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Morag McDowall
Health and Disability Commissioner

By email: review@hdc.org.nz

Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights | Ko te arotakenga o Te Ture Toihau Hauora, Hauātanga 1994 me te Tikanga o ngā Mōtika Kiritaki mō ngā Batonga Hauora, Hauātanga

Tēnā koē

Thank you for the opportunity to submit on the Review of the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code) 2024.

The Royal Australasian College of Surgeons (RACS) is the leading advocate for surgical standards, professionalism and surgical education in Aotearoa New Zealand and Australia in nine surgical specialties - Cardiothoracic Surgery, General Surgery, Neurosurgery, Orthopaedic Surgery, Otolaryngology Head and Neck Surgery, Paediatric Surgery, Plastic and Reconstructive Surgery, Urology and Vascular Surgery. RACS is a not-for-profit organisation representing more than 7000 surgeons and 1300 surgical trainees and International Medical Graduates across Australasia. We support healthcare and surgical education in the Asia-Pacific region and are a substantial funder of surgical research.

RACS supports the need to review of the Act and the Code. We note the close alignment of the drivers of your Review with our RACS mission 'to improve access, equity, quality and delivery of surgical care that meets the needs of our diverse communities'. You have importantly reinforced good communication with our patients, the importance of informed consent, and improving the application of minority rights in healthcare.

We have responded to the proposals and questions in your consultation document of April 2024 in the attached submission, which you may publish. I emphasise particularly the following points:

- Given the current pressures on the Health and Disability System, RACS would support HDC taking a more visible leadership role in system reform under its statutory function to use insights from complaints to influence policies and practice across the system.
- We recognise your focus Te Tiriti o Waitangi and working with Māori in this context. We support your clarification that this is separate from the need for culturally competent and safe services for consumers identifying with other cultures such as tāngata whaikaha and the Takatāpui LBGTQIA+SB community, and the impact of intersectionality on health equity.
- We consider the proposals should concurrently use and reference the health sector principles in the Pae Ora (Health Futures) Act 2022 to ensure equitable access to health services, equitable levels of service, and equitable outcomes, for Māori and other population groups. This would indicate greater emphasis on making your services more accessible.

Nāku noa, nā

Ros Pochin
Chair, Aotearoa New Zealand National Committee

Topic 1: Supporting better and equitable complaint resolution

- **Did we cover the main issues about supporting better and equitable complaints resolution?**
 - **What do you think of our suggestions for supporting better and equitable complaints resolution, and what impacts could they have?**
 - **What other changes, both legislative and non-legislative, should we consider for supporting better and equitable complaints resolution?**
1. RACS agrees that the HDC has covered the main issues regarding supporting better and equitable complaints resolution.
 2. A major complaint of the current code is it fails to fulfill its aim of “resolving complaints in a fair, timely, and effective way”. Currently the process takes far too long for both providers and consumers, even when investigations are not held. We agree there needs to be more effective communication and trauma-informed processes, and speedier resolution. The early resolution pathway takes too long with minimal support provided to the provider and consumer.
 3. We agree the triage process needs to be strengthened to focus on equity, identification of systemic issues, and supporting early resolution for both consumers and providers.
 4. Often the provider is left feeling the process is not impartial and is in fact punitive towards them, having a devastating personal and professional impact. This is well documented and a call for an increased focus on restorative approaches that enable process and healthcare provision improvement will result in a more positive outcome for all parties.¹ This may also avoid health care practitioners practising defensively, either as a result of an HDC investigation or concern about avoiding one in the future. It would also enable both parties to be heard.
 5. Definitions need to be strengthened and mutual understanding confirmed in each complaint – consumers, providers and the HDC may have varying understanding of the definition of “significant harm”.
 6. Timelines also need to be improved so consumers and providers are not left with the long waits currently experienced.
 7. We endorse the concept of using clinical navigators to help guide people through the complaints process, however it is not clear who these clinical navigators will be and the qualifications they will have.
 8. The current the purpose statement is:
 - “To promote and protect the rights of health consumers and disability service consumers, and to that end, to facilitate the fair, simple, speedy and efficient resolution of complaints relating to infringements of those rights.”
 9. We would like to see this broadened to:

“To promote and protect the mana and rights of health consumers and disability service consumers, by facilitating the fair, impartial, simple, speedy and efficient resolution of complaints relating to infringements of those rights and to advocate for continuous improvement of the health and disability services.”
 10. We support the proposals to clarify cultural responsiveness. We recognise our obligations to Te Tiriti o Waitangi and support the clarification that working with Māori in this relationship is separate from the need for culturally competent and safe services for consumers identifying with other cultures such as tāngata whaikaha and the Takatāpui LBGTQIA+SB community, and the impact of intersectionality on health equity.

