



# Recommendations Report | He Tuhinga Taunaki

**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 Ratonga Hauora, Hauātanga

December 2024 | Hakihia 2024



HEALTH & DISABILITY COMMISSIONER  
TE TOIHAU HAUORA, HAUĀTANGA

Tuia tō mana kia māia

Tuia tō mauri kia mau

Horahia te mātauranga

Kia puta ko te māramatanga

E kotahi ai te wairua

Kia tipu, kia hua, kia puāwai ngā mahi

Haumi e, hui e,

Tāiki e!

Retain and hold fast to your mana, be bold, be brave

Be widespread with knowledge to empower understanding

By working together we will grow, flourish, prosper

Join all together, bind all together, let it be done!



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**Commissioner's foreword |  
Kupu whakataki a te Toihau**



Korihi te manu  
Tākiri mai te ata  
Ka ao, ka ao, ka awatea  
Tihei mauri ora!

E ngā iwi, e ngā mana, e ngā reo, e ngā karangaranga maha huri noa o Aotearoa nei, tēnā koutou, tēnā koutou, tēnā koutou katoa. E rere atu ana ngā mihi aroha ki te hunga kua riro atu ki te pō, te tini me te mano kua tīraha ki ngā marae maha, moe mai rā koutou. Hoki mai anō ki a tātou ngā urupā o rātou mā, mauri ora ki a tātou. Nō reira, tēnā anō tātou katoa.

I am pleased to present the findings of the review and my recommendations for improving the Health and Disability Commissioner Act (the Act) and Code of Health and Disability Services Consumers' Rights (the Code).

The Code sets the benchmark for consumer-centred care in New Zealand. It gives people rights when using health and disability services and places corresponding obligations on providers. These rights are enforceable by law and the powers set out in the HDC Act. Together HDC's Act and the Code play a critical role in ensuring that consumers' voices are heard, and their concerns are addressed. They assist to mitigate power imbalances, preserve trust in the health and disability system, ensure accountability and drive quality improvement.

This report marks an important milestone in our ongoing work to protect and promote the rights of people using health and disability services. It follows extensive public consultation, during which New Zealanders from diverse communities shared their experiences, challenges and frustrations, and their aspirations for a system that places the needs of consumers at its centre, while supporting providers to deliver high-quality services. What we heard is clear: HDC and the Code of Rights play an important role in the system — a role that remains as relevant as ever. However, change is needed to ensure effectiveness for all communities, and to enhance their impact on the system, including for those who work within it.

A well-functioning complaints system is an important mechanism for identifying and addressing issues. Complaints can highlight aspects of care that people care about most, identify inequities, inform quality improvement, and ensure that the system learns from its mistakes. However, we also heard how challenging these processes can be to access and navigate, and how sometimes they add to the distress of those seeking resolution, whether as a consumer, a whānau, or a provider. This feedback has reinforced the need for a more people-centred approach to complaints — one that is timely, accessible, responsive, and keeps people safe.

The recommendations in this report reflect two complementary goals. Changes to the Code are focused on shifting practice across the sector, strengthening the focus on equitable, person-centred care that responds to the diverse needs of our communities and supports issues to be addressed early. For Māori and tāngata whaikaha | disabled people in particular, this means being more explicit about existing obligations to address systemic barriers and embed cultural safety. The changes we propose to the Act are designed to improve how HDC operates. They are focused on ensuring that our processes can better adapt to the situation at hand and that we have the mandate and capability to perform our role in a way that works well for everyone.

Central to these recommendations is a focus on relationships — between consumers and providers, between providers and the wider system, and between HDC and the communities we serve.

It was pleasing to see the level of participation in this review. This reflects the commitment of all stakeholders in upholding consumer rights. I am grateful to all those who gave up their time so generously to shape this review and the recommendations in this report. I would also like to thank my team for the incredible amount of work that went into producing this report — the record number of submissions we received is a testament to their hard work and dedication.

The recommendations in the report represent an important opportunity to ensure that HDC promotes and protects the rights of all New Zealanders, and that the Act and the Code respond effectively to our changing environment — now and into the future. Even when the system is under considerable pressure, the Code ensures that we remain focused on the needs and experience of the people the system is serving.

Ngā mihi nui

**Morag McDowell**

Health and Disability Commissioner

# Introduction | He kupu whakataki



The Health and Disability Commissioner (HDC) is legally required to review the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code) and make recommendations to the Minister of Health. This 2024 review has focused on hearing from as many people as possible and has benefited significantly from public and sector engagement.

HDC is an independent Crown entity, and our role is to promote and protect the rights of all people in New Zealand who use health and disability services. We do this through the resolution of complaints about the quality of care provided to people, as well as through providing education on the Code and by contributing to quality and safety improvement at an individual and system-wide level. HDC also contracts the Nationwide Health and Disability Advocacy Service to assist people to resolve their concerns directly with providers and to undertake community-level promotion of the Code.

**This report is structured in three parts.**

- Part 1 sets out our findings from the 2024 Act and Code review and recommendations to the Minister of Health and the Minister of Disability Issues. Part 1 will be available in English, Māori, and accessible formats following the tabling of this report in Parliament.
- Part 2 outlines our approach to the review, including who we heard from.
- Part 3 provides supporting analysis, including a summary by topic of themes from engagement, and our comment and response. A more detailed summary of engagement, along with submissions (where proactive release permission was given), will be published following the tabling of this report in Parliament.

# **1. Findings and recommendations | Ngā whakataunga kōrero**



This review of the Health and Disability Commissioner Act (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code) is the most comprehensive the Health and Disability Commissioner (HDC) has undertaken in a decade. We received 259 submissions during the public consultation period and met with hundreds of people and organisations across the course of the review. Some of these voices are quoted in this report.

**The review focuses on issues that matter most to people.**

The review is an opportunity to make sure the Act and the Code remain effective in protecting and promoting the rights of everyone using health and disability services. The review is also an opportunity to improve how things are done at HDC and identify changes to improve the health and disability systems.

We heard that overall, the Act and Code are generally working well. However, we identified five areas where the application of the Act and the Code has not kept up with modern advancements and system pressures. These are:

- Supporting better and equitable complaints resolution;
- Making the Act and the Code more effective for, and responsive to, the needs of Māori;
- Making the Act and the Code work better for tāngata whaikaha | disabled people;
- Considering options for a right of appeal of HDC decisions; and
- Minor and technical improvements.

**We found** that largely the Code is flexible enough to accommodate the changing context.

We propose several small wording changes to make existing obligations more explicit. These include:

- Changes to Right 1(3) (the right to services that take into account needs, values and beliefs), including the addition of regard to tikanga;
- Adding protection against retaliation for making a complaint;
- Enhancing the right to support to make decisions;
- Extending Right 8 (the right to support) to include accommodations where the support person cannot be physically present;
- Changing language to reinforce accessibility and support inclusion; and
- Streamlining providers' obligations when responding to complaints and clarifying the role of support people in making complaints.

**We found that the Act requires greater revision to ensure that HDC has the right mandate to perform its role successfully for all New Zealanders.**

We propose changes across multiple sections of the Act, including:

- Changing the principles for complaints resolution from ‘fair, simple, speedy, and efficient’ to ‘fair, accessible, responsive, and efficient’, with the further possibility of explicit reference to timeliness. This will support a more modern and people-centred approach to complaints resolution and consistency across the public sector;
- Revising the language of the pathways for complaints resolution to ensure they are fit for purpose and support greater use of culturally appropriate methods of resolution and restorative approaches;
- Introducing a range of measures to give practical effect to te Tiriti o Waitangi;
- Introducing collective requirements for Deputy Commissioners to ensure the necessary expertise in relation to disability and updating disability definitions in the Act to be strengths-based and to align with the language of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD);

- Providing a better framework for the protection of rights in the context of health and disability research;
- Providing for a statutory requirement for HDC to review decisions; and
- Revising timeframes and streamlining processes for reviews of the Act and the Code.

**These changes need to be considered within the context of other government reviews.**

For this reason, we recommend that the proposed changes to the Act are progressed in parallel with the reviews of the Health Practitioners Competence Assurance Act 2003 (HPCAA) and Pae Tū: Hauora Māori Strategy, and progress on the Mental Health Bill and the Law Commission’s review of adult decision-making capacity law, as well as the Government’s response to the recommendations of the Inquiry into Abuse in Care. We recommend that the proposed changes to the Code are in principle only and are finalised once language and policy direction has been settled.

**We found that most of the necessary changes can be made operationally.**

Changes to HDC practice and processes, and sector guidance, education and promotion can resolve many of the issues that were raised. Many of these changes are already in place, and this review has identified priority actions to make further

improvements within HDC’s current resources.

**The system needs to ensure that appropriate safeguards are in place to respond to advancing technology**

While there are real benefits to advancing technology, some consumers and communities are already being left behind as the design of digital tools fails to account for their needs.

Regarding the evolution of digital tools, it is also critical that there are sufficient standards and guidance in place — informed by the voices of consumers — to set expectations around quality of care, lines of accountability, and informed consent. We believe that currently the Code is flexible enough to respond to changing technology. However, there needs to be clarity for people about what they can expect when technology such as AI is involved in their care.

**The review comes at a time of significant growth in complaints to HDC.**

The 3,628 complaints received by HDC in 2023/24 was the highest number of complaints ever received in a single year. While around 70% of complaints received by HDC are closed within six months, this increase has placed us under significant pressure and has led to delays in the resolution of some of our complaints.

HDC is focused on reducing our aging profile of complaints and has

streamlined many of our processes to free up staff time to concentrate on older complaints. We are also investing in a fit-for-purpose complaints management system, which will improve the efficiency of our process and provide us with tools to improve the transparency and responsiveness of our process.

In the context of resource constraints and on-going increases in complaints, HDC’s process improvement work has focused on increasing use of our early resolution pathways (including supporting resolution between consumer and provider) to ensure that our resources are directed towards those complaints that require HDC intervention. We have also prioritised work to ensure that we have strong processes to escalate any public safety or time-dependent issues urgently to those agencies who can take action to protect consumers.

We have expanded our use of tikanga-led approaches to complaints resolution, including use of hui ā-whānau and assisting with the coordination of hohou te rongo processes.

This review has reinforced the value of what we are already doing and has identified opportunities to make further improvements and ensure that our resources are being used where they are needed the most.

**The findings of this review can support wider sector improvement.**

HDC aims to take a timely, collaborative approach to working with sector leaders and other agencies to share issues of concern, amplify the consumer voice, and monitor the implementation of our recommendations. We will work with the sector to share learnings from the review, including the issues people have raised that are outside the scope of HDC.

This review aligns with the Minister’s expectations as outlined in the Government Policy Statement on Health (GPS), and in particular the review contributes to his focus on quality (ensuring that New Zealand’s health care and services are safe, easy to navigate, understandable and welcoming to users, and are continuously improving). The recommendations and findings of this report will allow both HDC and the sector to better promote and protect the rights of people using health and disability services — contributing to a system that puts people’s experience at the centre of quality.

The recommendations and findings of this review also support the achievement of the health sector principles set out in section 7 of the Pae Ora (Healthy Futures) Act 2022 — particularly those focused on engendering equitable, culturally safe, and culturally responsive services that are tailored to people’s needs, circumstances, and preferences and providing opportunities for Māori to exercise their decision-making authority on matters of importance to Māori.

The review has also highlighted some areas that require further work by the sector to improve consumer experience and better uphold people’s rights.

We note that currently (as directed by the GPS) a systems safety strategy is under development. This strategy may assist to facilitate a collaborative approach to addressing some of the system issues identified throughout this review.

## People generally agree with us about the changes needed.

Overall, most people and organisations we heard from supported the issues we set out in the consultation document and the principles behind our suggestions for change. Generally, people and organisations were united in wanting a fair, accessible, and responsive Act and Code.

Differing views generally related to technical details around how a suggestion was worded, concerns about adding provider obligations in the context of current pressures in the system, or whether changes would have a negative impact on the timeliness of HDC decisions.

Some of the more technical issues highlighted areas where there is a need for more dialogue to support a shared understanding and direction between the sector and the general public/consumers.

## Key things we learned from this review

- Generally, the Act and the Code are working well and have the flexibility required to respond to an evolving system.
- One size does not fit all.
  - People who are most likely to understand their rights and make complaints are those who have high health literacy, have the skills and capacity to advocate for themselves, and are motivated by quality improvement.
- We heard that Māori engage less often in complaints processes because of a lack of trust in the health and disability system, an expectation of poorer care, and approaches to complaints resolution that don't align with tikanga values and practices.
- Tāngata whaikaha face additional barriers to accessing complaints processes, are not provided with clear information about what to expect from disability support services, and fear losing essential supports if they complain.
- Other communities also face barriers to understanding their rights and accessing complaints processes. Current complaints processes are not designed to accommodate different cultural values or practices, such as collective decision-making and alternative approaches to conflict resolution.
- Small changes are needed to the language of the Act and the Code to help encourage practice that would be more responsive to the needs of all New Zealanders. Some of this practice is already happening, but wording changes will reinforce this as the standard expected.

## Recommendations to the Minister of Health

- 1. Note** that the review has identified opportunities to better promote and protect consumer rights through changes to both law and practice, particularly to improve complaints processes, support good practice, and improve responsiveness to the needs of Pae Ora populations — Māori, tāngata whaikaha | disabled people, and Pacific peoples.
- 2. Note** that changes to the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumer’s Rights (the Code) should be progressed in parallel with changes to the Health Practitioners Competence Assurance Act 2003 (HPCAA), the Mental Health Bill, Pae Tū: The Māori Health Strategy, the Law Commission’s review of adult decision-making capacity law, and the Government’s response to the recommendations made by the Inquiry into Abuse in Care.
- 3. Agree** to put the development of a bill to update the Act in line with this report on the Ministry of Health’s work programme and the Government Legislation Programme, and progress in parallel with the review of the HPCCA and Mental Health Bill.
- 4. Direct** the Ministry of Health to establish a technical working group to refine the detail of proposed changes to the Act that includes community and provider representatives, and HDC as an independent advisor.
- 5. Agree** in principle that the Code should be strengthened to address matters identified in this review; and that changes should occur after changes to the HDC Act to ensure cohesive legislative change. HDC will provide you with a revised Code following changes to the Act, or at the next review, whichever is earlier.
- 6. Note** that most of the issues identified and outcomes sought in the Act and Code review can be addressed operationally by HDC, and that HDC is progressing a work programme to implement operational improvements that can be made within current resources.
- 7. Note** that HDC will discuss options and resource implications for other improvements with the Ministry of Health.

## Recommendations to the Ministers of Health and of Disability Issues

- 1. Note** that sector standards, guidance, commentary, and education are important levers to improve quality of care in the health and disability systems. The responsibility for these levers is shared across agencies and providers. This review has:
  - Reinforced the need for a disability services quality framework as recommended by HDC in our July 2024 *Report on complaints to HDC about Residential Disability Support Services*;
  - Identified gaps in commentary, guidance, and education in several areas, with the highest priorities being supported decision-making, upholding Right 1(3), and complaint resolution; and
  - Identified the need for a whole-of-system approach to ensure cohesive safeguards and appropriate accountability for the use of AI in health and disability care.
- 2. Note** the critical roles of the Ministry of Health and Whaikaha | Ministry of Disabled People, Te Tāhū Hauora | Health Quality and Safety Commission (HQSC), Health New Zealand | Te Whatu Ora, and the Ministry of Social Development in responding to the issues identified in this review.
- 3. Note** that we will prioritise and respond to gaps in commentary, guidance, and education that are best addressed by HDC, and will work with the health and disability sector in relation to issues and suggestions identified through this review that require a wider system response.

## **2. Approach | Ngā āheinga**



Our approach was designed to ensure that the voices of a diverse range of consumers and providers were central in shaping the issues to be addressed and our response, with a particular focus on Māori, tāngata whaikaha | disabled people, and Pacific peoples. We heard from hundreds of people and organisations across the course of the review.

We approached the review in four phases:

- **Scoping (February to May 2023)**  
To help focus the review on what matters most to people, we wrote to 49 organisations and individuals to ask what is working well, what is not working well, and what can be improved. We received 30 responses and used them to help form the five topics of the review. A list of those to whom we wrote in the scoping phase is set out in **Appendix 2**.
- **Developing (June 2023 to March 2024)**  
We drew on literature to develop the five topics of the review further and tested our thinking through workshops and wānanga with a targeted but diverse selection of stakeholders. A list of activities and contributors to the **developing** phase is set out in **Appendix 3**.
- **Listening (April to August 2024)**  
We sought feedback on a public consultation document between 30 April and 14 August 2024. The consultation document can be found at [review.hdc.org.nz](https://review.hdc.org.nz). We received 259 submissions. We also held over 60 face-to-face and virtual engagements across the country.

- **Recommending (September to December 2024)**

We summarised submissions and feedback from engagement and used this to consider our response and recommendations to the Minister.

### **We heard from a diverse range of stakeholders.**

Throughout the project we used a mix of engagement approaches to ensure that we heard a diverse range of consumer, provider, and other agency perspectives.

We also had a particular focus on ensuring that we heard from priority populations as outlined in the Pae Ora (Healthy Futures) Act 2022 — including Māori, tāngata whaikaha | disabled people, and Pacific peoples.

This also provided HDC with an opportunity to enhance our engagement with these populations and understand the barriers they face in making complaints. We held dedicated hui, workshops, and talanoa and ensured Māori, tāngata whaikaha | disabled people and Pacific representation in the analysis and interpretation of feedback.

Given the different barriers faced by tāngata whaikaha | disabled people, we also focussed on hearing from different groups within the disability community,

including people with learning disability, the Deaf community, and people with lived experience of mental distress.

We also acknowledge that some of the individuals and groups we engaged with belonged to more than one of these focus populations. We made sure that there was diverse representation in our consultation meetings wherever possible — for example, tāngata whaikaha Māori were involved in meetings on making the Act and the Code more responsive to Māori and in meetings on making the Act and the Code more responsive to tāngata whaikaha | disabled people.

