****

**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**

**A consultation document | He tuhinga uiui**

**April 2024 | Āpereira 2024**

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!

**Contents | Ngā Ihirangi**

[Commissioner’s foreword | Kupu whakataki a te Toihau 1](#_Toc161331410)

[Acknowledgements | He whakamihi 3](#_Toc161331411)

[Introduction | He kupu whakataki 4](#_Toc161331412)

[Aim of this consultation document 4](#_Toc161331413)

[How to have your say 5](#_Toc161331414)

[Official Information Act 6](#_Toc161331415)

[Draft wording to give effect to suggestions for the Code 6](#_Toc161331416)

[Next steps 6](#_Toc161331417)

[Other relevant work 7](#_Toc161331418)

[Words we use in this document | Ngā kupu ka mahia i tēnei tuhinga 8](#_Toc161331419)

[Overview of the Act and the Code | Tūhura whānui o te Ture me te Tikanga Mōtika 13](#_Toc161331420)

[Origins of the Act and the Code 13](#_Toc161331421)

[The Code and your rights 14](#_Toc161331422)

[The Act and the functions of HDC 16](#_Toc161331423)

[The complaint process 16](#_Toc161331424)

[Topic 1 — Supporting better and equitable complaint resolution |Kaupapa 1 — Te tautoko kia pai ake te whakatatū amuamu, kia mana taurite hoki……………………………19](#_Toc161331425)

[Issues 19](#_Toc161331426)

[Legislative suggestions for change 21](#_Toc161331427)

[Topic 2 — Making the Act and the Code effective for, and responsive to, the needs of Māori | Kaupapa 2 — Ka a whakaritea Te Ture me Te Tikanga kia mauritau atu, kia urupare atu hoki ki ngā matea o te Māori 27](#_Toc161331428)

[Issues 27](#_Toc161331429)

[Legislative suggestions for change 28](#_Toc161331430)

[Topic 3 — Making the Act and the Code work better for tāngata whaikaha | disabled people | 35](#_Toc161331431)

[Kaupapa 3 — Kia tika Te Ture me Te Tikanga mō ngā tāngata whaikaha 35](#_Toc161331432)

[Issues 35](#_Toc161331433)

[Legislative suggestions for change 37](#_Toc161331434)

[Topic 4 — Considering options for a right to appeal HDC decisions | Kaupapa 4 — Kia whakaaro kōwhiringa mō tētahi mōtika hei pīra i ngā whakatau a te HDC 43](#_Toc161331435)

[Issues 43](#_Toc161331436)

[Legislative suggestions for change 45](#_Toc161331437)

[Topic 5 — Minor and technical improvements |Kaupapa 5 — He whakapai itinga, mea hangarau hoki 48](#_Toc161331438)

[Issues and suggestions for change 48](#_Toc161331439)

[Appendix 1 — Consultation questions | Āpitihanga 1 — Ngā pātai uiui 53](#_Toc161331440)

[Appendix 2 — How our suggestions could translate into a revised Code | Āpitihanga 2 — Me pēhea a mātou huatau e whakawhiti ai ki tētahi Tikanga hou 56](#_Toc161331441)

# Commissioner’s foreword | Kupu whakataki a te Toihau

Korihi te manu

Tākiri mai te ata

Ka ao, ka ao, ka awatea

Tīhei mauri ora!

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 seek your feedback to improve the Health and Disability Commissioner Act (the Act) and Code of Health and Disability Services Consumers’ Rights (the Code).

These laws matter. Every New Zealander will access health services at multiple points across their lifetime, and around 45,000 people per year will also access disability services. The Act establishes the office of the Health and Disability Commissioner (HDC), and the Code sets out your rights when using health and disability services. Together they address the power imbalance that exists between people and providers of services, and ensures people are at the centre of care. These laws support people to know their rights and have a voice when things go wrong. They provide accountability through an independent complaint mechanism, and support service improvement through learning from complaints.

2024 marks 30 years since the Act came into law. Two years later the Code was drafted. In a time where health and disability services are increasingly under pressure, the need for HDC and the Code to promote and protect the rights of people accessing services remains critical.

In preparing for this review, the team and I heard from many people with health and disability sector expertise that the Act and the Code are generally working well. However, we heard that some people and groups benefit more than others from these laws, and the Act and the Code should be updated to respond to the needs of all New Zealanders, particularly Māori and tāngata whaikaha | disabled people. We also heard that the Act and the Code should be updated to respond to changing service models and reflect modern expectations of complaint resolution, including to move towards people-centred approaches to complaint resolution and enabling greater levels of challenge to HDC decisions.

In this document I seek feedback on small changes to the Act and the Code that I believe will make a significant difference to the promotion and protection of the rights of all New Zealanders. Suggestions include broadening the purpose statement of the Act to support people-centred complaint processes; incorporating tikanga into the Code; strengthening the right to supported decision-making in the Code; and providing a statutory pathway to review HDC decisions in the Act.

I welcome your thoughts and feedback on the issues and suggestions set out in this document, as well as any other thoughts on how we can improve the Act and the Code and how they are applied. I will use your feedback to inform my report to the Minister of Health, and to support quality improvement.

I look forward to hearing your views.

Ngā mihi nui

**Morag McDowell**

Health and Disability Commissioner

# Acknowledgements | He whakamihi

In preparing this document HDC is grateful for the many wānanga (discussions), hui (meetings and workshops), and other contributions of consumer, provider and sector leaders and government agencies, as well as review of tikanga and use of te reo Māori.

