

Privacy Commissioner's submission on the review of the Health and Disability Commissioner Act 1994 (HDC Act) and the Code of Health and Disability Services Consumers' Rights (the Code)

1. I am pleased to make a submission to the Health and Disability Commissioner (HDC) on the review of the HDC Act and the Code.
2. The Privacy Act 2020 is New Zealand's main privacy statute. One of the Privacy Commissioner's functions under the Privacy Act is to examine proposals that may affect the privacy of individuals.
3. I refer to the HDC's April 2024 Consultation Document throughout this submission and have focused my comments on the topics raised in the Consultation Document.

Topic 1(c) – Clarify the role of whānau

4. The Consultation Document makes three proposals to clarify the role of whānau:
 - a. Amend Right 3 to say 'autonomy' instead of 'independence'.
 - b. Strengthen Right 8 to include the right to have whānau involved even when not physically present.
 - c. Amend Right 10 allow complaints to be made by representatives of the consumer.
5. I understand that the policy intent of these proposals is to better enable culturally appropriate and inclusive care in health settings. There can be real benefits to this approach as articulated in the consultation document. The challenge is finding an approach which recognises the role the whānau or support person can play while protecting the agency of the individual and their control over how their personal health information is shared. There may be circumstances where whānau involvement could be harmful to the individual or could unreasonably intrude on their privacy. I suggest that care must be taken to ensure that the individual's opinions are a central consideration.
6. The first two proposals (listed at paragraphs 4(a) and (b) above) are reasonable changes to meet the policy intent and are unlikely to intrude on individual privacy. However, I will need to see more analysis on the third proposal (paragraph 4(c)) to understand the privacy implications. The individual's wishes must remain at the centre, and representatives should not gain access through the complaints process to health information the individual has not consented to. In my view, if the individual's wishes are central to all decision making (resulting in their information being shared, or not), then I am in favour of the proposals.

Topic 1(f) – Clarify provider complaint processes

7. I note that the complaints process in Right 10 of the Code is the model that is replicated in the Health Information Privacy Code (HIPC). My Office will need to consider any implications for the HIPC if the proposed changes to Right 10 are accepted, and I would like to be kept informed of your decisions about this proposal.

Topic 4(b) – Lower the threshold for access to the Human Rights Review Tribunal (HRRT)

8. I agree that there may be some value in aligning the threshold to access the HRRT with comparable Acts such as the Privacy Act 2020 and Human Rights Act 1993. I am interested to see further analysis on this proposal and the effects it may have for consumers.

Topic 5(c) – Give the Director of Proceedings the power to require information

9. Since it relates to how information, including personal information, is shared with the HDC, I am interested to see some further analysis on this proposal. The material in the discussion document is not enough for me to express an opinion on this proposal.

Topic 5(f) – Provide HDC with grounds to withhold information where appropriate

10. I refer to the letter I sent to the acting Health and Disability Commissioner, dated 13 March 2023. The Privacy Act 2020 includes a secrecy provision at section 206. I rely on this provision to ensure my Office's correspondence with complainants and respondents is kept secret. I suggest that this may be a useful option for HDC to explore, as it would assist with your complaints process.

Topic 5(j) – Respond to advancing technology

11. I support the Code continuing to be technology-neutral, meaning it can adapt as technology develops and the health sector changes over time. Technological developments will deal with some of the most challenging issues of our time and will affect individual privacy and the safe provision of health services.
12. I refer to my functions under section 17(1)(j) of the Privacy Act, which states that one function of the Privacy Commissioner is to undertake research and monitor developments in data processing and technology to ensure that individual privacy continues to be protected. I suggest that a similar function of monitoring the implications of technological developments be useful to the HDC, as it would allow the Commissioner to monitor emerging issues, promote public debate, and set expectations for the sector on how they integrate new technologies. You may find it useful to proactively assess the risks and benefits of new technologies to understand the potential impact on the rights in the Code before they occur.

13. Emerging technologies will change the landscape of patient care. For example, artificial intelligence (AI) changes who is interacting with consumers and how they communicate. AI has the potential to support the relationship between consumers and health practitioners, but it also has the potential to harm that relationship and make it difficult to know who is ultimately responsible for the consumer's care. My office has produced [guidance on AI and privacy](#).
14. I note that my Office is progressing work on biometric technology. I recently conducted public consultation on an exposure draft of a [Biometrics Code of Practice](#), and health agencies were excluded from the draft Code in relation to matters that are already covered by the Health Information Privacy Code. This work may be of use for you to consider as you consider the effect of new biometric technologies on health consumers.

Conclusion

15. I trust that my comments are of use to the review of the HDC Act and Code. I look forward to seeing the proposals and recommendations that result from this review, and commenting further on any that have privacy implications.



Michael Webster
Privacy Commissioner

7 August 2024