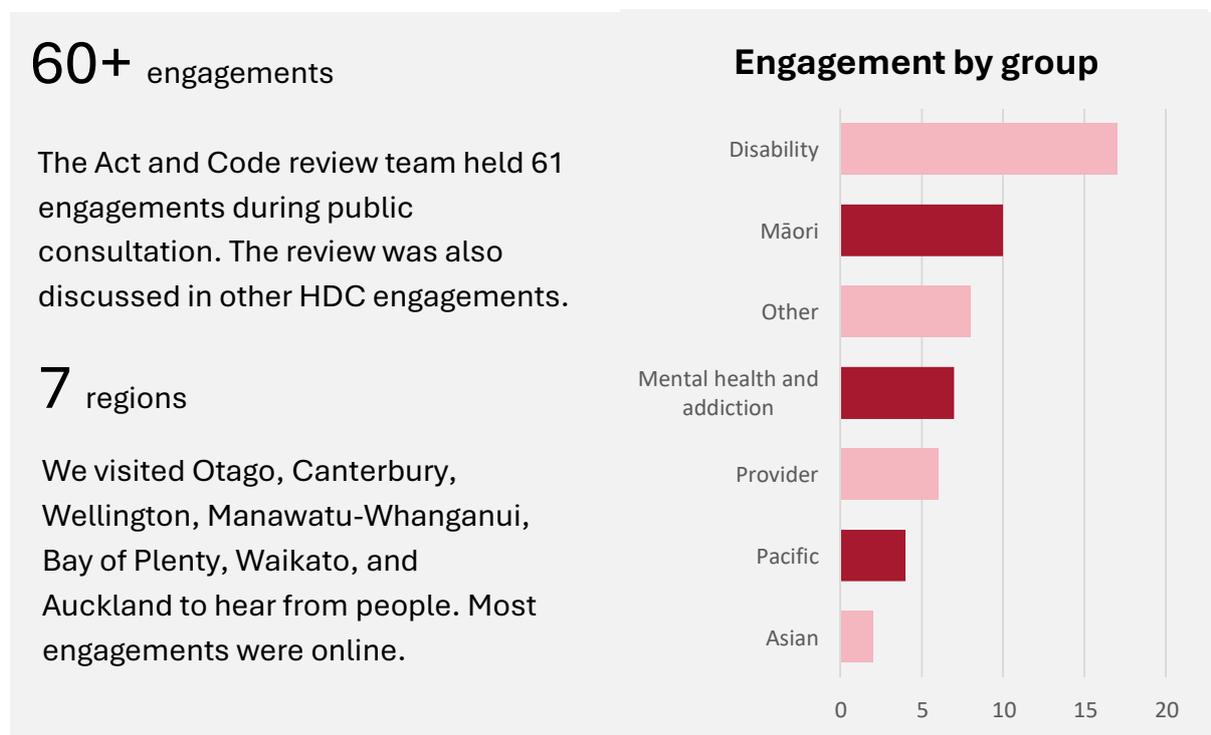
### **We received a record number of submissions.**

We received a total of **259** written submissions during the public consultation period, including three in te reo Māori. Submissions were from a mix of individuals and organisations,

representing a range of perspectives, including consumer and whānau, clinical, legal, and academic. Two hundred and twenty-eight submitters agreed to us publishing their submission, and these submissions will be available at [review.hdc.org.nz](http://review.hdc.org.nz) once this report is tabled in Parliament. A breakdown of demographics is set out in Figure 2.

During the consultation period we also held 61 online engagements in several regions across the North and South Islands. Engagements included meetings with individuals and meetings with large groups of people. We met with anyone who requested a meeting, and we undertook targeted engagement to ensure that the consultation was accessible and that we heard from those communities who are less likely to make complaints. A breakdown of engagements is set out in Figure 1.

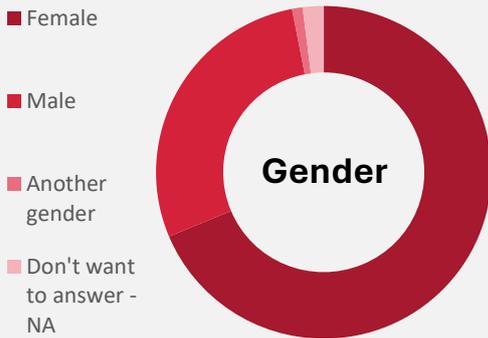
**Figure 1 — Act and Code Review Engagements during public consultation**



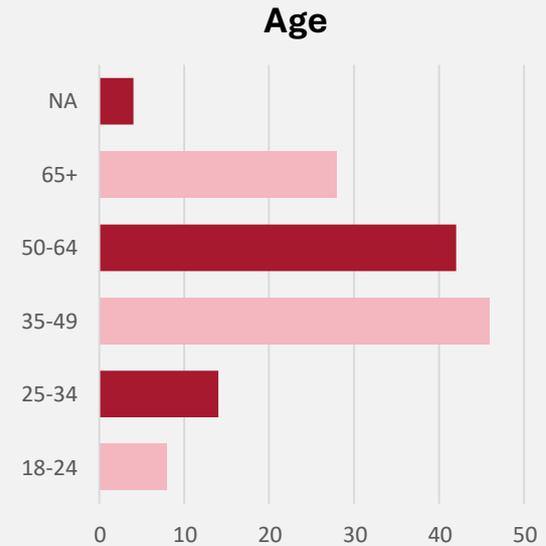
**Figure 2 — Act and Code review submissions**

**149** individual submissions

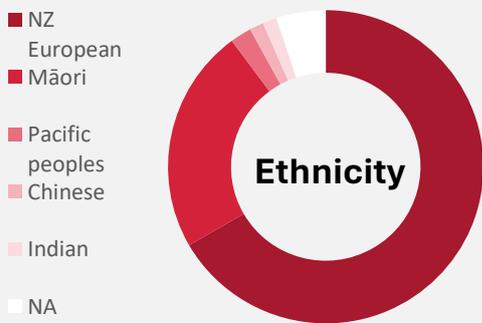
Most submitters identified as female (68%)



32% of submitters were aged 35–49 years



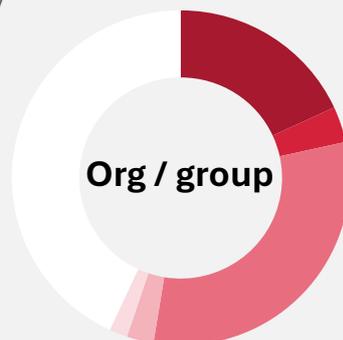
Most submitters (66%) were NZ European, followed by Māori (23%)



**28%** of submitters identified as having a disability

**110** submissions on behalf of a group or organisation

- Consumer organisation / group
- Iwi/Māori group
- Health and/or disability services provider
- Central government
- University/Academic
- Other



## **We are mindful of alignment with other reviews.**

This review is occurring at a time when the Government has sought advice on, or is revising, legislation that interacts with the Act and the Code. We are mindful of the need for a cohesive regulatory framework for consumers and providers of health and disability services and have taken this into account in developing our findings and recommendations.

Relevant reviews and policy direction are set out below.

- **The Health Practitioners Competency Assurance Act 2003** (HPCA Act) is currently under review. The HPCA Act regulates health practitioners to protect the public from harm by ensuring the competence of professionals. Some HDC complaint pathways are interdependent with HPCA Act processes.
- **The Mental Health Bill** to replace the Mental Health (Compulsory Assessment and Treatment Act) 1992 is currently before a Health Select Committee. It will set a direction for supported decision-making within the context of compulsory mental health assessment and treatment, as well as potentially updating language relating to capacity and will and preference.
- **The Review of the law relating to adult decision-making capacity** by Te Aka Matua o te Ture | Law Commission will make recommendations for updating the Protection of Personal and Property Rights Act 1998 (PPPR Act). It will include suggested language for decision-making capacity and a framework for supported decision-making where a person has an enduring power of attorney or welfare guardian.
- The Government's response to the recommendations made by the **Royal Commission into Abuse in Care**, which includes requests to strengthen complaints pathways, and oversight and collaboration between agencies in relation to abuse in state care.
- **Pae Tū: Hauora Māori Strategy** is currently under review. It sets the direction for improving the health and wellbeing of Māori, providing the guiding framework by which health entities will achieve Māori health equity.

### **3. Supporting analysis | Ngā whakataunga tautoko**



This section sets out a topic-by-topic summary of what we heard in submissions and engagement on our consultation document, and our response.

## Topic 1: Better and Equitable Complaints Resolution

This topic aims to ensure that the Act and Code assist us in achieving our purpose<sup>1</sup> for all New Zealanders. The issues identified during the scoping stage and set out in the consultation document are that:

- HDC processes aren't always focused on people;<sup>2</sup>
- HDC processes aren't always 'fair, simple, speedy, and efficient';
- Not all people can see themselves in the Code; and
- There are barriers to making complaints.

We put forward eight suggestions to change the Act and the Code to support

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<sup>1</sup> To 'promote and protect the rights of health consumers and disability services consumers, and, to that end, to facilitate the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights' (section 6 the Act).

<sup>2</sup> 'People-centred' in this review means respecting people (consumers, whānau, providers) in the resolution of complaints, including by recognising the importance of relationships, appropriately keeping people informed and responding to their communication needs, and providing culturally responsive options to engage in person, including hui ā-whānau and restorative processes where appropriate.

better and equitable complaints resolution. These were to:

- Amend the purpose statement;
- Clarify cultural responsiveness;
- Clarify the role of family and whānau;
- Ensure gender-inclusive language;
- Protect against retaliation;
- Clarify provider complaints processes;
- Strengthen advocacy services; and
- Improve the language of complaint pathways in the Act.

### What we heard

Generally, submitters and people we engaged with supported and reinforced the issues we identified and the intent of the suggestions for change. The main themes are outlined below.

**Timeliness in resolving complaints:** HDC's timeliness was often identified as the most important factor to the experience of consumers and providers in the complaints process. Some shared the impact that delays in resolution had on both consumers and providers.

*‘Timely resolution of complaints is essential for maintaining trust and confidence in the process — delays lead to frustration, a sense of injustice, prolonged stress, and uncertainty.’*

**Communication and choice in the complaints process:** People considered that HDC’s complaints processes could be overly legalistic, adversarial, or transactional. There was strong support for HDC’s introduction of hui ā-whānau and hohou te rongu, with many wanting to see similar processes extended to all consumers, including greater alignment with restorative processes (for example, as laid out in HQSC’s National Adverse Events Policy<sup>3</sup>).

There was also support for greater choice over resolution pathways, noting that many people are motivated to complain *‘to make it better for the future rather than to hold someone accountable’*, and for more visible and effective use of advocacy services to support early resolution.

*‘A cultural approach that is more inquisitorial, respectful, and collegial than adversarial, cumbersome, and legalistic would serve all parties better.’*

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<sup>3</sup> Healing, learning and improving from harm: National adverse events policy 2023 | Te whakaora, te ako me te whakapai ake i te kino: Te kaupapa here ā-motu mō ngā mahi tūkino 2023.

**Education and complaints processes that work for all communities:** People identified barriers to accessing the Advocacy Service and HDC. Such barriers included information not reaching their communities, complaints processes being complex or not aligning with their values, and a lack of trust in complaints processes and the health and disability system. For example, we heard that:

- Because of the impact of colonisation, many Māori do not trust that rights apply to them or that making a complaint will result in change;
- Complaining does not always align with the values of Asian or Pacific cultures;
- Reliance on written communications in the complaints process created barriers for tāngata whaikaha | disabled people and migrants where English is a second language;
- The lack of clear standards for disability support services made it difficult to determine what people could reasonably expect from services and therefore identify when their rights had not been upheld; and
- Reliance on the care provided made people fearful to complain in case it affected their care. For example, disabled people, people accessing opioid substitution treatment, and other mental health and addiction

services can be fearful of the repercussions of complaining.

*‘I believe we are missing a large cohort of consumers who for health literacy or language barriers will not progress complaints.’*

Many considered that operational change would have a greater impact than changes to the Act and the Code, and that adequately resourcing HDC and health and disability services was needed for meaningful improvement.

*‘If no corresponding resources are provided to support change, it will create a risk that the expectations of providers and consumers are not able to be met by the HDC.’*

People also took the opportunity to share experiences where they felt that their rights, or the rights of a group, were not being upheld by providers (as well as some positive experiences). People from within the health and disability workforce shared the difficulties they face in upholding people’s rights in a system under pressure, with many providers calling for greater system accountability in relation to resource constraints.

*‘We must acknowledge our medical professionals are being asked to do more with less, in an increasingly resource-constrained environment, and this puts them at greater — and importantly, unfair — risk of HDC complaints in the first instance.’*

Feedback in relation to each suggestion, and our comment and response, is addressed in Table 1.

**Table 1 — Topic 1: suggestions, themes, comment, response**

**a. Amend purpose statement in section 6 of the Act to focus on people as well as processes**

- Themes**
- There was general support for additional wording to encourage a people-centred response to complaints resolution.
  - While many supported incorporating the concept of ‘mana’, others expressed caution about its use, including the importance of protecting the integrity of the term, or wanting clarification of its meaning.
  - Some provided alternative wording for complaints resolution principles.

**Comment** The view of many was that ‘mana’ best captured the desired shift in complaints resolution practice. However, we also note the caution from some submitters about its use, including the concerns raised by some Rangatira Māori | Māori leaders about the danger in separating out aspects of tikanga from an interrelated whole. On balance, we consider that the desired changes towards people-centred resolution can be made operationally and recommend not proceeding with that suggestion, particularly considering HDC’s current strategic priority to implement a more timely and people-centred complaints process.

The direction towards people-centred complaints resolution is also reinforced by the Government’s expectation around improving ‘the national approach to gathering feedback and responding to and learning from complaints and health care harm, including the development of culturally-appropriate and accessible feedback channels, as well as restorative practice’.<sup>4</sup>

Other changes recommended in this review will also support a more people-centred approach to complaints resolution, including those around clarifying provider complaints processes and improving complaints pathways.

The principles for complaints resolution set out in the Act (fair, simple, speedy, and efficient) were designed to support HDC to resolve complaints at the lowest appropriate level (that is, to support resolution between the parties where possible). We have reflected on feedback regarding these principles, including that ‘speedy’ implies ‘haste’ rather

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<sup>4</sup> Government Policy Statement on Health 2024–2027, page 22.

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giving necessary attention in a timely way, and that ‘simple’ implies ‘basic’ rather than being accessible and easy to navigate.

We agree and note that the Act’s principles only partially reflect Ombudsman guidance<sup>5</sup> that an effective complaints process must be grounded in the principles of fairness, accessibility, responsiveness, and efficiency. We consider that close alignment with the Ombudsman principles will support the public and providers to understand how HDC’s complaints resolution principles are applied in practice and create a positive obligation for HDC to be more responsive to people’s accessibility needs, promote consistency of complaints processes across public services, and align with contemporary models and practice. Arguably, the importance of such processes being timely is captured by both ‘efficient’ and ‘responsive’, and these principles will continue to support HDC to focus on enabling the resolution of complaints between complainant and provider where appropriate. However, given that timeliness was the primary concern for almost all submitters, we consider it may be appropriate to include an explicit reference to timeliness as well.

- Response**
- **Do not progress suggestion** to incorporate ‘mana’ into the purpose statement.
  - **Note** that a more people-centred approach to complaints resolution can be achieved operationally.
  - **Propose** new change to replace the complaint resolution principle ‘simple’ with ‘accessible’, and ‘speedy’ with ‘responsive’ in the Act’s purpose statement and in Right 10, making the new principles ‘fair, accessible, responsive, and efficient’.
  - **Recommend** the Ministry of Health consider whether there should also be an explicit reference to timeliness within the complaint resolution principles.

## b. Clarify cultural responsiveness

- Themes**
- General support for our proposed wording to make Right 1(3) more inclusive.<sup>6</sup>
  - Alternative wording provided, including adding tikanga, rights, spirituality, and cultural safety.
  - Feedback that HDC needed to strengthen its own cultural responsiveness.

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<sup>5</sup> Office of the Ombudsman | Tari o te Kaitiaki Mana Tangata. *Effective complaint handling*. 2 October 2012.

<sup>6</sup> Our proposed Right 1(3) wording was: ‘Every consumer has the right to be provided with services that take into account their needs, culture, language, identity, values and beliefs.’

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**Comment** Feedback generally reinforced our proposed wording for Right 1(3). We have reflected on additional suggestions and consider that the addition of ‘tikanga’ would add value to the wording in Right 1(3). This would reflect the cultural needs unique to Māori, without ‘othering’ or describing Māori as a homogenous group. This language would support Māori who identify with tikanga to see the Code as more reflective of their values.

We consider that other suggested additions are already adequately captured by the Code and would be best addressed through guidance to support awareness, including the interpretation and application of Right 1(3).

The new wording will encourage responsiveness to tāngata whaikaha | disabled people, people from LGBTQIA+ communities, as well as people from diverse ethnic groups. We consider that this wording will support existing obligations and expected practice, rather than substantially changing practice or adding new obligations. We note that professional standards and guidance to support culturally competent and culturally safe practice exists already within the health and disability workforce, and the suggested changes better align to those standards, as well as the principles of Pae Ora.

We also note the feedback that HDC should strengthen its own capability to take into account people’s needs, tikanga, culture, language, identity, values, and beliefs in promotion of the Code and complaints resolution.

- Response**
- **Confirm proposed Right 1(3) wording** with change to add ‘tikanga’ after ‘needs’ so that the right becomes ‘Every consumer has the right to be provided with services that take into account their needs, **tikanga, culture, language, identity**, values, and beliefs.’
  - **HDC to consider opportunities** to strengthen capability to assess and respond to potential breaches of Right 1(3), including reviewing our processes and guidance to staff to ensure that the correct information is obtained during the complaints process to accurately identify elements of tikanga and further cultural considerations.
  - **HDC to continue** to strengthen our internal cultural capability, including the use of tikanga-led approaches to complaints resolution.

### c. Clarify the role of family, support people and whānau (changes to Right 3, 8 and 10 of the Code)

- Themes**
- Replace ‘independence’ with ‘autonomy’ in Right 3 (Dignity and Independence)**
- General support for the intention to recognise the interdependence people often have with whānau and support networks. Noted that Māori, Pacific, and many Asian cultures have a collective world view.

- Mixed views about the suggestion to replace ‘independence’ with ‘autonomy’, with a small majority supporting change.

#### **Strengthen Right 8 (Support)**

- General support for expanding Right 8 to include circumstances where support people cannot be physically present, with several noting that it was the consumer’s right and choice, not the supporters.
- Some raised concerns about logistical challenges for providers of meeting this obligation, while others noted that the suggested wording reflected current practice.

