarified

21. Subclause 8(h)(ii) requires a person's medical practitioner to "do his or her best to ensure that the person expresses his or her wish free from pressure from any other person" by talking with members of the person's family who are "approved by the person".
22. It should be clear to a person who requests assisted dying what will happen to their personal information and what the consequences are if they object to it being disclosed. I do not consider that the Bill is currently clear regarding whether a person will be required to authorise their practitioner to disclose their wish to their family.
23. The fact a person is considering seeking assisted dying is highly sensitive and, depending on the circumstances, not something they may want to share with family, or with a particular family member. If it is compulsory to approve a family member for their practitioner to talk to, this seems at odds with other provisions that give the person control over disclosure. For example, subclause 8(e) only requires a practitioner to "encourage" the person to talk to family and subclause 8(f) requires the practitioner to tell the person that he or she is "not obliged to talk to anyone".
24. I **recommend** subclause 8(h)(ii) is amended to clarify whether it is compulsory or optional for the person requesting assisted dying to authorise their practitioner to talk to at least one family member. If it is intended to be optional, I recommend clause 8(h)(ii) is amended to read as follows:

"...talking with members of the person's family, if the person has approved any for this purpose".

Conclusion

25. I do not seek to appear before the Committee, but would be happy to should the Committee find that helpful in its consideration of this Bill.



John Edwards
Privacy Commissioner