¹ Wilkinson J, Marshall C. Health Practitioner experience of Health and Disability Commissioner investigations. J Prim Health Care 2021;13(3):213–221. doi:10.1071/HC21026.

11. RACS supports the proposals to change the Code to create and clarify a role for whānau in the consumer-provider relationship. This benefits all consumers, whilst specifically enabling Māori, Pasifika and Tangata Whaikaha for whom such processes will align better with cultural norms and preferred practice.
12. RACS supports the use of gender-inclusive language to make the code more accessible and safe for all people to access.
13. RACS supports the introduction of a non-retaliation clause – however this statement should also be extended from the consumer to the provider. Some providers have been subjected to abuse as a result of a complaint made, even if that complaint is not upheld. Both consumers and providers might be resident in rural settings which makes interactions in the future inevitable. Some providers have had to move job and relocate as a result of complaints made and subsequent abuse.
14. RACS agrees often complaints are best resolved between the consumer and provider and often may result from misunderstandings in communication. Promoting the process for providers to communicate via their own complaints process would be valuable and hopefully will expediate resolution of issues.
15. RACS endorses the HDC strengthening the advocacy service, advocates provide an excellent service and a valuable conduit between the consumer and provider. Increasing use of the Advocacy service to enable expediated resolution of complaints using the Direct resolution pathway should be encouraged. The Advocacy service should ensure it has good representation of Māori, Pasifika and other cultural groups such as tāngata whaikaha and the rainbow community. Promotion of the Advocacy service to different cultural groups is important to facilitate their use of the service.
16. RACS agrees with improving the language of the complaint pathways in the Act. Using the term “no” is automatically disempowering and makes consumers feel they haven’t been heard. We endorse the use of strength-based terms.
17. We suggest consideration of moving from the current wording: ‘Take no action or no further action’ to ‘Identification of appropriate care’ or “Written recommendations or educational action proposed”.
18. We agree that the term “facilitated resolution” is more reflective of a constructive process than “mediated conference”. We recommend the majority of complaints should be resolved using facilitated resolution, the current investigative route is inquisitorial and conducted predominately in private which doesn’t allow the consumer or provider the same levels of procedural fairness offered through the court system.
19. Given the current pressures on the New Zealand Health and Disability System, RACS would support HDC in taking a more visible leadership role in system reform. This could be achieved by increased focus on the words underlined in the fourth of its functions set out in the Act:
 - ‘Assess and use insights from complaints to influence policies and practice across the health and disability system and educate people about the Code.’

Topic 2: Making the Act and Code more effective for, and responsive to, the needs of Māori

- **Did we cover the main issues about making the Act and the Code more effective for, and responsive to, the needs of, Māori?**
 - **What do you think about our suggestions for making the Act and the Code more effective for, and responsive to, the needs of Māori, and what impacts could they have?**
 - **What other changes, both legislative and non-legislative, should we consider for making the Act and the Code more effective for, and responsive to, the needs of Māori?**
20. RACS works to ensure Te Tiriti o Waitangi is recognised and given practical effect in all aspects of its work. We also advocate for Te Tiriti o Waitangi to be recognised and given practical effect in all aspects

of the health system. As such, we are supportive of the proposed changes to ensure the Act and the Code give such practical effect.

21. RACS notes the involvement of rangatira (Māori leaders) and Māori health and disability sector leaders and the use of a Critical Treaty Analysis Framework, in the preparation of these proposals.
22. We are generally supportive of the proposals set out in the consultation document. We support the proposals to bring tikanga into the Code and the focus on 'mana' to encapsulate the essence of other elements of tikanga, and to have the strongest impact. We support further consideration of the suggestion to add to Right 1 of the Code (Respect) that every consumer has the right to have their mana upheld.
23. We support the proposal to consider introducing further aspects of tikanga into the Code and increasing workforce training regarding the re reo Māori translation and elements of tikanga to ensure greater cultural competence within our healthcare workforce.
24. RACS suggests in addition to recognising tikanga in the Code, and as an example its role in influencing policies and practice across the health and disability system (refer comment under Topic 1), HDC develops a companion document that explains the aspects of tikanga that are relevant to understanding and using the Code. This would include content set out on pages 11 and 28 to 33 of your consultation document. We suggest a stand-alone document would likely be more accessible and effective than just a section within the Code.
25. Further, and separate from obligations under Te Tiriti o Waitangi, we consider that the proposals should concurrently use and reference the health sector principles in the Pae Ora (Health Futures) Act 2022 (section 7):