#### **Clarify that complaints to providers can be made on behalf of a consumer**

- Cautious support for explicitly providing for people to complain to providers on behalf of the consumer in Right 10. This was on the proviso that the consumer’s wishes remain at the centre, including consent where possible, and that representatives would not gain access through the complaints process to health information the individual has not consented to sharing, or for the family or whānau to ‘take over’.

#### **Comment Replace ‘independence’ with ‘autonomy’ in Right 3 (Dignity and Independence)**

We acknowledge the different preferences shared about the terms ‘independence’ and ‘autonomy’. While some people supported the term ‘independence’, many people in the disability community expressed concern about its use as it implies that requiring support is a negative thing. We note that providing recognition of interdependence and collectivism, as determined by the consumer, is an important concept and any term will need interpretation. On balance, we consider that a change from ‘independence’ to ‘autonomy’ better provides for these concepts, while still advancing people’s ability to make their own choices and is more inclusive of people with learning disabilities and others who may require support. We consider that such a change will need to be supported by the release of guidance around what is meant by autonomy.

#### **Strengthen Right 8 (Support)**

We acknowledge the concerns raised by some that the suggested wording<sup>7</sup> does not provide detail about how support people can be involved in other ways. However, it is important that the Code retains flexibility across a range of circumstances. We therefore do not consider it beneficial to set

<sup>7</sup> The suggested wording is: ‘Every consumer has the right to have one or more support persons of **their** choice present, except where safety may be compromised or another consumer’s rights may be unreasonably infringed. **Where support people cannot be physically present, this includes the right to have support people involved in other ways.**’

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out specific scenarios in the Code.

We also note that Clause 3 of the Code (Provider Compliance) states that ‘a provider is not in breach of this Code if the provider has taken reasonable actions in the circumstances to give effect to the rights, and comply with the duties, in this Code’, placing a ‘reasonableness’ interpretation over the obligations of the provider. HDC’s assessment process also always considers the circumstances within which care was provided, including what was practicable at the time.

We consider that commentary would support people to understand what this right might look like in practice.

### **Clarify that complaints to providers can be made on behalf of a consumer**

The Code of Rights is designed to give rights to people who are using health and disability services (the consumer). On reflection, it would be too complex and, in some cases, inappropriate for the Code to bestow rights on people who are not consumers.

We note the desire for defined terms (eg, representative) that have the consumer’s wishes at the centre. This is relatively straightforward when a consumer is able to consent to a person making a complaint on their behalf. It is less straightforward when a consumer does not have capacity to consent and does not have a legal representative.

A balance must be struck between enabling these consumers to have people make complaints on their behalf in alignment with their will and preferences and protecting these consumers from representation that does not reflect their will and preferences. We consider that making it explicit that people have the right to support when making a complaint, meets that balance. It captures situations where full support will be required to help uphold a consumer’s right to complain, while still centring the consumer in the Code of Rights.

We note that Right 10 sets an obligation on providers to respond to complaints from consumers. However, all concerns and complaints should be taken seriously and responded to regardless of who has raised them. We are concerned to hear that there have been situations where providers have refused to address complaints from people who are not consumers, and we encourage providers to consider how they can respond to such concerns appropriately and communicate the actions taken without breaching the consumer’s privacy. The consideration of how much information can be shared with a third-party complainant without the consent of a consumer should not preclude a provider from considering the concerns raised.

Our experience in complaints management also shows that there are situations where the involvement of consumers in a complaint is not possible or would cause further harm, including where the consumer is very unwell or in significant pain, or where they may not be in a position to

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recognise that their welfare is at risk.

It is important that we reduce the barriers to people raising concerns where a person’s safety or welfare is at risk. We also heard from a broad range of people about the fear they have in making complaints, particularly when they are reliant on care. Sometimes it takes a third party to raise a serious issue that the consumer would be too afraid to raise themselves. It is important that providers appropriately balance the importance of consumer consent to complaints with ensuring that complaints processes are accessible for anyone to raise a concern where it is warranted.

- Response**
- **Confirm proposed wording** to replace ‘independence’ with ‘autonomy’ in Right 3 and change this right to: ‘Every consumer has the right to have services provided in a manner that respects the dignity and *autonomy* of the individual.’
  - **Confirm proposed wording** in Right 8 to change this right to: ‘Every consumer has the right to have one or more support persons of their choice present, except where safety may be compromised, or another consumer’s rights may be unreasonably infringed. *Where support people cannot be physically present, this includes the right to have support people involved in other ways.*’
  - **Revise proposed wording** for Right 10(1) to: ‘Every consumer has the right to complain about a provider in any form appropriate to that consumer. *This includes the right to support to make a complaint.*’
  - **HDC to update commentary and education** to promote consumer and whānau understanding of these rights and avenues for complaints, and provider awareness of their obligations to support changes.
  - **HDC to consider opportunities** to share learning and guidance with the sector on responding to complaints from third parties.

#### d. Ensure gender-inclusive language

**Themes** Majority supported. Small amount of feedback concerned with the potential for proposed language to create confusion.

**Comment** We note that this suggestion is consistent with the Parliamentary Council Office Plain Language Standard.

**Response** • **Confirm proposed** gender-neutral language for the Code.

#### e. Protect against retaliation

**Themes** • Mixed views about the introduction of a clause to explicitly protect complainants against retaliation. A small majority of written submissions and most people and organisations we engaged with

were in favour.

- Those people/organisations who were not in favour of including a non-retaliation clause noted that it was unnecessary (as the Code already protects against this), or unclear/difficult to implement, and saw potential for unintended consequences where there were legitimate reasons for ending the provider–patient relationship.
- Many were concerned about how a non-retaliation clause would be enforced.

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**Comment** We agree with the feedback shared by many that the proposed insertion of Right 10(9) (protection against retaliation) is largely symbolic, that is, it does not pose new obligations or rights, as currently professional standards and the Code protect people against retaliation. However, it gives a positive and more explicit signal to support people to feel safe to raise concerns.

We also note the caution expressed by some that there may be circumstances where there are legitimate reasons to terminate the provider–patient relationship and agree that appropriate termination of care should not be prevented by a non-retaliation clause. We are satisfied that the proposed wording allows for this. We note that it is consistent with a long-standing expectation that clinicians will not terminate a relationship solely on the basis that a complaint was made about them.<sup>8</sup>

We consider that there would be benefit in increasing awareness of the rights people already have to be protected from being treated unfavourably because of a complaint, including protections under the Protected Disclosures (Protection of Whistleblowers) Act 2022 where applicable.

**Response**

- **Confirm proposed wording** of new Right 10(9): ‘A provider may not treat, or threaten to treat, less favourably than other people in the same or substantially similar circumstances —
  - (a) any consumer of services who is, or may be, the subject of a complaint;
  - (b) any person who makes, has made, intends to make, or encourages someone else to make, a complaint; or
  - (c) any person who provides information in support of, or relating to, a complaint.’
- **HDC to consider opportunities to promote awareness** of protections

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<sup>8</sup> See, for example, [Ending the doctor-patient relationship \(medicalprotection.org\)](https://www.medicalprotection.org/ending-the-doctor-patient-relationship).

people have against retaliation.

## f. Clarify provider complaints processes

- Themes**
- Some people/organisations raised concerns that the proposal oversimplified provider obligations, some provided wording suggestions for improvement (including to encourage people-centred processes and making complaints to the provider first), and one raised a concern that revised obligations would require updating of resources.

**Comment** We agree with feedback emphasising the need to keep the process required of providers and wording as simple as possible, while also strengthening provider obligations for communication, and allowing flexibility to support people-centred and restorative approaches.

We are also mindful that any changes to the purpose statement in section 6 of the Act, as proposed in this review, will need to be reflected in provider obligations as set out in Right 10(3). Accordingly, we consider that the proposed wording to streamline Right 10 should be confirmed after any changes to the purpose statement in the Act.

We acknowledge the experiences shared of provider complaints processes not being visible and varying in quality between providers, including in relation to access to culturally appropriate and restorative practices. We also acknowledge the desire to foster a system learning environment where providers are open to complaints and feedback. We note that Priority 4 of the NZ Health Strategy is a ‘learning culture’, and the Government Policy Statement on Health 2024–2027 sets the expectation to ‘*improve the national approach to gathering feedback and responding to and learning from complaints and health care harm, including the development of culturally-appropriate and accessible feedback channels, as well as restorative practice*’. We also note that guidance and frameworks already exist to support good practice responses when things go wrong and in dealing with complaints.<sup>9</sup>

HDC works closely with the health and disability sector to improve their capability to resolve complaints themselves. This includes the publication of a provider education module focused on good complaints management. HDC will share the concerns raised during this review with relevant agencies and will continue to work with the health and disability sectors to support good practice in complaint handling.

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<sup>9</sup> See, for example, [Healing, learning and improving from harm: National adverse events policy 2023 | Te whakaora, te ako me te whakapai ake i te kino: Te kaupapa here ā-motu mō ngā mahi tūkino 2023](#); Ministry of Health guidance ‘[Making a complaint about your residential care](#)’; and Ombudsman guidance ‘[Effective Complaint Handling](#)’.

- Response**
- **Note** that recommended changes to the purpose statement of the Act will have implications for Right 10(3) and the wording changes being considered to streamline Right 10.
  - **HDC to ensure that** finalisation of the revised wording of Right 10 occurs in parallel with revised wording of section 6 of the HDC Act, or at the next review, whichever is earliest.
  - **HDC to share feedback** from this review with the Ministry of Health, Whaikaha (Ministry of Disabled People), Health NZ, Ministry of Social Development, HQSC, and other relevant organisations, to support improvement of the visibility, consistency, and quality of provider complaint processes.

### g. Strengthen advocacy services

- Themes**
- Feedback on how Health and Disability advocacy services could be strengthened related to diversity of advocates and reach within marginalised communities; strengthening community relationships; strengthening people-centred and restorative practices; diverting more complaints to advocacy services and extending advocacy support; promoting and clarifying the role of the Advocacy Service in the complaint process; and more holistic support.
  - Suggested levers to strengthen advocacy services included resourcing; training and capability; including advocates in service standards; strengthening oversight; developing memoranda of understanding with providers; and improving reporting and evaluation to identify trends to contribute to quality improvement.
  - A few people commented on the independence of advocacy services, with some seeing it as a strength and one submitter suggesting direct contracting by HDC.

**Comment** The feedback we received underscored the value communities see in advocacy services, and reflected concerns that advocates need to be more visible, available, connected, and better able to meet the diverse needs of different communities. We acknowledge the key role that advocates play in promoting the Code and the potential for this to be strengthened, including by better promoting the work of advocacy services and partnering with community organisations and peer workforces.

We also acknowledge the general support we received for a focus on early resolution, and the potential seen by some for advocacy services to have a more active role in facilitating the resolution of complaints between consumers and providers. This happens to some extent now but is constrained by resources. We see benefit in exploring and clarifying operationally what it could look like for advocates to facilitate resolution while remaining partial to the consumer, including greater integration with the HDC process. Advocates are skilled at working with consumers to

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clarify their resolution needs, and then to support them to raise their concerns directly with the provider.

The Director of Advocacy and HDC are reflecting on the feedback provided and identifying opportunities to respond within current resourcing. This includes a focus on building relationships and partnerships with local/community organisations to increase reach into diverse communities.

The most recent advocacy services contract prioritises engagement with focus populations, including Māori, disabled people, older people, and communities who are particularly reliant on the care provided (and so face additional barriers in self-advocacy). HDC and the advocacy service are also working collaboratively to encourage early resolution of complaints and ensure that appropriate complaints are directed towards advocacy services in the first instance (rather than HDC).

- Response**
- **HDC and the Director of Advocacy to consider opportunities to improve communication and education** to consumers and providers about the role of advocacy services and the benefits of involving an advocate in the complaints resolution process.
  - **HDC and the Director of Advocacy to consider opportunities** for HDC and advocacy services to identify more effective and efficient ways of working together.
  - **Director of Advocacy to explore with advocacy services any operational changes** that can be made within current resourcing to respond to feedback provided during this review.

#### **h. Improve the language of complaint pathways in the Act**

- Themes**
- Most agreed that the language of ‘no further action’ in complaint resolution was disempowering and did not reflect the work involved to reach the decision. However, the suggestion to change the language of ‘no further action’ to ‘no investigative action’ was generally not supported.
  - Some suggested a more holistic review of section 38, including to provide for more people-centred pathways.
  - A majority supported changing the language of ‘mediation conference’ to capture other forms of resolution such as conciliation, and to explicitly recognise and provide for resolution practices from an ao Māori perspective.
  - Many supported the suggested wording ‘facilitated resolution’, although some considered it too complicated and other wording was suggested, including to recognise ao Māori forms of resolution.

**Comment** We acknowledge the feedback that the language of ‘no further action’ in section 38 is disempowering and accept that the suggested wording of ‘no investigative action’ was not viewed as an improvement. Many of the concerns about the use of this language were intertwined with concerns about HDC’s reliance on written, legalistic communication. In our view, it may be that many of the concerns raised about the use of this section can be addressed by HDC taking a more people-centred, accessible approach to communication. This includes more explicit, transparent communication with consumers about action taken by HDC to facilitate change at a systems level in response to complaints.

Many agreed that ‘mediation conference’ is not fit for purpose and does not convey the range of approaches people want to see available to the Commissioner. We acknowledge the mixed views about the suggested term ‘facilitated resolution’. We agree that currently section 61 is not fit for purpose and requires change, but also note feedback suggesting that the term ‘facilitated resolution’ may be too complicated.

In our view, the term ‘facilitated resolution’, while imperfect, gives HDC the flexibility and discretion required to consider a broad range of resolution needs expressed during the review and respond appropriately (including, for example, houhou te rongo, restorative practice, conciliation, etc). It would also support HDC to engage in more face-to-face and people-centred resolution approaches. We therefore recommend that the term ‘mediation conference’ is replaced in section 61 with the term ‘facilitated’ resolution’. It is important that HDC ensures that our communication supports people to understand the use of this term.

- Response**
- **Confirm proposed wording** of section 61 to replace ‘mediation conference’ with ‘facilitated resolution’.
  - **HDC to review** and improve its communication in response to feedback provided during this review.

### Other feedback to support better and equitable complaints resolution

- Themes**
- Most submitters who provided other suggestions for change in all topics focused on changes to the complaints process. These included suggestions that would require legislative amendments as well as operational changes. Legislative amendments suggested included:
  - **Allowing group, third party, or systemic complaints:** Many submitters thought it was important for people to be able to make complaints on behalf of other people or make complaints as a group. This was seen as particularly helpful to address systemic issues and power imbalances, including supporting people who may be fearful of raising complaints on their own.
  - **Introducing/changing statutory timeframes:** Many submitters felt

that the Act needs to include statutory timeframes for the HDC complaints process, including assessments and decision-making. Some people thought that timeframes for provider responses to complaints or for others to provide comment needed to be lengthened. Some people noted that these could be operational targets rather than legislative changes.

- **Expanding HDC’s jurisdiction, including the right of people to access services:** Some submitters thought that HDC’s jurisdiction should be extended to cover a broader range of situations and contexts. This included faith-based care, access to services (particularly for people with disabilities), and to remove limitations on HDC being unable to consider complaints about care provided prior to 1996.
- **Streamlining processes with Responsible Authorities (RAs):** Several submitters raised issues relating to the interaction of HDC and RAs (eg, Medical Council, Nursing Council). Currently, notifications to RAs by patients must be referred to HDC to determine the pathway for resolution. The RA is precluded by the HPCA Act from investigating conduct matters while HDC is assessing/investigating a complaint. Amendments were suggested to both the Act and HPCA Act, as well as operational changes to make better use of existing provisions (eg, engagement with RAs in sections 34–45).
- **Other legislative amendments** suggested by one or two submitters included providing a definition for the term ‘complaint’; extending Code rights to people after death; requiring HDC to give effect to the Code of Expectations; and providing an exemption to obligations under the Code in public health emergencies.
- **Operational changes** suggested by submitters included making the complaints process more restorative and culturally safe (eg, through more face-to-face resolution, being trauma-informed, and providing more support, including peer support, to those involved in a complaint); improving the way we collect and share data and evaluate new initiatives; better communication about HDC and its processes, including using words that resonate with all communities; improving the accessibility of HDC’s tools, information, and processes; making our triage process fairer, and more efficient and transparent; ensuring greater diversity of HDC staff and expert advisors; fostering a learning culture, including greater education of the health and disability sector workforce.

**Comment** While we appreciate the intent behind the suggestions, we do not support legislative change in the following areas:

**Allowing group, third party, or system complaints:** HDC can (and does) accept complaints from anyone about a consumer rights issue, including

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complaints made by a group or a third party, or about systemic issues. Many complaints to HDC are made by a third party (eg, a family member, provider, etc). HDC can also undertake an investigation in the absence of a complaint. This feedback highlights a need to improve the way we communicate these as options, including what people can expect in these situations.

**Streamlining processes with RAs:** We agree with the need for us to work more efficiently with RAs. We are making several improvements to our processes in these areas, including updating our MOUs with RAs to establish more efficient referral processes and changing our triage process to ensure that appropriate complaints are referred to RAs in a timely manner. We have also shared feedback we received in relation to RAs with the Ministry of Health to support its review of the HPCAA.

**Giving effect to the code of expectations:** This is something HDC is already committed to, both of its own accord and as required by the Minister. Ways in which HDC gives effect to the code of expectations are outlined in our performance documents (including our Annual Report and Statement of Performance Expectations).

**Providing an exemption to Code rights in public health emergencies:** Public health emergencies should not override people's rights as a matter of course. In fact, where restrictions are placed on people, some rights may become even more important. In addition, Clause 3 of the Code already allows for such events to be taken into consideration, focusing on what providers can reasonably be expected to do under the circumstances.

**Expanding HDC's jurisdiction:** HDC already has a broad jurisdiction, and some of what people specifically requested to be included (eg, faith-based care) can sometimes fall within it, when a health or disability service is being provided. We considered whether to include access to services as part of the review and concluded that ultimately this is a funding consideration, and therefore the responsibility of Government. However, this does not preclude HDC from being able to make comment on access issues as part of our broader system improvement role. While we understand people's desire to remove the pre-1996 time limitation on complaints, it is challenging to hold providers to account for rights that were not enforceable at the time (ie, before the Code was drafted).