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. Thank you.

We then had deeper engagements to understand the issues better and build suggestions for public feedback informed by sector knowledge. In particular, we are grateful to the rangatira (Māori leaders) and Māori health and disability sector leaders who generously shared 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, Maaka Tibble, Kahurangi Naida Glavish, Moe Milne, Keri Opai, Dr Claire Charters, Dr Maria Baker, Dr Huhana Hicky, 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.

We are similarly grateful to the lived experience leaders who shared their wisdom and guidance 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, Kim Robinson, Anne Wyrill, Rebekah Graham, Jenna Maguren, and Esther Woodbury); Te Tāhū Hauora | Health Quality and Safety Commission’s 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.

We are also grateful to the providers, consumers and other sector leaders who attended hui to shape **Topic 1 Supporting better and equitable complaint resolution** and **Topic 5 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.

We look forward to continuing dialogue with you all through public consultation to support HDC to develop recommendations to the Minister of Health.

# Introduction | He kupu whakataki

In this section we provide an overview of:

* The aim of this consultation document
* How to have your say
* Next steps
* Other relevant work.

## Aim of this consultation document

This consultation document provides information to help you make a submission on the review of the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumers’ Rights (the Code). A summary consultation document with accessible format translations is also available on our website: <https://review.hdc.org.nz>.

The Health and Disability Commissioner (HDC) is required by law to review the Act and the Code regularly and recommend to the Minister of Health what changes should be made.

These reviews are an opportunity to make sure the Act and the Code remain fit for purpose in promoting and protecting the rights of all New Zealanders accessing health and disability services.

This consultation document covers five topics where we think the Act and the Code can be improved. These are:

* Supporting better and equitable complaint 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.

To help us identify and develop these topics for public feedback, we engaged with a wide variety of organisations and individuals.

Overall, we heard that the Act and the Code are working well, but that there are concerns about the timeliness of complaint resolution and that some people and groups benefit less than others under the Act and the Code. Māori leaders told us that the Act and the Code needed to reflect what was important for Māori, including by giving practical effect to Te Tiriti o Waitangi. Tāngata whaikaha | disabled people told us that the Act and Code should do more to make sure services and complaints processes are accessible and support HDC to maintain an appropriate focus on the experiences of tāngata whaikaha | disabled people when accessing health and disability services. There was also recognition of the need to update the Act and the Code to align with the evolving health and disability system, new legislation, and modern expectations of complaint resolution.

While this consultation document may not cover every issue raised by stakeholders, it provides an opportunity for people to offer their views and suggestions for improving the Act and the Code.

## How to have your say

For each topic in this consultation document, we ask for your feedback on:

* Whether the main issues we are seeking to address have been covered;
* Our suggestions for changing the Act and the Code, and their potential positive and negative impacts; and
* Any other changes we should consider.

You can answer as many or as few of the questions as you wish. Appendix 1 sets out our consultation questions in one place.

You can give us your feedback in the following ways:

* Complete our online survey at <https://review.hdc.org.nz>;
* Download the survey at <https://review.hdc.org.nz> and send your completed form to review@hdc.org.nz or PO Box 1791, Auckland, 1140; and
* Send us your thoughts to the email or postal address above.

**Closing date for feedback is 5pm, Wednesday 31 July 2024.**

You can learn more about the consultation and consultation events on our website: <https://review.hdc.org.nz>. If you have any questions, you can:

* Email review@hdc.org.nz;
* Call or text 027 283 2219 or 6448975955 if you are using the New Zealand Relay Service [www.nzrelay.co.nz](http://www.nzrelay.co.nz); or
* Freephone 0800 11 22 33, available Monday to Friday 8.30am–6pm, to arrange for the review team to call you back.

## Official Information Act

Please note that any feedback you give us is official information under the Official Information Act 1982 (the OIA). Your feedback may be requested under the OIA and may need to be released.

If your feedback contains information that you believe should be withheld, please make it clear in your feedback what this content is and why you think it should be withheld. Any request for withholding information on the grounds of confidentiality or for any other reason will be determined in keeping with the OIA. Personal health information about identifiable individuals will generally be withheld due to the private and sensitive nature of this information.

## Draft wording to give effect to suggestions for the Code

Our Act requires us to consult on draft wording for the Code. Appendix 2 sets out a draft of revised Code wording to give effect to suggestions in this document. You can include feedback on draft revised Code wording when you respond to our questions.

It is essential for Code wording to be easy to understand and accessible. People need to understand their rights and providers need to understand their obligations. Rights must be able to be applied flexibly to respond to the circumstances, values, and cultural considerations of people accessing services, as well as to appropriate standards within different professions, and for different types of treatment. Flexibility ensures that the Code can be applied to all people equitably and remains responsive to change within the health and disability sectors.

## Next steps

Your feedback will help us create a report to the Minister of Health recommending changes to the Act and the Code. We will continue to work with the health and disability sectors in the preparation of this report, noting that the HDC is the final decision-maker.

Our report is due to the Minister of Health by 20 December 2024. The Minister must present a copy of our report to Parliament within 12 working days of receiving it. We will also provide a copy of the report to the Minister of Disability Issues and publish the report and summary of submissions on our website. It is up to the Minister of Health and the Government to determine whether to progress those recommendations.