"The health sector should be equitable, which includes ensuring Māori and other population groups:

- (i) have access to services in proportion to their health needs; and*
- (ii) receive equitable levels of service; and*
- (iii) achieve equitable health outcomes."*

26. The principles require the sector to ensure equitable access to, and outcomes from, health services.
27. The current proposals (use words such as promotion, tend to focus on) making sure Māori, Pasifika and tāngata whaikaha understand and engage with the process (as if the deficit is with the population group), rather than ensuring the process is equitably accessible (acknowledging that the deficit is with the process).
28. For example, on pages 33 and 34 (underlining added):

"Article 3 | Ōritetanga: Suggestions to provide for Māori to enjoy the promotion and protection of consumer rights as Māori, on an equal basis as non-Māori.

- *Functions of the Director of Advocacy to include promotion of equitable outcomes for Māori and all consumers (**section 25 Functions of Director of Advocacy**).*
- *Addition to **Section 25 Functions of Director of Advocacy** to include promotion of advocacy services to Māori and other communities to ensure equitable access.*
- *Amend **Section 30 Functions of advocates** to explicitly respond to the needs of Māori and promote and provide for processes led by the tikanga of the whānau where appropriate.*
- *Review and amend the legislative process for assessing complaints to enable and better align processes with tikanga (**Part 4 Complaints and Investigations, Sections 31–49, and specifically sections 33 preliminary assessment, 38 taking no action and 40 investigation**).*

29. Whilst these mention “equitable outcomes’ and “equitable access”, the onus and emphasis differ from the Pae Ora principles. Equity of access is not achieved by “promotion of advocacy services” provided by HDC.
30. Accessibility requires consideration of some important and related issues, including:
 - a. location, particularly remote and/or rural, where the population is often disproportionately low income whānau Māori with limited transport options
 - b. preferred and available communication modes – te reo, kanohi ki te kanohi, virtual, online
 - c. digital connectivity constraints, which adversely impact low income whānau and rural/remote locations
 - d. costs of engaging with the process, including costs of transport and connectivity.
31. RACS requests all proposals to change provisions in the Code and the Act to make them more effective for, and responsive to, the needs of Māori be tested through three filters to ensure they align with the principles set out in Pae Ora (Healthy Futures) Act 2022 thus to ensuring Māori and other population groups have:
 - a. equitable access to services
 - b. equitable levels of service
 - c. equitable health outcomes.

Topic 3: Making the Act and Code work better for tāngata whaikaha | disabled people

- **Did we cover the main issues about making the Act and the Code work better for tāngata whaikaha | disabled people?**
 - **What do you think of our suggestions for making the Act and the Code work better for tāngata whaikaha | disabled people, and what impacts could they have?**
 - **What other changes should we consider (legislative and non-legislative) for making the Act and the Code work better for tāngata whaikaha | disabled people?**
32. RACS supports the suggested changes to strengthen disability functions within the Act.
 33. RACS supports updating the definitions within the Act related to disability. This should be done in conjunction with tāngata whaikaha to ensure that terminology is constructive, enabling and encourages tāngata whaikaha to feel safe and heard when accessing the Act.
 34. RACS requests that all proposals to change provisions in the Code and the Act to make them work better for tāngata whaikaha be tested through three filters to ensure they align with the principles set out in the Pae Ora Act 2022 to ensure that Māori and other population groups have:
 - a. equitable access to services
 - b. equitable levels of service
 - c. equitable health outcomes.
 35. RACS supports the provision to enable health and disability research to be conducted where it is in the best interests of the community and has limited risk or burden. We agree suitable persons interested in the welfare of the person should be able to veto their participation in research and all research should have appropriate ethics committee approval and oversight. Research is vital to improve practice and outcomes for all people and to exclude a certain set from participating in research that aims to improve practice and outcomes for that population would stifle improvements.