We do think that clarifying that **Code rights extend beyond death in limited situations** is worthy of further exploration. Currently we see situations where the care that is provided in death is inextricably linked to the care that was provided in life. Examples include the treatment of unviable embryos or the body parts of a person who dies in hospital, as well as the pre- and post-death care of a dying person and their body | tūpapaku. The provider should still have obligations to show appropriate care and respect for the body and body parts. As we see from complaints, this expectation strongly aligns with people's values and cultural norms.

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This was reinforced by the Supreme Court’s decision in the *Ellis* case,<sup>10</sup> which found that a person’s mana still needed to be considered after that person had died.

While we may take jurisdiction in such cases, we recognise that currently the law is unclear. The definitions that set our jurisdiction in the Act, notably that of health consumer, disability services consumer, and of health service, tend to be interpreted as applying only to those situations where the consumer is living.

While we do not think it is appropriate for HDC’s jurisdiction to extend to all death services (eg, funeral planning or death certificates) — areas already covered by other legislation (eg, the Human Tissues Act 2008) — or to duplicate the role of the Coroner, we do think that there is benefit in clarifying our jurisdiction to cover specific circumstances as outlined above. This would align with the Supreme Court’s recent rulings about tikanga as well as allow HDC to better uphold Right 1(3). We would encourage the Ministry of Health to consider this and note that further consultation would likely be required.

In relation to the operational changes people suggested, many of these reflected aspects of the process we are working to improve, noting the resource-constrained environment within which we operate (more information about this can be found in HDC’s Annual Report). We have shared the feedback we received during the consultation with the Commissioner and our Executive Leadership Team, and it is being considered in the context of our continuous improvement programme.

- Response**
- **Note** that most of the suggested changes are already being addressed by HDC’s current work or existing provisions in the Act and the Code.
  - **HDC to consider feedback** as part of its continuous improvement programme.
  - **Recommend** the Ministry of Health explore clarifying HDC’s jurisdiction in relation to specific situations after the death of a consumer.

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<sup>10</sup> *Peter Hugh McGregor Ellis v R* [2021] NZSC 63 [15 June 2021].

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

This topic aims to address inequities in experience and outcomes in relation to the Act and the Code for Māori by strengthening Māori leadership and engagement, and ao Māori ways of being and understanding. The issues set out in the consultation document are that:

- Neither te Tiriti or ao Māori is reflected in the Act or the Code;
- Māori are under-represented in complaints to HDC and the Advocacy Service given their experiences with the health and disability sector; and
- Information about the Code and HDC is not reaching Māori communities.

We put forward two suggestions to change the Act and the Code to be effective for, and responsive to, the needs of Māori. These are to:

- Incorporate tikanga into the Code; and
- Give practical effect to te Tiriti o Waitangi in the Act.

### What we heard

The majority of submitters and people we engaged with supported and reinforced the issues we set out in the consultation document and the intent

of the suggestions for change. The main themes are as follows.

**Intergenerational experiences have reduced whānau trust in ‘the system’:** Many Māori we engaged with noted that they and their whānau have often become conditioned to experience cultural biases in health and disability settings, and so are less likely to raise issues.

*‘When you don’t experience the rights being upheld, the poster feels like just a piece of paper on the wall.’*

**Giving practical effect to te Tiriti will benefit Māori and all New Zealanders:**

Positive impacts of affirming mātauranga Māori (Māori knowledge and systems) and tikanga in the Act and the Code included that it *‘would enable Māori to see rights expressed in a way that is meaningful to Māori’* and enable *‘all New Zealanders to benefit from an ao Māori understanding of rights’*. Some suggested that this in turn would contribute to quality care for everyone, as well as help address health inequities for Māori. For Māori we engaged with, partnership with Māori was essential to support any changes that came out of the review.

**Incorporation of tikanga is supported, but care is needed in application:**

Most submitters and people we engaged with supported incorporating Māori concepts and language into the Code and complaints resolution. Many suggested that additional training and

guidance would be needed to support implementation.

Many Māori emphasised the need for leadership oversight and capability within HDC to interpret cultural concerns and uphold tikanga in complaints processes.

*‘[Incorporating tikanga] could significantly enhance the cultural sensitivity and relevance of the Code, making it more meaningful and respectful for Māori.’*

**Providers need to be responsive to the needs of all New Zealanders:**

Several noted that Pacific, Asian, and other ethnic groups face significant challenges and barriers within the

health and disability sector that also need to be addressed. Some also noted that Right 1(3) of the Code already requires cultural responsiveness, including in relation to tikanga, and that this relates to individual needs rather than assuming a particular ethnicity or community-based response.

*‘Putting us all in the same basket misses the differences of how we operate ... sometimes service providers need to know how to wear different hats to connect.’*

Feedback in relation to each suggestion, and our comment and response, is addressed in Table 2.

**Table 2 — Topic 2: suggestions, themes, comment, response**

**a. Incorporate tikanga into the Code**

- Themes**
- General support for explicitly incorporating tikanga, and many saw this as an important lever to improve system responsiveness to Māori.
  - Many Māori advocated for appropriate oversight and expertise to interpret and implement tikanga so that it didn't become 'recolonised', while also enabling tikanga to be recognised as part of their hauora (health and wellbeing). Some raised concern about isolating specific Māori concepts given the richness and interconnectedness of tikanga.
  - Several raised concerns about the ability for providers to interpret tikanga, with most suggesting that additional training and support was needed to support implementation.
  - Some noted the existing te reo Māori translation of the Code as being rich in tikanga and providing an ao Māori understanding of Code rights. Some also raised that Right 1(3) already provides an obligation for providers to be responsive to the tikanga of individual consumers.
  - Some suggested better promotion of the te reo Māori translation of the Code to providers and consumers and to promote the Code more effectively with Māori. Some also noted the work of the Law Commission to consider the intersection of tikanga and the law, and the direction it has taken in one of its recent issues papers to favour a general tikanga clause over incorporating specific terms such as 'mana'.<sup>11</sup>

**Comment** We note the general support for incorporating tikanga, and for the specific suggestion of incorporating the word 'mana' into Right 1 as a term that resonates widely. However, we also appreciate the risks raised regarding the isolation of individual concepts of tikanga and the need to protect the integrity of meaning and application.

We agree with submissions stating that tikanga and the te reo Māori translation of the Code are already an aid to interpretation, and implicitly captured within Right 1(3).

On balance we consider that greater promotion of the te reo Māori translation of the Code and of expectations of cultural safety will support tikanga to be incorporated into provider practice where appropriate. We also consider that explicitly referring to tikanga in Right 1(3), as proposed in Topic 1, acknowledges considerations that are important to many Māori, without 'othering' Māori.

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<sup>11</sup> See He Poutama (NZLC SP24); and He Arotake I te Ture mō ngā Huarahi Whakatau a ngā Pakeke | Review of Adult Decision-Making Capacity Law (NZLC IP52, 2024).

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We note that the principles of Pae Ora and professional guidance on cultural responsiveness and cultural safety for Māori and all communities guide the application of Right 1(3). Continued training of the health and disability workforce is encouraged, and HDC commentary to support the interpretation and application of Right 1(3) would strengthen providers' understanding of their obligations.

- Response**
- **Do not progress** proposed wording to incorporate 'mana' into Right 1.
  - **Propose new wording** to include 'tikanga' after 'needs' in Right 1(3).<sup>12</sup>
  - **HDC to consider opportunities to promote** provider obligations under Right 1(3), and the te reo Māori translation of the Code. Note that the revised posters are tri-lingual, incorporating Māori, NZSL, and English.

## b. Give practical effect to te Tiriti in the Act

- Themes**
- Strong support to incorporate te Tiriti into the Act.
  - Most supported both a general clause and specific changes, as well as operational changes.
  - The specific changes most commonly called for related to:
    - Māori leadership
    - Engagement with Māori, particularly in relation to reviews of the Act and Code or the advocacy guidelines and the importance of engaging with representatives that have been determined by mātauranga Māori | Māori knowledge systems
    - Establishing and maintaining meaningful relationships with Māori
    - Providing for the promotion and protection of tikanga in complaints management, including in the delivery of hui ā-whānau and hohou te rongo.

**Comment** We note the strong support for our suggestions to give practical effect to te Tiriti in the Act, and the varied wording provided by submitters to express these suggestions. Progressing these changes would help to ensure that HDC is working effectively for and with Māori, thereby enhancing our ability to support the system to do the same. We note that these proposals align with the health system principles in Pae Ora, the vision set out in He Korowai Oranga: Māori Health Strategy, the objectives of Whakamaua: Māori Health Action Plan 2020–25, and the priorities of Pae Tū: Hauora Māori Strategy, including the focus on enhancing system accountability. Furthermore, while giving practical effect to te Tiriti within the Act will

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<sup>12</sup> The new wording of Right 1(3) would now be: 'Every consumer has the right to be provided with services that take into account their needs, *tikanga*, culture, language, identity, values, and beliefs.'

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support the promotion and protection of hauora Māori, it is likely to benefit all New Zealanders.

As such, we continue to support the suggestions we put forward in our consultation document (see Appendix 4). However, on balance, we believe that a different proposal is required to best embed Māori leadership within HDC.

Many Māori we engaged with, as well as most of those who made submissions, thought embedding Māori leadership within the Act was the most important change we could make. This was seen as essential to ensuring that an ao Māori lens is applied in decision-making, to protect the interpretation and application of tikanga, and to support authentic engagement and partnership with Māori.

We support this view. We considered a suggestion to provide for general Māori leadership rather than a specific Deputy Commissioner role, but the Deputy Commissioner model has proven success in bringing focus and expertise to a particular area. Deputy Commissioners are appointed by the Governor-General, so are independent statutory decision-makers in relation to complaints.

While wanting to embed Māori leadership within HDC, we are also mindful of the need to provide sufficient flexibility to allow HDC to respond to emerging issues and changing contexts, particularly if we were to have fewer Deputy Commissioners than we do currently. Given the broad scope of HDC's jurisdiction, we need to retain the potential for Deputy Commissioners to have a generalist focus across complaints, as well as specific areas of expertise.

Therefore, rather than establishing a specific 'Deputy Commissioner Māori' role (noting that there were various suggestions for the title of this role), we suggest that section 9 is amended to create collective qualifications for the appointment of the Deputy Commissioners. Similarly to section 12(3) of the Pae Ora Act and section 8(2) of the Mental Health and Wellbeing Commission Act, section 9 would set out the attributes they would hold collectively to allow for a Deputy Commissioner with the appropriate expertise to ensure that an ao Māori lens is applied to the work of HDC, protect the interpretation of tikanga, and support authentic engagement with Māori. These qualifications should include:

- In-depth knowledge, experience, and expertise in relation to te ao Māori, mātauranga (Māori knowledges, intelligences, systems, and ways of being), tikanga (Māori practices, values, and principles), kawa (Māori processes), and reo Māori (Māori languages);
- Proven ability to establish and maintain effective relationships with tāngata whenua, hapū and iwi, tāngata Tiriti, and Te Moana Nui a Kiwa; and
- Knowledge and experience in the application of te Tiriti o Waitangi.

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We note that an additional benefit of this solution is the potential for multiple Deputy Commissioners with these attributes.

Given the broad jurisdiction and role of HDC and the varied responsibilities of Deputy Commissioners within the organisation, we consider that additional attributes reflecting more generalist responsibilities will also need to be included as part of these collective requirements.

We also agree that giving effect to te Tiriti needs to be a whole-of-organisation endeavour — and currently this is a priority for HDC. We consider that changes to the qualifications of appointment and functions of the Commissioner in section 10(1) of the Act would help to fulfil this intent — for example, the ability to demonstrate experience in engaging effectively with, and working collaboratively with, tāngata whenua, whānau, hapū, and iwi.

We note that the suggestions for the Act can be (and currently are) implemented operationally without legislative changes, but that such changes would ensure that operational changes are enduring.

- Response**
- **Confirm suggestions** to give practical effect to te Tiriti in the Act (see Appendix 4).
  - **Confirm new proposal** to strengthen HDC’s leadership by amending section 9 of the Act to create collective requirements for Deputy Commissioners that include, but are not limited to, in-depth knowledge, experience, and expertise in relation to te ao Māori, mātauranga (Māori knowledges, intelligences, systems, and ways of being), tikanga (Māori practices, values, and principles), kawa (Māori processes), and reo Māori (Māori languages).
  - **Confirm proposal** to include specific provisions in section 10(1) to strengthen qualifications for the appointment of the Commissioner in relation to the Commissioner’s ability to serve Māori effectively.
  - **Recommend** that the Ministry of Health seek guidance from the submissions we received for how these suggestions could be expressed in the development of any Amendment Bill.

### Other feedback to support the Act and the Code to be more effective for, and responsive to, the needs of Māori

- Themes**
- Resourcing operational change was seen as being more important for the Act and the Code to be effective for, and responsive to, the needs of Māori. This included ensuring appropriate leadership, capability, and relationships to interpret and apply tikanga and give practical effect to te Tiriti within advocacy services, HDC, and the health and disability sector. The need for HDC and the advocacy services to undertake more engagement with Māori communities was a strong

theme, as was ensuring that our resources and promotional material are accessible for Māori.

- Strong support for HDC’s introduction of tikanga-led hui ā-whānau and hohou te rongo processes. Many wanted to see this continue and be available to all consumers. Several highlighted the importance of evaluating the effectiveness of this and other initiatives to ensure that Māori needs are being met and to support continuous improvement. Several also emphasised the importance of partnerships, including with regulatory authorities, local providers, iwi, and hapū to support change.

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**Comment** It is a priority for HDC and advocacy services to be effective for, and responsive to, the needs of Māori in the delivery of our functions. Honouring our responsibilities under te Tiriti o Waitangi underpins the Strategic Direction we set in 2021. HDC employed dedicated resource on our leadership team to assist us in this work and has a focus on raising the cultural capability of the organisation in relation to te ao Māori, including tikanga-led approaches to complaints resolution. Currently we are reviewing our te Tiriti o Waitangi policy and strategic plan to support HDC to continue to prioritise and embed actions to give practical effect to te Tiriti. Feedback from this review will be considered as part of this update.

Actions we have undertaken/are undertaking are highlighted below.

- The Director Māori team are building relationships with Hauora Māori providers and other relevant local leaders, to promote the Code and support the safe implementation of hui ā-whānau and hohou te rongo by providers;
- The Director Māori team are also working with regulatory authorities to support a more consistent approach to cultural standards;
- Promotional material for the Code has been simplified and updated, including to incorporate English, Māori, and NZSL into the posters;
- A new te Tiriti o Waitangi strategy is being developed by HDC; and
- HDC has commenced a review of the hui ā-whānau using a kaupapa Māori evaluation framework to assess its achievement of intended outcomes and inform future approaches.

**Response** • **HDC is working on its te Tiriti o Waitangi policy and strategic plan** to support HDC to prioritise and embed actions to give practical effect to te Tiriti. Feedback from submissions and engagement will be considered as part of this work.

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

This topic aims to address the needs of tāngata whaikaha | disabled people by updating the Act and Code to strengthen alignment with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), including to focus on accessibility, supported decision-making, and ethical research. The issues set out in the discussion document are that:

- Understanding of disability rights has changed since the Act and the Code commenced;
- Services and supports have also changed; and
- HDC wanted to hear feedback on a review on unconsented research.

We put forward five suggestions to change the Act and the Code to work better for tāngata whaikaha | disabled people. These were to:

- Strengthen disability functions in the Act;
- Update definitions relating to disability;
- Strengthen references to accessibility in the Code;
- Strengthen and clarify the right to support to make decisions; and
- Progress consideration of HDC's 2019 draft recommendations relating to unconsented research.

### What we heard

Generally, submitters and people we engaged with agreed with the issues raised in the consultation document. Strong themes are as follows.

**Tāngata whaikaha | disabled people, including Deaf people and tāngata whai ora,<sup>13</sup> face barriers** to receiving quality care because information and services are not always accessible.

*'So many devices aren't accessible for a blind person. Don't think [providers] understand the barriers they create. Providers first assume everyone has a smart phone, or the internet, and then on top of that the information is not screen readable.'*

*'Often we hear the Pacific interpreter does not have the right language skills or health literacy to communicate effectively.'*

Tāngata whaikaha | disabled people, particularly people with learning disabilities, Deaf people, and people experiencing mental distress, are not being supported as well as they could be to make informed choices and give informed consent. There is strong support for the practice of supported decision-making to be strengthened in practice and within the Code. Some also wanted the application of advance directives strengthened and clarified.

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<sup>13</sup> People seeking wellness. We use this term to refer to people who use mental health and/or addiction services.

*‘People are only interested in who can make the decision and how quickly we can make the decision rather than ensuring the person is able to make their own decisions.’*

*‘In our elder abuse practice, we often find that service providers ... have little understanding of the rights of decision-making even with diminished capacity. Rather, many decisions are made on the presumption of incompetence and without reference to the person.’*

**There are multiple barriers to making complaints.** This includes a lack of clear standards for disability support services to assist people to understand the level of service that can be expected; confusion as to which services are within HDC’s jurisdiction; fear of losing access to essential, but restricted, services because of making a complaint; the complexity of HDC complaints processes; and privacy concerns when making complaints about interpreters. Many also considered that the ability to make group complaints, and a greater focus from HDC on investigating systemic issues, would encourage people to raise concerns.

*‘Group complaints would make people feel protected and have a degree of support. Also meets the need for people to have a collective mindset, particularly Pacific, Māori, rather than an individual approach.’*

**There was support for stronger disability-focused functions** in the

HDC leadership and its workforce (including peer advisors) to effectively enable monitoring and reporting. For some, this included HDC taking on a much wider jurisdiction that included access to services and holistic disability and wellbeing needs.

*‘Need to have a team. There’s a lot of disabled people, diversity, to just have one person to do that work wouldn’t be enough.’*

**The 2019 HDC review into unconsented research struck an appropriate balance** between enabling potentially beneficial research to occur in populations unable to consent and providing appropriate safeguards. One noted that *‘while tāngata whaikaha | disabled people have significant vulnerability in research, they, like women in general (who are underrepresented in medical research), are more likely to be left out of research because of the challenges of navigating the health and consent challenges’*.

Some also considered that a broader consideration of the appropriate framework for ethics committees should be addressed as part of an Act change, rather than addressing unconsented research in the Code.