While this review is about changes to the law, we recognise that many improvements can happen through changes in the way we do things. Your feedback on HDC and broader system issues will be shared with the Minister of Health in our report and within HDC and with relevant sector leaders to support quality improvement.

## Other relevant work

As we review the Act and the Code, we are thinking about related work and possible impacts for this project. This includes:

* Te Aka Matua o te Ture | The Law Commission’s review of adult decision-making capacity law; and published study paper *He Poutama* that examines tikanga Māori and its place in Aotearoa New Zealand’s legal landscape;
* The New Zealand Disability Strategy 2016–2026 and the Provisional Health of Disabled People Strategy 2023;
* The Manatū Hauora | Ministry of Health’s work to repeal and replace the Mental Health (Compulsory Assessment and Treatment) Act 1992; and review of the Health Practitioners Competence Assurance Act 2003;
* The Privacy Commissioner’s review of the privacy of children;
* The Royal Commission of Inquiry into abuse in State care;
* The Accessibility for New Zealanders Bill; and
* Whaikaha | Ministry of Disabled People engagement forums: Growing voice and safety.

We are mindful of the health sector principles set out in the Pae Ora (Healthy Futures) Act 2022 (Pae Ora Act) and its purpose, which is to –

* Protect, promote, and improve the health of all New Zealanders; and
* Achieve equity in health outcomes among New Zealand’s population groups, including by striving to eliminate health disparities, in particular for Māori; and
* Build towards pae ora (healthy futures) for all New Zealanders.

The Pae Ora Act also provides for a code of consumers’ expectations, overseen by Te Tāhū Hauora | Health Quality and Safety Commission, which supports consumer and whānau engagement in the health sector and the enabling of consumer and whānau voices to be heard.

#

# Words we use in this document | Ngā kupu ka mahia i tēnei tuhinga

In this section, we explain 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.

**Advocates and the Advocacy Service**

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.

**Consumer**

The word ‘consumer’ in this document means a person accessing 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.

We acknowledge that some people do not prefer this word. Where the word ‘consumer’ is not required for clarity, we say people accessing services and other terms such as tāngata whaikaha | disabled people and tāngata whai ora (see below).

We also acknowledge that some people and cultures approach decision-making collectively rather than as an individual. The Code enables people who can make decisions about their care to determine who their whānau and support people are when interacting with health and disability services and the extent to which they are involved. The concept of whānau is described below and explored further in **Topic 1 proposal c. Clarify the role of whānau.**

**Complaint**

The Code provides the right to complain about health and disability services. It 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.

**CRPD**

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is a human rights treaty. It focuses on identifying and removing social and physical barriers that stop disabled people from being fully included. This social and rights-based model of disability includes people with lived experience of mental distress and/or harm from substance use or gambling.

**Disability**

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 and/or harm from substance use or gambling.

The experience of disability is influenced by the nature of a person’s impairment. An individual’s experience of disability can be influenced by things like gender, age, ethnicity, and culture.

**Decision-making capacity and affected decision-making**

The Code currently uses the language ‘competence’ and ‘diminished competence’ to describe people’s ability to understand information, to make informed choices, and to give informed consent. This language is outdated. The Law Commission is using the terms ‘decision-making capacity’ and ‘affected decision-making’ in its review of adult decision-making. We propose in this document to update the Code using this wording.

We note that many things can affect a person’s decision-making capacity. People whose decision-making capacity is affected may need support to make decisions about their medical treatment, or may be unable to make a particular decision at a particular time, because they are unable to:

* Understand information relevant to the decision; or
* Retain such information; or
* Use such information to make the decision; or
* Communicate their decision in any way; or
* Make a particular decision because they are comatose or otherwise unconscious.

**Topic 3 Making the Act and Code work better for tāngata whaikaha | disabled people** outlines consumer rights where a person is assessed as having affected decision-making capacity and sets out proposals to clarify and strengthen these rights.

**Hohou te rongo**

Kia hohou te rongo. Hohou te rongo describes methods of resolving disputes using principles and values from te ao Māori (Māori worldviews).

Hohou te rongo is a newly implemented approach within HDC’s complaint management process facilitated by Māori. Hohou te rongo provides an opportunity for the nawe (wrong doings 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 rongo is conducted ā-kanohi (in person), either in the medium of te reo Māori, English, or both. Tikanga for the process is led by whānau.

**Hui ā-whānau**

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).

Hui ā-whānau is a new 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 takes place in te reo Māori, English, or both.

It is a process led by tikanga where whānau are the experts of their experience and are supported to decide what resolution looks like for them.

**Provider**

The word ‘provider’ in this document means a healthcare provider or a disability 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.

**Tāngata whaikaha | disabled people**

Tāngata whaikaha is a strengths-based description of disability meaning to have strength, to have ability, and to be enabled.

The term ‘disabled people’ is used by the New Zealand Disability Strategy. Many people prefer using identity-first language, ‘disabled people’, to express pride in their disability.

We 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 prefer other words. For example, many tāngata whaikaha who are Māori identify as Māori first, and many Deaf people identify as being part of the Deaf community and do not always identify as being disabled. Likewise, people with disabling mental health conditions may identify with communities with lived experience of mental distress or harm from substance use or gambling and not the disability community.

**Tāngata whai ora**

Tāngata whai ora means ‘people seeking wellness’ and can refer to people using mental health and addiction services.