Topic 4: Considering options for a right of appeal of HDC decisions

- **Did we cover the main issues about considering options for a right of appeal of HDC decisions?**
 - **What do you think about our suggestions for considering options for a right of appeal of HDC decisions, and what impacts could they have?**
 - **What other options for a right of appeal of HDC decisions, both legislative and non-legislative, should we consider?**
36. RACS supports the introduction of a right of appeal of HDC decisions for both consumers and providers and appreciates the introduction would be complex and requires careful consideration. An HDC appeals process would support application of natural justice.
37. Ideally the pathway for review would be via an independent agency rather than through the HDC. Lowering the threshold for access to the Human Rights Review Tribunal (HRRT) would offer an independent review but may be seen as restrictive and difficult to access by consumers and providers. Any process of review through the HRRT would need to have a specific pathway for appeal that is streamlined. Ideally a review panel should include lay members, Māori, legal, and ethics expertise.
38. Currently the changes only support appeal for those cases taken through to an investigation. There should be a review that is able to quickly assess those in other categories that haven't resulted in an investigation that wish to appeal.

Topic 5: Minor and technical improvements

- **What do you think about the issues and suggestions for minor and technical improvements, and what impacts could they have?**
 - **What other minor and technical improvements, both legislative and non-legislative, should we consider?**
 - **What are your main concerns about advancing technology in relation to the rights of people accessing health and disability services?**
 - **What changes, both legislative and non-legislative, should we consider to respond to advancing technology?**
39. RACS agrees reviewing the Act every five years and the Code every three years is time consuming and resource intensive, we support a move to performing reviews every ten years with the option of earlier reviews as needed. The process for requesting earlier reviews needs to be considered and well documented so external parties are able to trigger an earlier review if deemed necessary.
40. RACS supports an increase in the maximum fine for an offence under the Act from \$3,000 to \$10,000, this is more likely to provide an incentive for those to comply with the Commissioners processes.
41. RACS endorses the introduction of a definition of an "aggrieved person" however we consider using "impacted person" is a more reflective and constructive term. The term "aggrieved" assumes all persons are "aggrieved", some are impacted and would like to improve things for the future rather than aggrieved.
42. RACS is supportive of allowing a substituted service for advising specified persons about the results of an investigation.
43. The proposal to provide HDC with grounds to withhold information where appropriate needs to be carefully considered, particularly if timelines are not tight and investigations continue to take several years. The term "where appropriate" needs to be carefully defined and considered and a process of appeal needs to be in place.
44. RACS endorses the expansion of the requirement for written consent for sedation that is equivalent to anaesthetic. Sedation is used for many surgical procedures and generally written consent is gained,

sedation does have significant impact on a person's ability to remember and make decisions. Requiring written consent would make sure that the person is adequately informed of the impacts of sedation.

45. RACS supports clarifying written consent is required when there is a significant risk of serious adverse events and ensuring there is appropriate definitions and shared understanding of what is meant.
46. RACS agrees the rights in respect to teaching and research are very broad. We suggest reference to the publication "Informed consent for medical student involvement in patient care: an updated consensus statement"² which gives a good overview of issues from a medical student viewpoint but is also applicable to other healthcare trainees. The HDC, Medical Colleges, Te Kaunihera Rata o Aotearoa, Medical Student Association and Te Whatu Ora were all consulted in the development of this consensus statement.
47. With regard to a consumer's rights in relation to research we suggest stating clinical research where the patient's clinical course could be altered, including prospective studies, clearly need separate ethics committee approval and consent from the consumer; however retrospective studies that have no impact on the consumer's care do not infringe the consumer's rights.
48. RACS has concerns regarding advanced technology in healthcare. It is vital that we keep up to date in this area and ensure adequate training is available for surgeons both in training and post fellowship. The potential for bias is huge, particularly if data sets are used to inform Artificial Intelligence (AI) models that are not based on our specific ethnic demographics in Aotearoa New Zealand. We are aware significant health disparities for Māori, who often present with disease at a younger age than their Caucasian counterparts and have poor health outcomes. Ensuring there is adequate quality control in the use of AI is vital, to ensure it doesn't widen current health inequities for Māori.

² Simon Walker, Papaarangi Reid, Lynley Anderson, Susan Bull, Monique Jonas, Joanna Manning, Alan Merry, Suzanne Pitama, Sarah Rennie, Jeanne Snelling, Tim Wilkinson, Warwick Bagg. Informed consent for medical student involvement in patient care: an updated consensus statement. NZMJ VOL. 136 NO. 1579 | 21 JULY, 2023
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