*‘There remains no overarching legal framework for research ethics committees ... Ethics committees that are independent of the researchers and the institutions was a key recommendation of the Cartwright Inquiry in 1988.’*

Feedback in relation to each suggestion, and our comment and response, is addressed in Table 3.

**Table 3 — Topic 3: suggestions, themes, comment, response**

**a. Strengthen disability functions in the Act**

- Themes**
- General support for strengthening disability functions in the Act. Most explicitly favoured the suggestion to provide for a Deputy Commissioner Disability within the Act, with some calling for a separate Disability Commissioner, or a disability team, and for lived experience representation, engagement, and co-design. Some cautioned against being overly prescriptive and called for flexibility in delivering disability leadership.
  - There was general support for the suggestion to require reporting to the Minister of Disability Issues. Feedback suggested use of more generic language to allow for portfolio changes, some suggested adding the Minister of Mental Health, and some queried how reporting would operate.
  - Groups wanted a broad understanding of disability within HDC’s work, for example considering the experiences of groups who are sometimes excluded from service-led definitions of disability, for example tāngata whai ora, and people with rare disorders, eating disorders, and chronic fatigue syndrome.

**Comment** We consider that it is essential to set a positive obligation for HDC to continue to bring a focus to the experience of tāngata whaikaha | disabled people. While we acknowledge the suggestion for a Disability Commissioner, the current practice of having a Deputy Commissioner, Disability has worked well in bringing an important focus on disability to the work of HDC. We also note that Deputy Commissioners are appointed by the Governor-General and, as such, are independent statutory decision-makers.

We agree that there are benefits of flexibility in delivering disability leadership. In a small organisation such as HDC, this includes the ability for people to hold multiple portfolios. As such, as with the proposal for a ‘Deputy Commissioner Māori’, rather than establishing a legislative requirement for the role of Deputy Commissioner Disability, we suggest amending section 9 of the Act to set out the attributes that Deputy Commissioners would hold collectively to allow for the appointment of a Deputy Commissioner with the appropriate expertise in disability. These qualifications should include:

- Lived experience of disability;
- Proven connections to, and ability to establish and maintain effective relationships with, the disability community; and

- An understanding of the rights of disabled people and the operation of the disability support sector.

We consider that lived experience is important and of value, but not sufficient on its own given the nature of a Deputy Commissioner role. Again, we note that one of the potential benefits of this option is that multiple Deputy Commissioners will have these attributes.

We also consider that the Commissioner qualification for appointment relating to disability (section 10(1)(e)) should also be strengthened, particularly as the current provision does not use strengths-based language.

HDC has recently developed a Strategic Plan to give more prominence to the rights of tāngata whaikaha | disabled people. HDC has committed to 14 actions to make our systems, processes, and communications more responsive to the needs of tāngata whaikaha | disabled people and to support improvements to health and disability services for tāngata whaikaha | disabled people. The plan includes ensuring that HDC’s recruitment policies, reasonable accommodations, and commitment to rights and dignity make us an attractive and safe employer for tāngata whaikaha | disabled people.

Regarding reporting, we consider that the section 14(k) requirement to report to the Minister from time to time on the need for, or desirability of, legislative, administrative, or other matters relating to the rights of health consumers or disability services consumers or both should be expanded to include reporting to Ministers responsible for disability issues and other relevant portfolios such as Mental Health. We suggest an addition of ‘and any other relevant Ministers’ to allow for any future changes in portfolios. We note that the HDC also has functions under section 14(d) and (i) to make public statements, publish reports, and make suggestions to any person in relation to the Code.

- Response**
- **Confirm new suggestion** to strengthen HDC’s leadership by amending section 9 of the Act to create collective requirements for Deputy Commissioners that include, but are not limited to, lived experience of disability and an understanding of the rights of disabled people and the operation of the disability support sector.
  - **Additional suggestion to** strengthen the qualification for appointment of the Commissioner in section 10(1)(e) by replacing the phrase ‘the person’s understanding of the various needs of disability services consumers’ with ‘*the person’s understanding of disability rights and disabled people’s experiences of the health and disability system*’.
  - **Confirm suggestion with revisions** to extend reporting in section 14(k) to any relevant Ministers.

- **Note that HDC’s Disability Strategic Plan** includes actions to make our systems, processes, and communications more responsive to the needs of tāngata whaikaha | disabled people and to support improvements to health and disability services for tāngata whaikaha | disabled people.

## b. Update definitions relating to disability

- Themes**
- Generally supported, with feedback supporting strengths-based language in line with UNCRPD and reflecting a social and rights-based model of disability.
  - Several suggested that definitions should be confirmed in collaboration with tāngata whaikaha | disabled people, and several referred to the Pae Ora (Healthy Futures Act) definition as a useful template.
  - Several sought clarity on the interpretation and scope of disability support services.

**Comment** We support strengths-based language in line with the UNCRPD and reflecting a social and rights-based model of disability.

We note that the current definition of ‘disability support services’ in the Act is sufficiently broad to reflect the range of services that promote the autonomy of tāngata whaikaha | disabled people, and we consider it important to maintain this broad scope. We acknowledge feedback that the interpretation of ‘disability support services’ (and therefore what is in our jurisdiction) can be unclear and has been interpreted inconsistently over the years by HDC.

- Response**
- **Confirm suggestion** to update definitions, and suggest the Ministry of Health collaborate with tāngata whaikaha | disabled people on language to be used.
  - **HDC to provide the public with clear communication** of the definition of ‘disability supports and services’ that are captured by the Code.

## c. Strengthen references to accessibility

- Themes**
- Generally supported, with some reservations about providers being able to meet accessibility requirements in a resource-constrained health system, and whether HDC would account for system pressures appropriately.
  - Removal of where ‘reasonably practicable’ for interpreters in Right 5 was generally supported. Concerns were raised about resources in relation to the availability of interpreters. Conversely, some wanted stronger requirements around interpreters (eg, that they are qualified,

culturally competent, etc).

- Intent of adding ‘accessible’ and ‘appropriate supports and/or support people’ in Right 5(1)<sup>14</sup> was supported. Some suggestions were given for wording improvements. Additional suggestions that ‘time’ be added as a factor and to replace ‘form’ with ‘format’ were also given.
- Other Code changes suggested included to build an expectation of reasonable accommodations into the Code, and to delete ‘written’ in Right 6(4).<sup>15</sup>
- People also shared experiences of inaccessible care, including poor hospital booking systems resulting in interpreters being unavailable, and technology upgrades such as touchscreens and online booking systems disadvantaging some groups, for example blind people.

**Comment** We consider that ‘reasonably practicable’ in Right 5 is redundant because of Clause 3 (which states that a provider will not be in breach of the Code if the provider has taken reasonable actions in the circumstances). We do not consider that removing ‘reasonably practicable’ in Right 5 would create a new or different obligation but it would send an important signal that the right to a competent interpreter is as important as other rights. We do not consider it necessary or appropriate to specify the qualifications of interpreters. As noted previously, the Code needs to retain its flexibility so that it can be applicable and practicable across a range of different circumstances. This may also risk unintended consequences by reducing access to interpreters owing to the diversity of interpretation needs. The central requirement is that interpreters enable effective communication.

We note the feedback from some people that there is a lack of clarity as to whether and to what extent clause 3 is applied in HDC’s decision-making. HDC does not always explicitly state when clause 3 has been considered. We consider that clear communication from HDC about clause 3 would be beneficial. However, we also note that HDC’s assessment process requires HDC always to take into consideration the context within which the care was provided, including system pressures and resource constraints.

We consider that the addition of ‘accessible’ to Right 5(1) makes the

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<sup>14</sup> Proposed Right 5(1): ‘Every consumer has the right to effective **and accessible** communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary, this includes the right to **appropriate supports and/or support people, including a competent interpreter.**’

<sup>15</sup> Right 6(4): ‘Every consumer has the right to receive, on request, a written summary of information provided.’

existing right more explicit and does not add any additional burden on providers.

We have considered feedback to improve ‘appropriate supports and/or support peoples’ in Right 5(1) and propose new wording of ‘appropriate assistance and supports’.

We note the feedback for HDC to consider its own accessibility and communication, and we are incorporating this feedback into our quality improvement programme and the implementation of our Disability Strategic Plan.

- Response**
- **Confirm proposal** to remove ‘reasonably practicable’ from Right 5(1).
  - **Confirm proposal** to add ‘accessible’ to Right 5(1).
  - **Confirm new proposal** to change ‘appropriate supports and/or support peoples’ in Right 5(1) to ‘appropriate assistance and supports’.
  - **Note that these proposals will change Right 5(1) to:** ‘Every consumer has the right to effective *and accessible* communication in a form, language, and manner that enables the consumer to understand the information provided. This includes the right to *appropriate assistance and supports, including a competent interpreter.*’
  - **HDC to share feedback** on accessibility barriers experienced by tāngata whaikaha | disabled people with the Ministry of Health, Whaikaha | Ministry of Disabled People, and Health New Zealand to support quality improvement.
  - **HDC to consider** feedback around our accessibility and communication internally and incorporate this into our quality improvement programme and Disability Strategy.

#### d. Strengthen and clarify right to support to make decisions

- Themes**
- General support for the intention to strengthen and clarify the right to support to make decisions, with multiple wording suggestions to Right 7(2), (3), and (4). Several suggested an alignment with the Law Commission review into adult capacity law and the Mental Health Bill.
  - Wording suggestions included:
    - Clarifying that decision-making is decision-specific; that support is of the person’s choosing; and what is meant by support
    - Alternatives to ‘affected decision-making’; incorporating a capacity test; and requiring adequate documentation of capacity assessment and steps taken
    - Simplifying Right 7(4); and providing for collective decision-making in Right 7(4), including ways to resolve where there is disagreement

- Defining advance directives and advance care preferences.
- Mixed views about changing ‘views’ to ‘will and preference’ in Right 7(4). Many supported this change, but some thought the language was too complicated, should include ‘rights’, or could raise expectations that could not be met around access to care, for example if their preference is for a service that is not available to them.
- Mixed views about retaining ‘best interests’ in 7(4). Some considered it outdated, some suggested replacing with the ‘wellbeing principle’, and another agreed it was imperfect but best describes duty of care.
- Some raised concerns that the discussion document did not address long-term decision-making under Right 7(4), including in relation to people who are placed in long-term residential settings under Right 7(4).
- Some raised concerns with practical implications of capacity assessments and supported decision-making, especially as good practice is evolving.
- Many suggested greater supported decision-making guidance in relation to health and disability services, and that HDC should take a lead role.

**Comment** We agree that appropriate alignment with the Mental Health Bill and Law Commission work is needed. Accordingly, the proposals to change the Code to strengthen and clarify supported decision-making are draft and directional, subject to progression of other work. We note that the Ministry of Health and Whaikaha | Ministry of Disabled People are also undertaking projects to consider the operation of supported decision-making in health care and society respectively.

We agree with the feedback to keep Right 7 as simple as possible. Simplicity also provides for flexibility to apply to individual circumstances and remain current as understandings of good practice evolve. We note that Right 7 needs to be responsive to disability support services as well as health services and cover a spectrum of decision-making ability and scenarios, including emergencies, fluctuating capacity, and long-term or ongoing care.

We support making it clearer that informed consent is decision-specific but think that incorporating a capacity test within the Code would be too prescriptive. We note that research<sup>16</sup> suggests that currently the application of capacity tests is inconsistent, and many people who make

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<sup>16</sup> Hickling N et.al. Examining the approaches used to assess decision-making capacity in healthcare practice. *New Zealand Medical Journal* 2024 Jul 5; 137(1598). Pp 22–32.

capacity assessment decisions are unaware of existing guidance.

We considered changing ‘views’ where they relate to the consumer, to ‘rights, will and preference’ in 7(4) and recognise that this is consistent with language in the UNCRPD. However, we think that the addition of rights is unnecessary in a Code of Rights (which already requires that all the rights be considered) and agree that there is a need to keep the language simple.

We note that there were also mixed views about the term ‘best interests’. We agree that it is an imperfect term but do not consider there to be a better alternative at present. We note that the Mental Health Bill avoids a ‘best-interests’ test for treatment decisions and instead includes principles for treatment. A similar approach could be taken for the Code.

We accept that Right 7(4) does not address long-term decision-making for persons who do not have decision-making capacity or a legal representative to make decisions for them. While HDC can assess complaints about this, we acknowledge that people in this situation often do not have a family member who can complain or advocate on their behalf. We consider that this gap in the law is best resolved through changes to the PPPR Act, and not the Code.

We agree that there is a role for HDC to promote and develop guidance, particularly in relation to support for people to make informed choices and give informed consent where their decision-making is affected and express their will and preferences where a person is unable to consent.

- Response**
- **Confirm in principle direction** to align the language relating to diminished capacity in Right 7 with the language recommended by the Law Commission (eg, currently ‘affected decision-making’ rather than ‘not competent’ or ‘diminished competence’) in their final report.
  - **Confirm draft wording** for Right 7(4)(b): ‘reasonable steps have been taken to ascertain the *will and preferences* of the consumer; and’
  - **Confirm draft wording for** Right 7(3): ‘Where a consumer has *affected decision-making capacity*, that consumer retains the right to make informed choices and give informed consent *with respect to a particular decision*, to the extent appropriate to *their level of decision-making capacity, in relation to that decision. Where necessary, this includes the right to support to make decisions.*’
  - **Confirm draft wording** for Right 7(4)(c)(i): ‘if the consumer’s *will and preferences* have been ascertained, and having regard to *their will and preferences*, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if *they had decision-making capacity*’.
  - **Confirm draft wording for Right 7(4)(c)(ii)**: ‘if 7(4)(c)(i) does not apply, the provider takes into account the *will and preferences* of the consumer *to the extent they are ascertained*, and the views of family

or *whānau* and other suitable persons who are interested in the welfare of the consumer’.

- **Note** that finalisation of proposed Code changes should occur following the passage of the Mental Health Bill and publication of the Law Commission report into adult decision-making capacity.
- **HDC to consider** its role in promoting and developing sector guidance to improve capacity assessments and provide greater clarity to providers of their obligations to support consumers to make informed choices and give informed consent, and where consent cannot be given, to ascertain their views.

#### e. Progress consideration of HDC’s 2019 draft recommendations relating to unconsented research

- Themes**
- General support for progressing the recommendations in HDC’s 2019 report ‘Health and Disability Research with Adult Participants who are Unable to Consent’ as long as proposed safeguards are put in place, and lived experience representation is incorporated into the specialist ethics committee. Delicate balance acknowledged between providing an opportunity for people who are unable to consent to benefit from research and ensuring safeguards.
  - Clarity was sought around how ‘suitable persons’ would be defined, the definition of ‘minimal foreseeable burden and minimal foreseeable risk’, and the interpretation of ‘best interests’.
  - Some, including the National Ethics Advisory Committee (NEAC), wanted changes to occur through the Act rather than the Code, and for the Act to establish a framework for research ethics.
  - Greater transparency was sought about next steps to progress recommendations.
  - Concerns were raised by some consumer groups about the use of ethics committees, noting a lack of trust in these committees by some communities and concerns about inadequate representation.

**Comment** We note the general support for progressing HDC’s 2019 recommendations and support the suggestion to implement changes through the Act rather than the Code. We consider that research should continue to be covered by the Code, but that incorporating exceptional circumstances for research where consent is not possible has the potential to overwhelm and complicate Right 7.

We suggest the incorporation of detail into the Act, and that consideration of what might be needed to strengthen the regulatory framework governing health and disability research be led by the Ministry of Health as part of the development of a Health and Disability Commissioner amendment bill. We further suggest that the Ministry of Health establish a

technical working group to refine the detail of proposed changes to the Act that includes consumer and provider representatives, NEAC, and HDC as an independent advisor.

- Response**
- **Recommend** that the Ministry of Health progress the HDC’s 2019 report recommendations ‘Health and Disability Research with Adult Participants who are Unable to Consent’, and ensure lived experience representation, as part of the development of a Health and Disability Commissioner Amendment bill.

### Other feedback to support making the Act and the Code work better for tāngata whaikaha | disabled people

- Themes**
- Many suggestions for improving the accessibility of HDC’s processes and advocacy services as well as better promoting the Code and including co-design with tāngata whaikaha | disabled people and Māori.
  - Some people thought the Act and the Code should make reference to international human rights conventions, particularly the UN Convention on the Rights of People with Disabilities (UNCRPD), the Rights of Children (UNCROC), and the UN Declaration on the Rights of Indigenous People (UNDRIP).
  - One person suggested that HDC provide tools and templates for providers to self-audit their services against the Code.

**Comment** We consider that many of the changes suggested by submitters to make the Act and the Code more responsive to the needs of tāngata whaikaha | disabled people could be addressed through operational changes.

As noted previously, HDC has developed a Disability Strategic Plan to make our systems, processes, and communications more accessible and responsive to the needs of tāngata whaikaha | disabled people. This feedback will be fed into the implementation of this plan.

In this review we have worked to ensure alignment between the Act and the Code and other human rights instruments. HDC is also committed to upholding the UNCRPD in our work. However, we do not support the addition of specific references to UN Conventions or Declarations in our legislation. There is the potential that legislating for rights outside our core jurisdiction will dilute critical focus on Code rights regarding health and disability services. We also consider that such reference is more suited to general human rights legislation.

- Response**
- **Note** that HDC has committed to actions within its Disability Strategic Plan to make systems, processes, and communications more accessible and responsive to the needs of tāngata whaikaha | disabled people.

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

HDC was asked to consider this topic in its review following a petition to the Health Select Committee that expressed concern about the lack of options to appeal HDC decisions. We note that HDC provides opinions, not decisions (in the judicial sense), so we use the language of ‘challenge’ and ‘escalate’ in this report.

Current options for consumers or providers to challenge HDC opinions are to ask HDC to undertake a ‘closed file review’; make a complaint to the Ombudsman; and seek judicial review in the High Court.

Current complaint pathways exist where a matter has been investigated by HDC and results in a breach finding. In the more serious cases HDC can refer the matter to the Director of Proceedings (DP) for prosecution in the Health Practitioners Disciplinary Tribunal (HPDT) and/or proceedings in the Human Rights Review Tribunal (HRRT). The complainant can also take the matter to the HRRT themselves if the Commissioner has not referred the matter to the DP, or the DP has declined to issue proceedings.

When considering whether the ability to challenge or escalate HDC opinions should be strengthened, the following factors are relevant:

- The scope of review rights;
- The potential costs and delay;
- The need for finality; and
- The expertise of the decision-makers.