**Te ao Māori**

Te aronga a te Māori ki tōna ao Māori. Te ao Māori is about Māori ways of thinking and seeing the world. It draws on mātauranga Māori (Māori knowledge, values, perspectives, creativity and practices).

**Te Tiriti o Waitangi | the Treaty of Waitangi**

At the heart of te Tiriti o Waitangi | the Treaty of Waitangi (te Tiriti | the Treaty) is the exchange of rights and responsibilities between the British Crown and Māori / tangata whenua (indigenous people of Aotearoa New Zealand).

Te Tiriti | the Treaty promised to protect Māori property and enable tangata whenua to live as Māori in Aotearoa New Zealand. At the same time, te Tiriti | the Treaty gave the British Crown the right to govern Aotearoa New Zealand and to represent all New Zealanders’ interests, including Māori. There is a te reo Māori version and an English version. The two texts are different, particularly in relation to matters of governorship and sovereignty in Articles 1 and 2.

**Tikanga**

He kupu ārahi i ngā mahi tika. Tikanga Māori (tikanga) are customary practices rooted in core beliefs, values and principles broadly shared among Māori and informed by 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 knowledge systems, values, and beliefs that locate tikanga in its natural environment. To try and understand tikanga outside of that framework risks it becoming de-contextualised and abstract, and distorting its meaning.[[1]](#footnote-1)

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.

**Whānau**

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 define their whānau for themselves when using health and disability services.

**Will and preferences**

The CRPD provides that a disabled person’s rights, will, and preferences are guiding principles for all support for, or exercise of, decision-making.

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.

#

# Overview of the Act and the Code | Tūhura whānui o te Ture me te Tikanga Mōtika

In this section we provide an overview of:

* The origins of the Act and the Code;
* The Code and your rights;
* The Act and the functions of HDC; and
* Complaint processes.

## Origins of the Act and the Code

The Act and the Code were created following what came to be known as the ‘unfortunate experiment’. In 1966 an unethical study led by Dr Herbert Green at National Women’s Hospital followed women with significant changes to their cervical cells without treating them properly. This occurred without the women’s knowledge or consent. Twenty years on, many had developed cervical cancer and some had died.

The study was exposed by journalists Sandra Coney and Phillida Bunkle. It sparked a formal inquiry in 1987 and 1988 into the treatment of cervical cancer at National Women’s Hospital. Judge Dame Silvia Cartwright led the ‘Cartwright Inquiry’, which identified significant and sustained failures in doctors’ ethical practices concerning respect, communication, information sharing, and obtaining informed consent.

Judge Cartwright recommended reforms to protect patients’ rights, including establishing:

* A legislated Code of Patients’ Rights;
* An independent Health Commissioner to consider and help resolve patients’ complaints, and to educate professionals on patients’ rights; and
* Independent patient advocates.

The Act and the Code were created in 1994 and 1996 respectively to bring Judge Cartwright’s recommendations to life. The Code sets the benchmark for a system of care with consumers at the centre of services. It doesn’t make new rights but brings together existing rights from different laws and treaties into one easy-to-understand place.

## The Code and your rights

Everyone who uses a health service or a disability service in Aotearoa New Zealand has rights as set out in the Code. The Code places corresponding duties on providers of health services and disability services. These rights can be enforced by the HDC as set out in the Act. These rights are summarised in English and in te reo Māori below:

1. Respect | Mana
2. Fair treatment | Manaakitanga
3. Dignity and independence | Tū rangatira motuhake
4. Appropriate standard of care | Tautikanga
5. Effective communication | Whakawhitiwhitinga whakaaro
6. Full information | Whakamōhio
7. Informed choice and consent | Whakaritenga mōu ake
8. Support | Tautoko
9. Teaching and research | Ako me te rangahau
10. Right to complain | Amuamu

You can watch an animated video about your rights and/or read the Code in full and in different languages on our website: [www.hdc.org.nz/your-rights/](http://www.hdc.org.nz/your-rights/).

### Application of the Code to children and young people, and people whose decision-making capacity is affected

The Code helps to make sure that everyone gets fair treatment, even if they’re young or their decision-making is affected.

The Code has a starting assumption that people can make informed choices and give informed consent to their treatment (Right 7(2)). Where a person’s decision-making is affected, they have the right to make informed choices and give informed consent to the extent of their decision-making ability (Right 7(3)). Right 7(4) sets out limited circumstances where third parties can make decisions for people. Legislation such as the Protection of Personal Property and Rights Act 1988 (PPPR Act) and the Mental Health (Compulsory Assessment and Treatment) Act 1992 can also override rights to informed consent in specific situations. In those situations, all other Code rights continue to apply.

For children and young people:

* Young people 16 years or older with capacity to make decisions can say yes or no to medical treatment just like adults can (Care of Children Act 2004).
* Children and young people under 16 years may still be able to decide about treatment depending on the type of treatment and the age and understanding of the child or young person. This is called ‘Gillick competence’ and requires an assessment of the person’s intellectual maturity and mental state to consent to that treatment.
* Where a child or young person under the age of 18 years is not able to consent, then consent may be given by a guardian of the child/young person, or where no guardian can be found, by a person in New Zealand who has been acting in the place of a parent (Care of Children Act 2004).
* If no one is available to provide consent, then the provider may provide services where it is in the consumer’s best interests, and other conditions in Right 7(4) have been satisfied.

For adults who are unable to provide consent:

* A person appointed under an Enduring Power of Attorney (EPOA) or a Welfare Guardian appointed by the Family Court can consent on behalf of the consumer (PPPR Act). There are limits to the types of the decisions that an EPOA or Welfare Guardian can make, eg, the person can’t be enrolled in a medical experiment unless to save their life or prevent serious harm to their health, and the EPOA or Welfare Guardian can’t refuse consent to standard medical treatment intended to save the person’s life or prevent serious harm to their health.
* Parents/guardians do not have the right to consent for their children over 18 years unless they are the EPOA or Welfare Guardian.
* If no one is available to provide consent, then the provider may provide services where it is in the best interests of the consumer, and other conditions in Right 7(4) have been satisfied.

Note that **Topic 1 — Supporting better and equitable complaint processes**seeks your feedback on clarifying the role of whānau in the Code; and **Topic 3 — Making the Act and the Code work better for tāngata whaikaha | disabled people** seeks your feedback on whether rights relating to supported decision-making and a consumer’s will and preferences should be strengthened in the Code.

## The Act and the functions of HDC

The Act sets up the HDC as an independent watchdog to promote and protect the rights of people using health and disability services, and to facilitate the fair, simple, speedy, and efficient resolution of complaints.

The functions of HDC as set out in the Act include to:

* Assess and resolve complaints about health and disability services;
* Provide an Advocacy Service to support people in resolving their complaints directly with the provider and spread awareness of the Code;
* Refer providers who are found in breach of the Code to the Director of Proceedings (an independent, statutory function), who then decides if legal action is needed; and
* Use insights from complaints to influence policies and practice across the health and disability system and educate people about the Code.

HDC contracts the National Advocacy Trust to provide the independent Advocacy Service. Advocates offer free help and support to people who are unhappy with a health or disability service. They can help sort out problems and guide people through the complaint process.

## The complaint process

Anyone can complain, either for themselves or someone else, if they think a person’s rights when using services aren’t being met. Complaints can be made directly to the provider, including with the help of the Advocacy Service, or to HDC. In the 2022/23 year, the Advocacy Service and HDC received over 24,000 enquiries and 6,000 complaints about health and disability services. This is in addition to complaints that were made directly to providers.

### Direct resolution between the parties, and the Advocacy Service

Usually, it’s best to resolve complaints directly with the provider, as often it’s quicker and simpler and can help to restore relationships that are ongoing. Providers must have processes to facilitate the fair, simple, speedy, and efficient resolution of complaints (Right 10 Right to Complain). If a person has made a complaint with a provider and is unhappy with the response, they can raise their concerns with the Advocacy Service or HDC.

Advocates can help people self-advocate and resolve issues with providers. They don’t decide whether there has been a breach of consumer rights. Advocates are trained in complaint resolution processes to achieve positive outcomes for consumers and develop professional and respectful working relationships with providers and consumers. You can read more about the Advocacy Service on their website: https//:www.[advocacy.org.nz](file://hdc-fps01/data%24/Review%20of%20Act%20%26%20Code%202023/Consultation%20document/advocacy.org.nz).

### HDC resolution pathways

HDC assesses each complaint carefully, considering the issues raised and the evidence available. Following assessment, HDC will decide on the most appropriate resolution pathway. HDC can:

* **Refer the complaint to the Advocacy Service, or the provider** for direct resolution between the parties. The Advocacy Service and providers must report to HDC on the outcome of these referrals, so HDC can ensure that people’s concerns have been addressed appropriately.
* **Refer the complaint to other** **agencies** where the issues raised are more appropriately dealt with by that agency — for example, issues related to a registered provider’s fitness to practise are often better dealt with by their regulatory authority, who can assess and, if necessary, restrict their ability to practise (which HDC cannot do).
* **Call a** **hui or mediation** involving the parties in the complaint. This resolution pathway has not been used very often in the past. Recently, HDC introduced the option of hui ā-whānau, which brings a te ao Māori approach to complaint resolution, and, if appropriate and all parties agree, can lead to hohou te rongo (dispute resolution led by tikanga).
* **Take no action or no further action** on a complaint where the initial assessment indicates that a formal investigation is not needed. The HDC can decide to take no further action on a complaint. For example, no further action may be taken where the care was appropriate or matters are being addressed through other processes. This pathway can include educational comments or recommendations to improve the quality of care or help resolve the complaint.
* **Investigate,** which can result in the provider being found in breach of the Code, as well as recommendations to improve services. Under the Act, the Commissioner may also investigate any aspect of care that appears to breach consumer rights, even if there hasn’t been a complaint.
* **Refer a provider to the Director of Proceedings** where the Commissioner has investigated the complaint and determined that the Code has been breached. The Director of Proceedings can take legal action when providers are referred to them by the HDC and there is public interest in doing so.

You can read more about our complaint process, and the factors we consider, on our website: <https://www.hdc.org.nz/making-a-complaint/complaint-process/>.

# Topic 1 — Supporting better and equitable complaint resolution | Kaupapa 1 — Te Tautoko kia pai ake te whakatatū amuamu, kia mana taurite hoki

In this section we set out and ask you questions about:

* Issues we have identified for **supporting better and equitable complaint resolution** and the case for change; and
* Suggestions for the Act and Code to address those issues.