We put forward two suggestions for changes to the Act to allow for greater challenge and/or escalation of HDC opinions. These were to:

- Introduce a statutory provision for review of HDC decisions; and
- Lower the threshold for access to the HRRT.

### What we heard

There was general support for strengthening the ability to challenge HDC decisions. However, there was a range of views about what that should look like in practice.

Feedback indicated that **a review process should be accessible, transparent, trauma-informed, and equally available to providers and consumers**. Some considered that providing more structure to existing processes would be adequate. Many suggested that a statutory review process should exclude the original decision-makers. Some went further by suggesting that a review panel should have independent external members or be entirely independent of HDC.

*‘Having an independent right of appeal is an important mechanism to ensure*

*that the HDC is also subject to scrutiny and accountability for its decisions, including where it has gotten a decision wrong.’*

The main concern raised about introducing a statutory requirement for HDC to review decisions was the **potential to add delays (and associated stress) and put pressure on resources** in an environment where timeliness was already an issue. The Ombudsman also noted that they would not look into a procedural matter unless the review avenue had been exhausted. Other concerns raised included:

- That independent review would undermine and duplicate the role of HDC;
- The impact investigation delays would have on provider registration;
- The potential impact on professional insurance premiums;
- That it could disadvantage populations that favour restorative rather than adversarial resolution; and
- The need for finality.

**Many felt that greater effort should be directed towards improving current processes.** Whether through a statutory review or by updating current processes for review; introducing criteria for review, including to restrict to errors and be time-limited, was suggested by some as a way of prioritising, preventing frivolous or vexatious claims, and

managing resources required of a review wisely.

**Views in relation to options to lower the threshold for access to the HRRT were split** between those in favour of lowering the threshold, and those opposed.

The majority of those in favour supported a threshold at an equivalent level as a complaint under the Privacy Act 2020. This would allow a complainant to escalate to the HRRT if an investigation had been completed. Many also considered it important that lowering the threshold occur alongside the ability to have decisions reviewed (including decisions to take no further action).

Many of the same concerns for introducing a statutory requirement for HDC to review decisions were raised in relation to the threshold for access to the HRRT, including delay, resources, and finality. Many highlighted that the current timeliness of HRRT decisions was already a concern. An additional concern was the risk that lowering the threshold to access HRRT would increase the adversarial nature of complaints and push New Zealand towards a more litigious system, and away from a focus on safety and quality improvement.

Feedback in relation to each suggestion, and our comment and response, is addressed in Table 4.

**Table 4 — Topic 4: suggestions, themes, comment, response**

**a. Introduce a statutory requirement for HDC to review decisions**

- Themes**
- General support for some form of statutory requirement for HDC to review decisions, with some wanting an independent element, including independent consumer and/or clinical peers, or a completely independent panel. As long as a review was free, accessible, available to all parties, transparent, timely, and trauma-informed then it was viewed as important for fairness and access to justice.
  - Concerns raised about negative impacts of a statutory review requirement included timeliness, stress for consumers and providers, resources, effects on provider registration, indemnity insurance, opportunities for restorative processes, and the standing of HDC.

**Comment** We agree that there is merit in incorporating a statutory requirement for HDC to review decisions. The purpose of the provision would be to enable consumers, complainants, and providers to ask for a review of the substantive decision and the weight given to the evidence by HDC. While currently a review process is available to individuals by way of a closed file review, at present this option is not well communicated and is at the HDC's discretion.

Such a provision would strengthen transparency, HDC's accountability, and people's access to justice. Any provision would need to balance the need for finality and set limits on the scope and circumstance of review. It should not be sufficient that a party is unhappy with the decision. They must raise specific concerns about the process or outcome of the decision and/or new information.<sup>17</sup> We suggest that the request for review should be time-limited, for example within 40 working days of receipt of the original decision, and be accompanied by one or more of the following criteria:

- New information relevant to the original complaint but not previously provided to HDC;
- New issues relating to the scope of the original complaint but not previously raised with HDC;
- Details of any concerns the person has with the process followed by HDC when assessing or investigating the complaint.

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<sup>17</sup> P. Skegg and R. Patterson (eds), *Health Law in New Zealand*, Thomson Reuters NZ Ltd (2015), p 924.

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We consider that such a review should be for where a file has been closed under section 38(1) of the Act ('no action' or 'no further action'), or where an investigation has been concluded under section 45. Closures under other pathways are already eligible for review under section 33 of the Act. Following the revision of decisions under section 33, HDC may then investigate or close under section 38(1), a decision that then would become eligible for review under the new statutory provision we are proposing.

We acknowledge the feedback asking for a review to be partially or wholly independent of HDC. We do not consider it feasible for a wholly independent panel for numerous reasons, including but not limited to resourcing and the specialist expertise that would be required of reviewers. We note that HDC already provides an independent escalation pathway for where people have not been able, or it is inappropriate, to have their concerns resolved directly with providers. The addition of another independent layer has the potential to be cumbersome and add further fragmentation.

However, we agree that there should be a degree of independence to the review we are proposing, including that the review is undertaken by staff who were not involved in the original file, and that the final decision is made by a different decision-maker. HDC's statutory decision-makers are appointed by the Governor-General and are somewhat independent from each other.

We note that formalising a review process would likely result in greater requests for review and have resource implications. This change would therefore need to be supported by adequate resourcing.

We also note the feedback that improvements in other areas would help to resolve some of the frustration that can be the catalyst for people wanting to challenge HDC's decisions. This included making people feel more heard throughout the process, improving the way that we communicate our decision-making, and better promotion of our current review process.

- Response**
- **Confirm proposed suggestion** to incorporate a statutory requirement for HDC to review decisions in the Act, with a time-limit and criteria to limit the scope and circumstances of a review in the interests of finality.
  - **Consider opportunities** to make HDC's existing review processes, as well as external options to challenge HDC's decisions, more transparent.
  - **Consider opportunities** to improve HDC's complaints processes and communication of decisions to address reasons why parties may request a review.

## b. Lower the threshold for access to the HRRT

- Themes**
- While not many submitters commented on this option, for those that did, there was a mixed response with views both for and against lowering the threshold for accessing the HRRT. Slightly more submitters were against the suggestion than for it.
  - The majority of those in favour supported lowering the threshold to a completed investigation and considered it important that this option be progressed alongside a statutory review option.
  - The majority of those against lowering the threshold raised concerns including potential negative impacts related to promotion of an adversarial and litigious medico-legal environment, timeliness, stress for consumers and providers, resource constraints, and the cost of indemnity insurance.

**Comment** We recognise the need to balance access to justice with the specialist jurisdiction of HDC, potential cost and delay, and the need for finality. We note that there are key differences between the Privacy Commissioner, Te Kāhui Tika Tangata | Human Rights Commission (HRC), and HDC that may explain differences in thresholds to access the HRRT.

- HRC does not investigate complaints or decide whether the law has been breached, therefore to access the HRRT, the Human Rights Act requires only that a complaint is made to the HRC.
- HDC has specialist expertise to determine breaches of the Code, including to substantiate breaches that relate to a standard of care, with evidence from expert clinical peers. HDC exercises a quasi-judicial function whose opinions indicate whether Code Rights were breached, including whether clinical standards were met. There is an evidential threshold that needs to be met for this opinion to be reached. Without a breach decision, parties may need to source their own expert opinions and other evidence to support their case, which ultimately may result in inequity of access, favouring those with the means to obtain such evidence.
- It is relevant that registered providers can have proceedings brought against them in the Health Practitioners Disciplinary Tribunal.
- There is greater access to compensatory damages for privacy and human rights breaches than for breaches of the Code. The Accident Compensation Act 2001 bars compensatory damages for breaches that are connected to a personal injury from treatment.

Having considered the submissions, HDC does not have a position on whether access to the HRRT should be lowered. We consider this issue is better addressed by the Ministry of Health in consultation with other agencies. However, if a decision is taken to lower the threshold, we do not

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support it being lowered to the same extent as the HRC for the reasons that follow.

There are of course, important arguments in favour of a lowered threshold to the HRRT including the principle of access to justice and an increased opportunity to be heard. We also recognise that there would be benefits to the quality of our decision-making by having another body reflect on the same issues.

However, we also note that the fact we got so few submissions on this option may indicate this is not a high priority for most stakeholders. This aligns with what we heard from many communities in consultation, whose priorities were focused more around reducing the barriers people face to making complaints and a desire for more relational resolution. Some submitters also raised concerns about the potential for this change to increase inequity. We share these concerns in particular.

Given that we received so few submissions on this topic, and noting there may be significant resource implications involved in any change – particularly to ensure any changes would be equitable – we consider that this issue needs further consideration. We feel that the Ministry of Health is best placed to lead this work, including engagement with other relevant Ministries.

While we recognise that some feel differently, if the threshold is lowered, we do not support lowering it to the same level as the HRC. The array of issues that are closed without being formally investigated include a significant number of lower-level complaints. We also agree that lowering the threshold too far, risks overwhelming HRRT and has the potential to propel the complaints system in a more adversarial direction.

We do not consider that lowering the threshold from a breach decision to a closed investigation would result in a significant increase in demand to access the HRRT. While we do not collect statistics on independent applications to the HRRT, we believe there to have been only a few cases in the last decade. Conversely, in the 2023/24 year, HDC concluded 154 investigations, 127 of which resulted in breach opinions, and made 9 referrals to the Director of Proceedings. We also note that in many cases, complainants are wanting to be heard and see actions put in place to ensure that what happened to them will not happen to others, and that generally, these are matters that can be met by the HDC process.

**Response** • **Recommend** the Ministry of Health considers this matter further in light of these comments, in consultation with a diverse array of stakeholders and other Ministries.

**Other feedback to support consideration of options for a right of appeal for HDC**

## decisions

- Themes**
- Some people provided alternative suggestions for an appeals process, including having a completely new and independent appeals panel set up for HDC complaints and the establishment of an HDC Ombudsman based inside HDC but completely independent.
  - People also made several suggestions about what an appeals process would need to consider fairness and the wellbeing of people involved. These included:
    - Timeframes for appeals that allow for grieving, consultation, and the complainant to do their own research and gather appropriate evidence;
    - Support during the appeal process, eg, guidance, advocacy support, cultural support, and access to legal services; and
    - The use of specific experts as part of the process, including international experts and people with lived experience.
  - A range of operational changes were also suggested, including better information about the right to complain to the Ombudsman; reviews to be reported in the Annual Report, and HDC monitoring the impact of changes before making any further ones.

**Comment** Given the avenues that exist already, we don't think it is necessary or prudent in the current resource-constrained context to establish any new entities for the purpose of reviewing or appealing HDC decisions. As noted previously, the addition of another 'tribunal' of review would likely result in a cumbersome and fragmented system.

We agree that the timeliness of any appeal or review process is important, but in a context where we know that prolonged uncertainty is causing harm, the need to allow for sufficient time for people to gather or prepare themselves needs to be balanced against the need for prompt resolution. We have suggested 40 working days (two months) as the time limit for initiating an internal review to best balance these considerations.

We don't need to wait for changes to the Act to make improvements to the way we already provide internal review, or the other operational changes suggested. We will share the feedback provided with the appropriate teams to support ongoing quality improvement.

- Response**
- **Note** that we have recommended 40 days as the time limit for initiating internal review to best balance people's need to prepare and the need for timely resolution.
  - **HDC to consider** the operational feedback provided as part of its ongoing quality improvement work.

## Topic 5: Minor and technical improvements

This topic identifies a range of potential improvements to the Act and the Code. We put forward the following nine suggestions to change the Act and the Code:

- Revise the requirements for reviews of the Act and the Code;
- Increase the maximum fine for an offence under the Act from \$3,000 to \$10,000;
- Give the Director of Proceedings the power to require information;
- Introduce a definition for ‘aggrieved person’;
- Allow for substituted service;
- Provide HDC with grounds to withhold information where appropriate;
- Expand the requirement for written consent for sedation that is equivalent to anaesthetic;
- Clarify the requirement for written consent where there is a high risk of serious adverse consequences; and
- Clarify the Code’s definition of teaching and research.

We also asked for people’s views on how we can future-proof the Act and the Code to respond to the impacts of new technology on service provision. Key themes in relation to advancing technology are set out below.

## What we heard

People can see real benefit in greater use of technology in the health and disability sectors, including expanding access to care, allowing critical information to be shared easily, and improving efficiency in a system with limited resources.

However, **there are concerns people and communities are already being left behind, particularly in relation to the accessibility of digital tools.** Other commonly shared concerns largely reflected those raised in the discussion document, including:

- Concerns about the privacy and ownership of their health information and digital sovereignty;
- The risk of bias when tools were trained on datasets that did not reflect their communities;
- Losing the human touch and the nuances that would be missed if face-to-face interaction became increasingly rare;
- Informed consent and the difficulties posed by AI; and
- Accountability when things go wrong, particularly in a context where commercial interests are involved, including those from overseas.

People recognised the rapid pace of change and cautioned about the potential for significant harm if the right safeguards were not put in place, particularly to ensure the transparency

necessary to enable consumers to make informed choices. We heard that **it was important for all communities to have input into these safeguards and to understand and enforce their rights in this context.**

*‘We consider the issues raised by the use of AI in health are significant, complex, rapidly evolving and require multi-disciplinary and diverse input.’*

However, most people either did not comment on or felt that no changes were needed to the Act and the Code at this stage. People thought it was important for the Code to remain sufficiently flexible given the rapidly changing context. Some submitters noted that the Code of Rights already provided relevant protections in the context of advancing technology, including the right to be fully informed (Right 6) and the right to informed consent (Right 7). Many submitters felt that other mechanisms were better placed to deal with key issues raised by advancing technology, particularly in relation to data privacy.

Some of those who pointed to other safeguards already in place argued that rather than changing the Act and the Code, work was needed to ensure that there was a consistent framework for protecting people’s rights in this area across legislation, regulation, and guidelines, and that the implications were well understood by all stakeholders. They also noted that questions around accountability remain unresolved at this time and urgently require addressing. They saw this as beyond the jurisdiction of HDC alone, and something that government needed to take the lead on. We agree.

*‘(Current) protections are anchored in a myriad of Statutes, Codes, Regulations, Standards and Guidelines that are not necessarily easy to navigate. There is ... the need to ensure synchronicity and consistency between them and how they are translated into the clinical context.’*

**Table 5 — Topic 5: suggestions, themes, comment, response**

**a. Revise the requirements for reviews of the Act and the Code**

- Themes**
- Majority support for revising the requirements for the review, including aligning requirements for reviews of the Act and the Code.
  - Most of those in favour supported extending the timeframe for reviews to at least every 10 years.
  - Both those in favour and those against extending review timeframes thought it was important to be able to trigger a review earlier, when necessary. Some wanted clarity on what would trigger an earlier review, and some wanted external parties to be able to trigger a review.
  - Concerns raised by those who did not support changing the timeframes included the Act and the Code becoming outdated and greater difficulty revisiting unactioned recommendations from previous reviews.
  - People noted that reviews were time and resource intensive for all concerned and thought it was important that all reviews were robust enough, including engaging the right stakeholders. There was some frustration at the fact that previous reviews had not resulted in change.
  - Some felt that regardless of the review timeframe, HDC should do more to hear from stakeholders regularly.

**Comment** We note the support for changing the requirements for reviews and agree that it is important for reviews to be meaningful and inclusive. Such reviews are necessarily resource and time intensive. In addition, frequent reviews have significant resource implications for consumer and provider groups and restrict the ability for people to engage equitably. While we are also mindful of our own capacity, we think this adds to the rationale for extending the timeframes for reviews. Although we understand the concerns raised about lengthening time frames for reviews, we note that the Act allows for reviews to be started earlier where necessary by either the Minister of Health or the Commissioner. This provision should remain if timeframes change.

While reviews provide a focused opportunity for people to provide feedback, HDC is committed to engaging with its stakeholders. As well as engaging with people and organisations in the course of performing the Commissioner’s functions, we have several initiatives underway to ensure that we are hearing from, and sharing with, consumers, communities, providers, and others in the health and disability sector. This includes:

- HDC’s consumer advisory group ‘Whakawaha’ provides insight into the issues affecting their communities and input into HDC’s projects and policies. Currently this group has 10 members, representing a diverse array of communities.
- The development of an engagement strategy to support proactive engagement with tangata whaikaha | disability communities who have higher levels of contact with both health and disability supports and services, and who also face barriers to awareness about the Code, understanding how the Code may apply to their experiences of health and disability support services, and who may experience several barriers to raising concerns with providers or making complaints to HDC.
- In their work to develop local champions, ensure consistent approaches to cultural standards, and resolve complaints, the Director Māori team engages frequently with Māori whānau, both kaupapa Māori and non-Māori providers, as well as local rohe, kaumātua, rangatira, and others. The development of a te Tiriti o Waitangi strategy will support further engagement and a strategic approach for the whole of HDC.
- The Aged Care Commissioner has a mandate to engage widely with older people and the aged-care sector, including ensuring that HDC is responsive to the needs of older people.

**Response**

- **Confirm proposed suggestions** to make the reviews of the Act and Code concurrent and align their requirements, streamline the steps for reviews, and shift the requirements for reviews to ‘at least every 10 years’.
- **Consider opportunities** to engage more regularly with stakeholders — particularly communities who face barriers to making complaints.

**b. Increase the maximum fine for an offence under the Act from \$3,000 to \$10,000**

**Themes**

- Most submitters agreed that the maximum fine should be increased. Key rationale included increased deterrence, alignment with other legislation, and responding to inflation.
- Mixed views about what the fine should increase to, with most supporting the proposed alignment with relevant legislation and some suggesting up to \$50,000.
- Concerns about increasing the fine included punishing those already under pressure and creating inequity between providers with greater and fewer resources. Some felt that HDC did not provide a strong case for change and queried whether increased fines would lead to improved outcomes.

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- Other suggestions included extending fines to vexatious complainants, extending fines to entities as well as individuals, and providing HDC with the ability to issue spot fines. One person felt that any fine should become compensation for complainants.

**Comment** We note that most submitters supported this suggestion, sharing our view that it makes sense to align the maximum fine under our Act with comparable legislation. We are mindful that currently the Health Practitioners Competence Assurance Act is under review, but as it stands, both it and the Privacy Act have maximum fines of \$10,000.