## Issues

The primary goal of the HDC is to promote and protect the rights of people accessing health and disability services, and ‘to that end facilitate the fair, simple, speedy, and efficient resolution of complaints’ (section 6 of the Act).

‘Fair, simple, speedy, and efficient’ balances two aims. On the one hand, the early resolution of suitable complaints directly with the service provider. On the other hand, quality services for the public and proper accountability of providers through independent complaint resolution. HDC is charged with ensuring that the purpose of the Act is met as a whole and that this balance of interests is managed appropriately.

We are hearing that our complaint processes are not always working, and complaint resolution principles of ‘fair, simple, speedy, and efficient’ are not being met as well as they could be.

* There’s a call for more people-centred processes, including more effective communication, trauma-informed approaches, and culturally responsive resolution. There’s also a desire to focus on preserving and restoring relationships alongside considerations of public safety, accountability, and service improvement.
* Expectations for culturally responsive practice could be clearer and more inclusive, benefiting all New Zealanders by promoting understanding of rights and empowering individuals to raise concerns.
* Certain groups face barriers to accessing complaint resolution processes, particularly in ongoing provider–consumer relationships or in residential care settings because of a fear of damaging that relationship or impacting their ability to access care.
* Increased complaint numbers are impacting timeliness. While nearly 70 percent of complaints to HDC are closed within six months, the growing number of complaints is affecting assessment and resolution times. Delays can lead to increased stress for all involved parties and diminish the effectiveness of recommendations for quality improvement.

There is an opportunity to consider how the Act and the Code can be strengthened to support all New Zealanders to raise and resolve their concerns directly with the provider, where appropriate — in particular, through considering changes to Right 10 (Right to Complain) and best use of the Advocacy Service. Supporting self-advocacy and more effective use of direct resolution would enable HDC to concentrate on complaints that need our attention the most, improve communication and timeliness, and expand our use of culturally responsive resolution processes.

Enabling approaches such as restorative practice and hohou te rongo in complaint resolution can, in appropriate cases, support engagement, reduce the risk of further harm, and increase opportunities for healing, learning, and improvement.[[2]](#footnote-2) We note that Te Tāhū Hauora | Health Quality and Safety Commission encourages providers to use restorative practice and hohou te rongo in ‘adverse events’ (where harm has been caused because of health care).[[3]](#footnote-3)

### What we’re doing already

HDC is committed to continuous quality improvement of our processes, including a focus on making our complaint processes accessible for Māori, tāngata whaikaha | disabled people, Pacific peoples, and groups who experience inequitable outcomes in the health and disability system. Recent initiatives introduced by HDC include the following:

* Implementing hui ā-whānau and hohou te rongo options for complaint management where appropriate. HDC continues to explore the use of these options in complaint resolution;
* Strengthening our triage process to focus on equity, identification of systemic issues, and supporting early resolution where possible;
* Introducing surveys to see how we can improve how people (including providers) experience our process and to track the impacts of changes we make;
* Introducing clinical navigators to help guide people in the complaint process, assist them in understanding the care provided, and support early resolution where possible; and
* Introducing processes to fast-track complaints where possible and work more proactively with complainants and providers to achieve earlier resolution of more complex complaints.

### Question

* 1.1: Did we cover the main issues about **supporting better and equitable complaint resolution?**

## Legislative suggestions for change

We seek feedback on the following suggestions for changes to the Act and Code to support better and equitable complaint resolution for all New Zealanders.

### Amend the purpose statement of the Act

The current purpose statement (section 6 of the Act) is*:* ‘[T]o 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.’

While the Act’s purpose sets out principles for good complaint processes, it does not focus the HDC on the outcomes the Act and the Code should deliver for people. We have heard from people making complaints and providers that HDC too often focuses on processes rather than the people at the centre of the complaint.

Broadening the principles for complaint resolution in the purpose statement to include a focus on outcomes for people would create a different balance of interests for the HDC to manage.

We want to hear from you whether the purpose statement should be broadened, and if so, what words should be used. The most common suggestion we heard was to incorporate the concept of upholding mana into the purpose statement. Mana (one’s dignity and authority) is a concept from te ao Māori that describes a spiritual force or power that resides in all people(s), in objects, or the environment, and includes respect and autonomy. See also Topic 2, proposal **a. More explicitly incorporate tikanga into the Code** about incorporating the concept of mana into the Code.

An example of where ‘mana’ is in legislation is the purpose statement of the Substance Addiction (Compulsory Assessment and Treatment) Act 2017, which includes to ‘protect and enhance [the person receiving compulsory treatment’s] mana and dignity…’.Implementation of this legislation was supported by workforce guidance and training.

### Clarify cultural responsiveness

Right 1(3) provides that ‘[e]very consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori’.

While Right 1(3) sets important expectations for culturally competent services, we heard that it isn’t very clear. It also doesn’t reflect modern language or understanding of cultural responsiveness. It is unclear whether tāngata whaikaha | disabled people and groups with cultural identity, such as the LGBTIQA+ community, are included; it doesn’t reflect that people hold multiple identities; and the placement of Māori at the end is ‘othering’, reading as an afterthought.

We propose rewording the Code, alongside sector guidance, so that Right 1(3) is inclusive and sets expectations of cultural responsiveness that align with sector standards. We believe such a change would strengthen equity in the Code and support all communities to understand their rights.