While we understand the concerns about fines being punitive, the point of a fine is not to punish. It is to incentivise the cooperation required when people are impeding an investigation. Fines are easy to avoid. While we expect to use fines for deterrent effect only, we note that having to follow through would come with costs for us. It is illogical to have a situation where the imposition of a fine potentially has a bigger deterrent effect on us than those obstructing the process.

Although we appreciate some submitters' concerns about inequitable impacts, the proposal is for a maximum fine, already allowing us the flexibility to adapt to the provider's circumstances. We also note that the deterrent potential of the fine allowed under our Act has significantly diminished over time — particularly for those with more resources.

The suggestion that HDC should be able to issue spot fines has some appeal but would be challenging to implement and is even more likely to be perceived as punitive. We also don't support the suggestion for HDC to be able to fine vexatious complainants. It is difficult to determine when a complaint is vexatious (and indeed, contrary to assertions, truly vexatious complainants are rare), and there is a risk of putting people off coming forward with legitimate concerns. Consumers already face inequities in the complaints process, given that often providers are much better resourced than they are. Neither do we think it is appropriate for fines to be compensation for consumers. We consider that to be an unhelpful muddying of purpose.

It is important to note that fines are just one of the tools at our disposal, and one that we use only when necessary. People who refuse to cooperate can be breached under Right 10 for failing to uphold people's right to complain, and we can refer people to their regulatory authority or name people or organisations publicly if this is warranted.

**Response** **Confirm suggestion** to increase the maximum fine to \$10,000.

## c. Give the Director of Proceedings the power to require information

- Themes**
- Mixed views on this suggestion, with more support from individuals than organisations.
  - Some submitters felt there was not enough information provided to express an opinion on the proposal.
  - Both those for and against the suggestion raised concerns, and some of those who supported the suggestion did so only with caveats.
  - Concerns raised included the potential for further delays, divergence from the usual rules and laws on prosecutors obtaining evidence, misalignment with the intended independent function of the Director of Proceedings under the Act, and the need for consent from individuals to release information.

**Comment** We note the mixed views on this suggestion and are particularly sympathetic to concerns about the potential for this change to cause further delay and undermine the intended function of the Director of Proceedings (DP). While it is important for the DP to have sufficient information to decide whether further proceedings are warranted following a breach of the Code, we agree that it is equally important that this decision is timely, impartial, and aligned with Parliament’s original intent. We also note that there are other mechanisms available to support information gathering by the DP once proceedings have been initiated, including ongoing discovery and disclosure obligations, and the Health Practitioners Disciplinary Tribunal’s powers of investigation under the HPCA Act 2003. On balance, we believe that it is likely to be more beneficial to introduce operational changes in relation to HDC’s investigation process to address this issue than statutory ones.

Increasing internal understanding of the role and processes of the DP, including sharing lessons from decisions to proceed or not, is likely to support information gathering during the investigation process that is more mindful of the sort of information the DP may require. This is not to suggest that investigations should be carried out with future proceedings as the goal, just an appreciation of what would be required should that be the outcome.

- Response**
- **Do not progress suggestion** to give the Director of Proceedings the power to require information.
  - **HDC to improve internal communication/feedback** about the Director of Proceedings’ role and processes and any lessons from decisions to prosecute or not, to support continuous quality improvement.

#### d. Introduce a definition for ‘aggrieved person’

##### Themes

- Most submitters supported this suggestion, viewing it as a necessary change to recognise the impact of breaches of the Code on the wider whānau and the collective nature of decision-making in many communities. Some argued that the *Marks*<sup>18</sup> decision had unhelpfully restricted access to the Human Rights Review Tribunal.
- However, most stressed the importance of defining this term carefully to ensure that only legitimate people would be captured.
- Those against were concerned about unintended consequences, including creating conflicts between primary and secondary victims in relation to access to compensation. Others were concerned that this change would open the floodgates by encouraging people towards litigation due to grief or in search of monetary gain. Some felt that this proposal was counter to the intent of the no-fault ACC system and the Act and Code’s focus on consumers. Some argued that this should be considered settled law following the Court of Appeal’s decision in *Marks*.

##### Comment

While it is true that the Code is focused on consumers, we agree that the impact of breaches (and the circumstances giving rise to the breaches) can be felt more broadly, particularly by those associated with the consumer. Recognition of, and accountability for, these broader impacts reinforces the importance of upholding consumers’ Rights under the Code and is aligned with the purpose of the Act, including the prevention of future breaches and protection of public safety. We note that access to the Human Rights Review Tribunal (HRRT) is currently one of the few mechanisms for accountability in relation to unregulated providers, and that the Court of Appeal already left open the possibility of access to the Tribunal for secondary victims, although it viewed this as being restricted to fathers in obstetric cases (noting that the mother is already a consumer in her own right).<sup>19</sup> We also note that secondary victims/complainants have had access to the HRRT via the Human Rights Act since its inception.

Anyone can raise a complaint, and we understand people’s concerns that the suggested changes raise the potential for people with no close association to the consumer having access to the HRRT under section 51 and, therefore, to damages awards. However, we are not convinced by floodgate arguments. It is highly likely that only family members and

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<sup>18</sup> *Marks v Director of Health and Disability Proceedings* [2009] NZCA 151; [2009] 3 NZLR 108; the Court of Appeal left open one possible exception — fathers of a baby in utero and birth process — because the baby is not a consumer until after birth.

<sup>19</sup> The Court of Appeal also allowed for authorised legal representatives to bring complaints to HRRT but they would be acting on behalf of the consumer, not in their own right.

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those with a close association with the consumer, including significant involvement in their care, would have any incentive to expend the time, stress, cost, and effort of mounting civil proceedings. If completely unrelated people did decide to, they would still have to prove that the damages sought under section 57 were warranted. We also note that both the Commissioner and Director of Proceedings act as gatekeepers to the HRRT, and that even if we were to lower the threshold for access (see pages 56–57) there would still be only a small number of complaints each year where access to the HRRT was possible.

We are concerned about the potential for the suggested changes to create disparities between the consumer and secondary victims in relation to access to damages. Section 52 of the Act creates a statutory bar to all claims for compensatory damages for people covered by the ACC Act. Only punitive damages are available for people covered by ACC. As secondary victims are not covered by the ACC Act, it means that the potential damages available to a secondary victim via the HRRT could theoretically be greater than those available to the primary victim.

However, again we note the likely rarity of these situations, and that the *Marks* case established that while secondary victims can experience significant harms, many of the losses for which compensatory damages may be awarded under section 57 are limited to the primary victim only. Ultimately, our focus must be on achieving the purposes of our Act, rather than resolving broader legislative inconsistencies. On balance, we continue to support the change suggested by previous Commissioners to substitute the phrase ‘aggrieved persons’ with the phrase ‘the complainant (if any) or the aggrieved person (if not the complainant)’ where it appears in relevant provisions from section 51 onwards, and particularly sections 51–54 and section 57. We appreciate that potentially there is intersection with the Ministry of Health’s Review of the Health Practitioners Competence Assurance Act and suggest that this change be considered in parallel with that work.

- Response**
- **Confirm suggestion** to substitute the phrase ‘aggrieved persons’ with the phrase ‘the complainant (if any) or the aggrieved person (if not the complainant)’ where it appears in relevant provisions from section 51 onwards.
  - **Recommend that the Ministry of Health consider this change** alongside its review of the Health Practitioners Competence Assurance Act.

#### e. Allow for substituted service

- Themes**
- Most submitters supported this suggestion, recommending that regular contact is made with both consumers and providers during the complaints process, and that people are asked about their

preferred contact at the first instance, and this is checked/updated at every contact.

- People felt that use of social media was not ideal and should not be used frequently as a primary means of contact. One submitter suggested that HDC should seek permission to contact people via social media.
- Many submitters offered practical suggestions, including alternative avenues for contacting people and ways to collect alternative contact information.
- One submitter noted that it was important for HDC to be mindful of issues like homelessness and transience and ensure that processes do not disadvantage people further.
- One submitter thought that it was important for ‘reasonable attempts’ to be defined clearly.

**Comment** We note the majority support for this suggestion, as well as the focus on practical options for addressing this issue. Natural justice considerations are important, and we would want to be using this option only as a last resort. However, we don’t think it is necessary to define ‘reasonable attempts’, as the term ‘reasonable’ is commonly understood in law as relating to things that are fair, sensible, and appropriate to the circumstances. If something is reasonable, it aligns with what an average person would consider normal or acceptable in a similar situation. We agree that operational improvements are likely to be helpful and intend to explore some of the suggestions we received.

**Response**

- **Confirm suggestion with changes** to substitute the phrase ‘the Commissioner must advise’ with ‘*the Commissioner must make reasonable attempts to advise*’ in section 43(1).
- **Consider opportunities** to improve the way we collect and update people’s contact information as part of ongoing quality improvement.

## f. Provide HDC with grounds to withhold information where appropriate

**Themes**

- Mixed views on this suggestion. Individuals and organisations representing consumers tended to be in favour, viewing this as an option for ‘levelling the playing field’. Organisations representing providers were unanimously against the suggestion, viewing it as adversarial.
- Key concerns raised included inconsistency with procedural fairness and natural justice, disagreement with the comparison between the HDC’s investigations and those of the Privacy Commissioner, and the need for fairness and more rather than less transparency.

- The Ombudsman queried the appropriateness of a similar secrecy obligation to the Privacy and Ombudsman Acts given HDC’s different function and suggested that existing withholding grounds in section 9 of the Official Information Act (OIA) may be better utilised. The Ombudsman also directed HDC to the Law Commission’s 2012 recommendation for a new time-limited withholding ground to be added to the OIA to protect information supplied during an investigation.

**Comment** We note the mixed views from submitters and acknowledge the need to balance transparency and natural justice considerations with the ability to ensure orderly decision-making and an even playing field for all parties. We acknowledge that there are differences between the functions of the Ombudsman and Privacy Commissioner and our own and note that some of the organisations who have secrecy clauses in their legislation have found them unhelpfully restrictive in certain circumstances.

Ultimately, we view the Official Information Act as a better mechanism for balancing the issues at play here, as it would provide a more consistent approach, and the principle of availability is the central consideration. We note that in its 2012 report, the Law Commission recommended a new withholding ground be added to section 9 of the OIA in situations where ‘it is necessary to protect information which has been provided to an agency in the course of an investigation or inquiry, and disclosure is likely to prejudice the conduct or outcome of that investigation or inquiry’.<sup>20</sup> We continue to support this recommendation and urge the government to progress it.

**Response**

- **Do not progress** the proposal to provide HDC with grounds to withhold information where appropriate.
- **Recommend** that the government progress the Law Commission’s recommendation to introduce a new withholding ground into section 9 of the Official Information Act (R24).

### g. Expand the requirement for written consent for sedation that is equivalent to anaesthetic

**Themes**

- While fewer submitters commented on this suggestion, most of those who did, agreed with the suggestion. However, several submitters cited considerations that needed to be worked through.

<sup>20</sup> Recommendation 24. *The Public’s Right to Know: Review of the Official Information Legislation*. Law Commission report; no.125, p. 130.

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- There appeared to be some confusion among submitters around when written informed consent would be needed, with some linking it to the administration of medication to help a person cope with a medical procedure and some linking it to the administration of the medication itself.
  - Key considerations raised included the need for clear definitions of what constitutes a significant risk of serious adverse events; exemptions for certain situations (eg, emergencies); and the practicalities of written consent in some situations (eg, over-the-phone prescriptions).
  - One submitter argued that there needed to be recognition of unexpected clinical situations and the need for doctors to use reasonable clinical judgement where things have not been consented specifically.
  - One submitter thought this should be expanded further to include situations where medications pose a public health risk.
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**Comment**

While all health procedures, including the administration of medication, require informed consent, the intent of Right 7(6)(c) of the Code is aimed at safeguarding a consumer's right to informed consent in specific circumstances. When people are undergoing a medical procedure that requires the use of medication that will have an impact on their ability to make or remember decisions, it ensures that there is an unalterable record of what the consumer has consented to. We note that most people agree that this should be expanded to other medications that can have a similar effect on someone's cognitive abilities as a general anaesthetic.

While we agree that there would be situations where gaining written consent would be impracticable, and many of the situations people raised as requiring specific exemptions (eg, emergencies) would already be covered by Clause 3 of the Code, which focuses on providers taking reasonable actions in the circumstances. Rather than building specific exemptions into the Code, we suggest that these concerns, as well as specifics about which medications would be captured, are best addressed by developing guidance for the sector to support the proposed changes.

Even if no changes were to be made, guidance seems necessary. What public consultation has highlighted is that there is varying understanding in the sector of the rationale behind Right 7(6)(c) or what upholding this right looks like in practice. The concerns raised by multiple submitters focused on issues with requiring written informed consent for the

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medication itself rather than the procedure. We note that the current lack of clarity is not helped by the interaction of the current wording of Right 7(6) of the Code with the definition of healthcare procedure in the Act,<sup>21</sup> which would include the administration of medication. However, we believe this issue is addressed by the proposed new wording, which stipulates that the medication is being given ‘for the purpose of undertaking the procedure’.

- Response**
- **Confirm suggestion** to substitute the phrase ‘under general anaesthetic’ with ‘*given medication designed to alter their level of consciousness, or awareness or recall, for the purpose of undertaking the procedure*’ in Right 7(6)(c) of the Code.
  - **Consider guidance** by HDC to improve the sector’s understanding of Right 7(6)(c).

#### **h. Clarify the requirement for written consent where there is a high risk of serious adverse consequences**

- Themes**
- Few submitters commented on this suggestion. Most of those who did were not supportive of the suggested change.
  - Submitters’ main concerns related to who gets to make decisions over what is considered significant or serious. People felt that how these terms are defined is important, there are no nationally agreed definitions, and providers’ and consumers’ considerations of risk are likely to be different.
  - People also stressed the importance of open and transparent information to satisfy informed consent, and some raised concerns about the impracticability of obtaining written consent in all relevant circumstances.

**Comment** Public consultation has highlighted the need for further work to support best practice in relation to informed consent around risk. Given that informed consent is predicated on the information a reasonable consumer in that consumer’s circumstances would expect to receive, consumers’ understandings and views of risk are a vital component of this work. Rather than progressing the proposed suggestion at this time, we believe that encouraging improved practice and understanding in relation to informed consent and risk is likely to contribute to more meaningful outcomes. A collaborative all-of-system approach would be

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<sup>21</sup> Under the Act, healthcare procedure means ‘any health treatment, health examination, health teaching, or health research administered to or carried out on or in respect of any person by any health care provider; and includes any provision of health services to any person by any health care provider’.

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useful, and we would be keen to work with the Ministry of Health and others to progress this.

- Response**
- **Do not progress proposal** to add the word ‘serious’ into Right 7(6)(d).
  - **Recommend** that the Ministry of Health work with HDC and other key stakeholders to improve practice and understanding in relation to informed consent and risk. Note that this work needs to involve consumers.

### i. Clarify the Code’s definition of teaching and research

- Themes**
- We received a wide range of views in relation to this suggestion, with many submitters focusing solely on either teaching or research. Most submitters felt that definitions would be helpful, but some felt that they weren’t necessary or even possible given the range of activities that could be covered.
  - A few people argued that teaching and research had different characteristics and suggested separating them in the Code.
  - Some submitters suggested that teaching and research were areas where there needed to be further consultation.
  - **In relation to research:** There tended to be conflicting views between those coming from a clinical perspective and those coming from a consumer perspective about what should be included in definitions of research.
  - While most submitters agreed that prospective research requires informed consent and robust ethical standards, submitters with clinical backgrounds tended to view retrospective research as not requiring the same protections, because it does not have the potential to impact on consumers’ care.
  - Many consumer groups argued that informed consent is always necessary and expressed concern about any rolling back of informed consent protections in relation to research. Consumer organisations submitted that they want stronger protections around informed consent for retrospective research and clearer guidance for ethical practice when getting informed consent is not practical.
  - One submitter felt that HDC should have no role in research whatsoever and should remove all references to it in the Code, delegating ethical management of research to the National Ethics Advisory Committee.
  - However, many consumer groups expressed concern about national ethics committees, noting a lack of trust in these committees and a sense that there is insufficient consumer participation in the committees.

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- One submitter stressed that it is important that HDC collaborate with people with lived experience to interpret and apply the Code’s definition of research.
  - **In relation to teaching:** Again, there were mixed views that tended to diverge along provider and consumer perspective lines.
  - Those coming from a provider perspective tended to want to limit the definition of teaching to interactions where the primary or sole purpose is teaching rather than service provision.
  - Arguments for a narrow definition included the reliance of the healthcare system on both formal and informal training, and that requiring informed consent every time any learning is taking place would be impractical.
  - Some consumer organisations felt it was better to leave this term undefined to keep it flexible. Others thought that the definition of teaching should be broad, with one arguing that it should include situations where the consumer is present (including online) or referred to indirectly, such as being used as a case study.
  - One submitter suggested replacing references to ‘teaching’ with ‘education’ to better reflect current terminology.
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**Comment**

Overall, we agree with comments that these issues have separate characteristics and need to be treated differently. We also agree that definitions of terms that cover such a wide variety of activities are impractical and would render the Code too inflexible. We note the diverging views between those with more of a sector lens and those coming from a consumer perspective in relation to both terms, and we suggest that further work to understand both perspectives and the development of sector guidance is likely to be more beneficial. We note that HDC is not always best placed to lead this work.

**In relation to research:** People’s rights in relation to research, or lack thereof, was the catalyst for the establishment of HDC and the Code of Rights. While there are other mechanisms to support the ethical management of research, it is important that people continue to have rights in situations where they are the subjects of research, and an independent avenue to complain when they feel that their rights are not being upheld. It is apparent from this consultation that there are significant differences as to where people think the lines should be drawn.

We note the diverging views between the sector and consumers/the public. We also note the lack of trust expressed by consumers about some of the other mechanisms designed to protect their interests in relation to research, and the strong views shared on the need for wider change. We believe that this is indicative of a broader conversation that needs to be had, particularly in a system rightly focused on learning and

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innovation. Any definition of research that seeks to establish the limits of people’s rights is better to come out of that dialogue. We agree that HDC is not best placed to be leading that conversation, but we would need to be part of it.

**In relation to teaching:** This is an area where HDC receives several complaints each year, including those relating to areas of practice that providers recognised as requiring informed consent in submissions. We are working with the sector to try to reinforce an understanding of providers’ obligations in respect of teaching. While many regulatory bodies have supported this with useful guidance of their own, the focus has tended to be on the medical workforce, with less understanding among other parts of the workforce, including allied health and the disability sector.