Modern understandings of cultural responsiveness include acknowledging the right of Māori to bring te ao Māori (Māori worldviews) to health and disability services; and the importance of values such as respect, service, leadership, family, belonging, and relationships within Pacific cultures. Cultural responsiveness also recognises the culture, language, needs, values, and beliefs of groups such as tāngata whaikaha | disabled people, people from LGBTQIA+ communities, as well as people from diverse ethnic groups.[[4]](#footnote-4) Culturally safe services include providers being committed to addressing and holding themselves accountable to any of their own biases, attitudes, and structures and their impact on the quality of services provided.[[5]](#footnote-5)

### Clarify the role of whānau

The rights in the Code are based on the direct relationship between an individual consumer and a provider. Code rights do not extend to whānau. It is possible that such an extension could, in some cases, be against the wishes of the individual consumer and breach their privacy and cause them unwanted stress.

The Code provides rights for individuals to have support people and whānau involved in their care at the consumer’s discretion, including explicitly providing consumers with the right to support (Right 8). Other rights in the Code also support including whānau where appropriate, eg, it is often an expected standard of care (Right 4(1)), it can be culturally appropriate (Right 1(3)), and it can be essential for effective communication (Right 5).

For many people, the involvement of whānau in all aspects of their care, including decision-making, is an important aspect of who they are and how they want to interact with health and disability services. It is the lived experience of many tāngata whaikaha | disabled people that whānau are central to enabling them to live the lives they want and to fully participate in their care. It is equally important that tāngata whaikaha | disabled people maintain their autonomy to determine when, and to what extent, whānau are involved. Similarly, whānau engagement, where wanted, is associated with better outcomes for tāngata whai ora.

Within te ao Māori, decision-making is often communal, drawing on the principles of whakapapa (genealogical ties) and whanaungatanga (familial kinships). For many Pacific and Asian cultures, decision-making is also traditionally made within a collective rather than individually.

For children and young people, the involvement of a parent or caregiver may be necessary or helpful to provide consent. Under the law, people can consent or refuse to consent when they are 16 years of age. However, this does not prevent them from giving consent when they are younger, depending on the nature of the treatment and their intellectual maturity.

While the Code allows for people to have their whānau involved in their care to the extent determined by the person, we are hearing that how this works in practice is poorly understood.

Therefore, we propose changes to the Code, supported by guidance, to clarify the role of whānau in the consumer–provider relationship and to help providers to enable whānau participation appropriately. We propose:

* Changing the wording in Right 3 (Dignity and Independence) from ‘independence’ to ‘autonomy’ to recognise the interdependence people often have with whānau and support networks;
* Strengthening Right 8 (Support) to include the right to have whānau involved even where they cannot be present physically; and
* Clarifying Right 10 (Right to Complain) to explicitly allow for complaints to be made by support people on behalf of the consumer.

### Ensure gender-inclusive language

Currently, the Code uses the language ‘him or her’ to describe people in the Code. We propose changes to update the language in the Code to be gender-inclusive, making it more accessible to all people.

### Protect against retaliation

We heard that there may be barriers to making a complaint because of concern that it may negatively affect a person’s ongoing relationship with their provider or impact their access to care. This is particularly the case where people are reliant on the care provided, for example, disabled or older people in residential facilities, people who are reliant on home carer support (including where the carer may also be a family member), and people who require strictly controlled medications such as for opioid substitution treatment.

Currently, Right 10 does not explicitly protect consumers from retaliation from providers. However, people’s right to complain does not end once they have made the complaint, and the Code does provide for other rights that would protect against retaliation where a complaint has been made. This includes the right to be treated with respect (Right 1), freedom from discrimination, coercion, harassment, and exploitation (Right 2), and services of an appropriate standard (Right 4).

We propose changes to the Code to include a non-retaliation clause in Right 10 (Right to complain) to support people to feel safe to raise concerns and complain. An example of a non-retaliation clause in legislation is section 22 of the Protected Disclosures (Protection of Whistleblowers) Act 2022. This prevents a person (A) from treating, or threatening to treat, another person (B) less favourably because of a protected disclosure.

### Clarify provider complaint processes

We heard from people making complaints and from providers that the processes and timeframes for providers to respond to complaints set in Right 10 (Right to Complain) are overly prescriptive and confusing. There may be an opportunity to streamline Right 10 and include principle-based direction to provide more clarity and responsiveness.

Providers often relay their frustration that complaints to HDC could have been better resolved directly between the person and their provider. However, feedback from consumers and whānau suggests that often providers’ complaint processes are invisible or unclear. We heard that by comparison, the visibility of HDC’s posters encourages people to come to HDC first. It’s important for providers to communicate how to use their complaint process to support people to uphold their right to make complaints and to encourage early resolution.

We propose changes to Right 10 to simplify and set clearer expectations for provider complaint processes, including promoting the right to complain.

### Strengthen the Advocacy Service

The Advocacy Service assists to mitigate the power imbalance between people and providers by supporting people to self-advocate and resolve their concerns directly with providers. The Advocacy Service also helps in raising people’s awareness of their rights under the Code.

The Act sets out the functions of advocates and provides for HDC to appoint an independent Director of Advocacy, who oversees and contracts the Advocacy Service. The Act also provides for HDC to make guidelines to direct how the Advocacy Service should operate. The role of the Advocacy Service set out in the Act includes to promote the Code and resolution options for complaints; to help consumers with informed consent; and to help consumers make complaints and to seek resolution with providers.