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- Response**
- **Do not progress** suggestion to define teaching and research in the Code.
  - **Recommend the Ministry of Health**, in partnership with HDC and the National Ethics Advisory Committee, leads a work programme around effective settings for research that best balances people’s rights and sector context.
  - **Note that HDC has undertaken work** to promote informed consent in relation to teaching.
  - **HDC** to work with regulatory authorities to consider how expectations around informed consent in the context of teaching can be made clear across professions.

### Other feedback to support minor and technical improvement

- Themes**
- There was a wide variety of additional improvements suggested by submitters, including things we should consider when making recommendations, operational issues, and complex issues that would require significant consultation and legislative amendments. Most suggestions were raised by only one submitter.
  - **Timeframes:** A few submitters suggested changes to the requirements around timeframes for providers to respond to complaints in section 41 (currently 15 working days), with some people wanting these extended to 20/21 working days to allow for providers to properly consider and consult on a response, and some wanting HDC to be able to apply penalties if timeframes are not met.

- **Vicarious liability:** A few submitters thought that section 72 should be considered for reform as it was unclear, and, as identified by the Supreme Court,<sup>22</sup> its current wording ‘is not particularly well-tailored to the way people conduct business’ and creates a logical issue in that the principal of an agent or member is held to a stricter liability for those persons’ breach than an employer for an employee’s breach. One submitter noted that the Supreme Court considered that section 72 warranted reconsideration by Parliament.
- Other amendments suggested include:
  - Amending Right 7(6) of the Code to require written informed consent when sensitive examinations are going to be conducted by a medical student/trainee;
  - Including healthcare chaplains in the definition of ‘healthcare provider’ in the Act; and
  - Adding a specific requirement to the Act for HDC to consult/share information with agencies that have a shared interest in quality and safety of health systems.

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**Comment** While we appreciate the intent of the additional changes suggested, we think the following are unnecessary:

- We agree that the timeframes in section 41 can be impractical but note that in practice, HDC takes a more flexible approach to timeframes. Generally, providers are given six weeks to respond, and extensions are granted readily. We also already have options for holding providers to account if they fail to provide us with a response.
- It is important for the Code to remain principles-based and flexible enough to ensure protection in a wide range of situations rather than becoming prescriptive. HDC is already working to ensure that people’s understanding of their obligations in relation to informed consent is clear. Explicit consent for sensitive/intimate examinations is already an expectation under the Code, including consent for medical students to undertake and/or observe such examinations.
- Health chaplains would already be covered in the definition of ‘healthcare provider’ in section 3(k) of the Act, where they are holding themselves out to be providing such services. The definition of ‘health services’ in the Act is broad enough to cover services to support spiritual wellbeing | ara wairua.
- HDC has a responsibility to contribute to wider system improvement and takes a collaborative approach to sharing our data with other agencies and working on areas of shared concern. This includes

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<sup>22</sup> *Christopher Ryan v Health and Disability Commissioner* [2023] NZSC 42.

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regular reporting to the Ministry of Health and participation in the National Quality Forum.

However, we agree that the current wording of section 72 of the Act is unclear and not well designed to capture current practice or support appropriate accountability. We also agree with the Supreme Court that this section of the Act warrants reconsideration by Parliament and expect that a broad range of stakeholders would want the chance to comment on any changes. We suggest that changes are considered alongside the Ministry of Health's review of the HPCA Act.

- Response**
- **Recommend** that the Ministry of Health consider changes to section 72 of the Act to support clarity and appropriate accountability and better reflect current employment practices in the sector.

## Appendices | Ngā āpitihanga



## Appendix 1 — Glossary | Ngā kupu ka mahia i tēnei tuhinga

This Appendix explains important words and ideas we use in this document. Where appropriate, a description in te reo Māori is provided for kupu Māori (Māori words) alongside an English description. A vertical bar | is used for te reo Māori and English equivalent words that may not be direct translations.

<b>Advocates and the Advocacy Service</b>	Health and disability services consumer advocates (advocates) have a statutory role within the Act to promote the Code and support people using health and disability services. Advocates, operating within the Nationwide Health and Disability Advocacy Service (the Advocacy Service), have a role to guide and support people to ‘self-advocate’, that is to speak up about their needs and raise concerns and resolve complaints directly with service providers.
<b>Consumer</b>	The word ‘consumer’ in this document means a person using a health service, a disability service, or both. ‘Consumer’ is a term that is used not only in our Act, but in other health and disability-related legislation.
<b>Complaint</b>	The Code provides the right to complain about health and disability services and sets out expectations for providers to respond to complaints. The Act sets out how HDC can respond to complaints. A complaint is when someone isn’t happy with a health or disability service, wants to talk about it, and expects a response. A complaint is different from feedback or raising concerns, as it requires a resolution as set out in the Code and the Act.
<b>UNCRPD</b>	The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is a human rights treaty that New Zealand ratified in 2008. The focus of the UNCRPD is on identifying and eliminating discrimination and barriers that prevent disabled people from participating in society on an equal basis with others. In this context, disability includes people with lived experience of mental distress. Note that the UNCRPD does not mention people who experience harm from substance use, gambling, or addiction, who would not otherwise meet the definition of, or consider themselves to experience, disability.
<b>Disability</b>	We note that there are a range of definitions that tāngata whaikaha   disabled people identify with. We use the United Nations’ definition of disability meaning ‘people who have long-term physical, mental, intellectual or sensory impairments that, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others’. In this context, disability includes people with lived experience of mental distress. People’s experience of disabling barriers may also be influenced by their experience of other factors, including gender, age, ethnicity, and culture.

<p><b>Hohou te rongō</b></p>	<p>Kia hohou te rongō. Hohou te rongō describes methods of resolving disputes using principles and values from te ao Māori (Māori world views).</p> <p>Hohou te rongō is a newly implemented approach within HDC’s complaints management process facilitated by Māori. Hohou te rongō provides an opportunity for the nawe (wrongdoings of a person(s)) experienced by whānau to be acknowledged by the providers and for whānau to seek peace in the experience within a culturally safe and appropriate environment. Hohou te rongō is a tikanga-led process and is conducted ā-kanohi (in person), either in the medium of te reo Māori, English, or both.</p>
<p><b>Hui ā-whānau</b></p>	<p>Hui ā-whānau is a whānau gathering (inclusive of the consumer) facilitated using te reo Māori me ngā tikanga Māori (Māori methods of engagement and protocols).</p> <p>Hui ā-whānau is an approach within HDC’s complaints management process facilitated by Māori. Hui ā-whānau allows whānau voice to be heard and understood in a culturally safe and appropriate environment. Hui ā-whānau take place in te reo Māori, English, or both.</p> <p>It is a tikanga-led process where whānau are the experts of their experience and are supported to determine what resolution looks like for them.</p>
<p><b>Provider</b></p>	<p>The word ‘provider’ in this document means a healthcare provider or a disability support services provider, as defined in the Act (sections 3 and 2). This includes public and private services, paid and unpaid services, hospitals and rest homes, and individuals such as nurses, doctors, dentists, pharmacists, counsellors, chiropractors, naturopaths, and caregivers.</p>
<p><b>Tāngata whaikaha   disabled people</b></p>	<p>Tāngata whaikaha is a strengths-based term meaning ‘people who are determined to do well’. ‘Whaikaha’ means to have strength, to have ability, and to be enabled.</p> <p>The term ‘disabled people’ is used by the New Zealand Disability Strategy and aligns with the Social Model of Disability. Social Model language places emphasis on the barriers created by society that disable people, and places responsibility on society to remove barriers and create a less disabling world.</p> <p>While we use ‘tāngata whaikaha   disabled people’ in this report, we acknowledge the critical role that whānau and family play in the lives of tāngata whaikaha   disabled people. We also acknowledge that many people hold multiple identities and not all people who experience barriers created by an inaccessible society identify with the words ‘tāngata whaikaha’ or ‘disabled people’ or may simply prefer other terms. For example, many tāngata whaikaha   disabled people who are Māori identify as Māori first, while other groups use a range of terms to identify themselves, including, but not limited to, whānau hauā, tagata sa’ilimalo and their āiga-tele, people with disabilities, people with lived experience of mental distress, d/Deaf,</p>

	and neurodivergent.
<b>Tāngata whai ora</b>	‘Tāngata whai ora’ means ‘people seeking wellness’ and can refer to people using mental health and addiction services.
<b>Te ao Māori</b>	Te aronga a te Māori ki tōna ao Māori. Te ao Māori is about legitimate ways of thinking, belonging, engaging, and seeing the world from a Māori lens and draws on mātauranga Māori. (Mātauranga Māori is complete knowledge systems with its own organisations and includes, but is not limited to, languages, whakapapa, technology, systems of law and social control, systems of property and value exchange, and forms of expression. Understandings are developed and passed between generations at local whānau, hapū, and iwi levels.)
<b>Te Tiriti o Waitangi</b>	At the heart of te Tiriti o Waitangi (te Tiriti) is the exchange of enduring rights, responsibilities, and obligations between the British Crown and Rangatira representing many, but not all, hapū, mana to mana. (In traditional Māori society, hapū was the primary political unit that had authority to make decisions.) There are two versions — te Tiriti o Waitangi written in the Māori language, and the Treaty known as the Crown’s English-language version. The two texts are different, particularly in relation to matters of governorship and sovereignty in Articles 1 and 2.
<b>Tikanga</b>	He kupu ārahi i ngā mahi tika. Tikanga Māori (tikanga) are customary practices rooted in mātauranga Māori. Any discussion of tikanga needs to appreciate its place and function within te ao Māori. Understanding tikanga requires a journey through the Māori world, including its own knowledge systems and organisation, values, and principles that locate tikanga in its natural environment. To try to understand tikanga outside that framework risks it becoming de-contextualised and abstract, and distorting its meaning. <sup>23</sup> The Supreme Court recognises tikanga as the first law of Aotearoa New Zealand and part of the common law (see 2022-NZSC-114 Ellis). Tikanga has evolved and continues to adapt to societal and technological developments. While the intent of tikanga is similar across different hapū (whānau groups sharing descent across a common ancestor) and iwi (tribe), how these values are applied may differ.
<b>Whānau</b>	He herenga tangata, herenga whakapapa. Traditionally, ‘whānau’ most often refers to family members connected by blood but may include in-laws and adopted family members. In modern usage, whānau extends to include people with close relationships and who come together for a shared purpose. People

<sup>23</sup> Wiremu Doherty, Hirini Moko Mead and Pou Temara, ‘Tikanga’ (paper presented to Te Aka Matua o te Ture | Law Commission, Te Whare Wānanga o Awanuiārangi, 2023) at 1.2.

	define their whānau for themselves when using health and disability services.
<b>Will and preferences</b>	<p>The CRPD provides that a disabled person’s rights, will, and preferences are guiding principles for all support for, or exercise of, decision-making.</p> <p>A person’s ‘will’ reflects their underlying values or the direction they want to pursue. In contrast, a person’s ‘preferences’ reflect a greater liking for one choice over another.</p>

## Appendix 2 — List of organisations by group HDC sought feedback from in February 2023 scoping phase

- Ministry of Health
- Director of Mental Health and Addiction
- Health New Zealand | Te Whatu Ora
- Te Aka Whai Ora
- Whaikaha | Ministry of Disabled People
- Office of Disability Issues
- Office of the Ombudsman
- Te Kāhui Tika Tangata | New Zealand Human Rights Commission
- Office of the Privacy Commissioner
- Office of the Children’s Commissioner
- Te Hiringa Mahara | Mental Health and Wellbeing Commission
- Ara Poutama Aotearoa | Corrections
- Ministry for Pacific Peoples
- Te Tāhū Hauora | HQSC
- National Advocacy Service
- National Advocacy Trust
- Consumer Advocacy Alliance
- Mesh Down Under
- The Cartwright Collective
- Auckland Women’s Health Council
- Action to Improve Maternity
- 5 x Individuals
- Blind Citizens NZ
- Balance Aotearoa
- Deaf Aotearoa
- Disabled People’s Assembly
- Kapo Māori Aotearoa
- Muscular Dystrophy NZ
- People First
- Te Pou Consumer Leadership Group
- Ngā Hau e Wha
- NAMHSCA
- Take Notice
- Age Concern
- Grey Power
- Aged Care Association
- Rainbow Youth
- Te Kaunihera Rata o Aotearoa | Medical Council of New Zealand
- Nursing Council
- Midwifery Council
- Chief Medical Officers Group
- Council of Medical Colleges
- Health Research Council
- National Ethics Advisory Committee
- Donald Beasley Institute

## Appendix 3 — List of activities and people who contributed to the development of the consultation document

Note that our activities were to gain knowledge and insight to help shape public consultation material. The final consultation material represents the position of HDC only, having regard to the contribution of these stakeholders. HDC is grateful for their generous contributions.

We held:

- Wānanga with rangatira (Māori leaders) and Māori health and disability sector leaders to hear their wisdom and guidance on tikanga and the experiences and aspirations of Māori to help us shape ‘Topic 2 — Making the Act and the Code effective for, and responsive to, the needs of Māori’. We acknowledge and thank Tā Mason Durie and Meihana Durie, the late Maaka Tibble, Kahurangi Naida Glavish, Moe Milne, Keri Opai, Dr Claire Charters, Dr Maria Baker, Dr Huhana Hickey, Graham Bidois-Cameron, Gloria Sheridan, Angie Smith, Tania Miri Noa, Joanne Henare, and Kerri Nuku. We also thank the authors of the Critical Te Tiriti Analysis Framework we applied to this work.
- Wānanga with lived experience leaders to help us shape particularly ‘Topic 1 — Supporting better and equitable complaint resolution’, and ‘Topic 3 — Making the Act and the Code work for tāngata whaikaha | disabled people’. We thank the HDC’s Consumer Advisory Group; attendees of the disability workshops (including Jordan Milroy, Joanne Dacombe, Grace Lee, Oliver Halford, Zandra Vaccarino, Rachel Noble, Victoria Manning, Kim Robinson, Anne Wyrill, Rebekah Graham, Jenna Maguren, and Esther Woodbury); the Kōtuinga Kiritaki Consumer Network; the Lived Experience Knowledge Network; the Addiction Consumer Leadership Group; the family and whānau advisors network; and the National Association of Mental Health Service Consumer Advisors. We also thank Dr Brigit Murfin-Veitch, Iris Reuvecamp, and Erika Butters for their wisdom and advice on Topics 1 and 3.
- Wānanga with providers, consumers, and other sector leaders to shape ‘Topic 1 — Supporting better and equitable complaint resolution’ and ‘Topic 4 — Considering options for a right of appeal of HDC decisions’. We thank Tui Taurua, Sue Claridge, David Dunbar, Edna Havea, Sam Powell, Danae, Dr Tristram Ingham, Ann Buckley, Alison Eddy, Martin Thomas, Dianne Black, Rebekah Graham, Gabriel Lau, Renate Shütte, Charlotte Korte, Prof Jo Manning, the National Advocacy Trust Board, and advocates.

## Appendix 4 — List of suggested amendments to the Act to give effect to te Tiriti o Waitangi

Suggestions for descriptive/specific te Tiriti provisions in the Act, ordered by the Articles of te Tiriti, are set out below. Suggestions may relate to more than one Article.

Areas of alignment between these suggestions and the health-sector principles in section 7 of the Pae Ora (Healthy Futures) Act 2022 are noted in each section.

Preamble: suggestions to ensure that te Tiriti is central, and Māori are equal parties in policy development

- Add a te Tiriti clause (new section). This option had been recommended by previous Commissioners and ensures that our commitment to te Tiriti no longer relies on the discretion of the Commissioner of the time.
- Amend the long title of the Act, eg, to provide for the recognition of the Crown's obligations under te Tiriti or incorporate outcomes for Māori and all people in Aotearoa New Zealand in alignment with the Pae Ora Act (Title).
- Amend the purpose of the Act to incorporate principles important to Māori/specific reference to tikanga (section 6 Purpose).

Article 1 | Kāwanatanga: Suggestions to provide mechanisms to ensure equitable Māori engagement and/or leadership in the operation of the Act and the Code.

*(Alignment with Pae Ora principles 7(1)(a): equity, 7(1)(b): engagement and 7(1)(c): Māori exercising decision-making authority)*

- Strengthen the qualifications for appointment of Commissioner and Deputy Commissioners in relation to Māori (section 10(1)(f) Qualifications for appointment or additional subsection), eg, the ability to demonstrate experience in engaging effectively with, and working collaboratively with, tāngata whenua, hapū, and iwi.
- Require the appointment of a Deputy Health and Disability Commissioner Māori (new subsection in section 9 Deputy Commissioners). *Note: this proposal has been amended as outlined in this report.*
- Require the Commissioner to establish and maintain effective links with iwi (section 14(2) Functions of Commissioner).
- Add engagement with Māori, hapū, and iwi organisations in relation to section 20 Consultation on preparation and review of Code.
- Require engagement of Māori, hapū, and iwi in relation to the amendment or revocation of advocacy guidelines (section 28 Guidelines for Operation of Advocacy Service).

Article 2 | Tino Rangatiratanga: Suggestions to provide for Māori values and world views, overseen by Māori.

*(Alignment with Pae Ora principles 7(1)(c): Māori exercising decision-making authority and 7(1)(d): choice of quality services)*

- Expressly include promotion and protection of tikanga in the functions of the Commissioner in relation to the respect for, and observance of, the rights of health and disability services consumers (section 14(1) Functions of Commissioner).
- Require the appointment of a Deputy Health and Disability Commissioner Māori (new subsection in section 9 Deputy Commissioners) to oversee and ensure appropriate knowledge and protocols to assess and respond to cultural components of complaints. *Note: this proposal has been amended as outlined in this report.*
- Amend section 61 Mediation conference to refer explicitly to hohou te rongohui ā-whānau or processes in alignment with tikanga.
- Recognise and provide for tikanga in section 20 Content of the Code. This suggestion also aligns with the Ritenga Māori declaration by appropriately recognising wairua (spirituality) and tikanga.

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.

*(Alignment with Pae Ora principles 7(1)(a): equity; 7(1)(c): Māori exercising decision-making authority; 7(1)(d): choice of quality services; and 7(1)(e): protection and promotion of health and wellbeing)*

- 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.