We want to hear from you what opportunities there may be to strengthen the role of the Advocacy Service to better meet the needs of people and communities, and support collaboration with HDC.

### Improve the language of complaint pathways in the Act

We heard that the language of complaint resolution pathways to take ‘no further action’ and ‘mediation conference’ are confusing.

‘No further action’ has been described as a disempowering description and not reflective of the work that is undertaken to assess and resolve the complaint. We seek feedback on rewording, for example to ‘no investigative action’ to support more effective communication with complainants.

The process of ‘mediation conference’ is specifically prescribed in section 61 of the Act, and it has been suggested that this does not allow for a flexible resolution response to the needs and circumstances of those involved in a complaint. We seek feedback on using different language such as ‘facilitated resolution’ to capture other forms of resolution such as conciliation, and to explicitly recognise and provide for resolution practices from a te ao Māori perspective.

### Questions

* 1.2: What do you think of our suggestions for **supporting better and equitable complaint resolution**, and what impacts could they have?
* 1.3: What other changes, both legislative and non-legislative, should we consider for **supporting better and equitable complaint processes**?

# Topic 2 — Making the Act and the Code effective for, and responsive to, the needs of Māori | Kaupapa 2 — Ka whakaritea Te Ture me Te Tikanga kia mauritau atu, kia urupare atu hoki ki ngā matea o te Māori

In this section we set out and ask questions about:

* Issues relating to **making the Act and the Code Effective for, and Responsive to, the Needs of Māori** and the case for change; and
* Suggestions for the Act and the Code to address those issues.

## Issues

We’re focusing on making the Act and the Code more effective for, and responsive to, the needs of Māori to improve the experiences and outcomes of Māori in the health and disability system. Our complaints data and initial feedback suggest that Māori are not equitably benefiting from the Act and the Code. Māori engage less with HDC and the Advocacy Service than we would expect given what we know about the experiences of, and outcomes for, Māori in the health and disability sector.

We’ve heard from Māori that promotion of the Code is not reaching their communities, and when it does, many perceive that Code rights and complaint processes are not designed for them. The reasons given for this vary and include that:

* Universal approaches to promote the Code are not resonating with Māori;
* Experiences of racism and cultural bias in the health and disability system are leading to low levels of trust and confidence in complaint processes;
* Complaint processes and interpretation of rights often do not reflect te ao Māori values and tikanga; and
* Provisions to give practical effect to te Tiriti | the Treaty are largely absent from the Act and the Code.

Making the Act and the Code effective for, and responsive to, the needs of Māori will support the Crown to honour its obligations under te Tiriti | the Treaty, and contribute to:

* Greater knowledge and awareness by Māori of their rights under the Code;
* Greater understanding and protection of Code rights from te ao Māori worldviews, to the benefit of all people accessing health and disability services;
* An equitable space for Māori to raise concerns and make complaints;
* Better complaint processes that uphold the mana of all people; and
* Better outcomes for Māori using health and disability services.

### What we’re doing already

In addition to recently introducing hui ā-whānau and hohou te rongo as options within complaint resolution, HDC has established a Director Māori role on our leadership team. Our Director Māori, along with a small team, helps HDC to be more responsive to the needs of Māori, enhances provider capability address health equity for Māori, and works to raise awareness of HDC in Māori communities.

### Question

* 2.1: Did we cover the main issues about **making the Act and the Code more effective for, and responsive to, the needs of Māori?**

## Legislative suggestions for change

We want to hear your thoughts on our suggestions for changing the Act and the Code to be effective for, and responsive to, the needs of Māori.

### Incorporate tikanga into the Code

The te reo Māori translation of the Code was developed and consulted on alongside the original draft and identifies matters of tikanga in relation to consumer rights, including Mana (Right 1 — Respect), Manaakitanga (Right 2 — Fair treatment), and Tū rangatira motuhake (Right 3 — Dignity and independence). However, while the use of tikanga in the te reo Māori translation helps people to understand and apply the English language Code, they are subject to interpretation and the cultural competence of providers, HDC decision-makers, and Tribunals.

Introducing tikanga into the Code would:

* Enable Māori to see rights expressed in a way that is meaningful to Māori;
* Support providers to substantively understand and uphold Māori rights; from a te ao Māori perspective;
* Strengthen relationships with, and outcomes for, Māori consumers; and
* Enable all New Zealanders to benefit from a te ao Māori understanding of rights.

Legislative protections, education, and guidance would need to be put in place to ensure true interpretations of mātāpono (principles, values, and tikanga) and support provider understanding. This could include:

* Workforce training;
* Building the cultural competence of HDC, the advocacy service, and providers;
* Legislating for Māori leadership in the Act and developing guidance to interpretation/good practice.

HDC could also explore relationships with iwi and Māori organisations to share oversight of interpretation from a national perspective, or by partnering with local hapū and iwi to apply mātauranga Māori ā-hapū, ā-iwi (knowledge and custom particular to a hapū or iwi). Legislative protections are explored further in **suggestion** **b.** below.

We have sought guidance from rangatira and Māori leaders in the health and disability sector on the relationship of tikanga to Code rights. We heard that the application of tikanga to Code rights would give whānau a voice — ‘every service provider would need to understand the Code from a Māori perspective and give quality service for whānau’ (workshop participant). In relation to the tikanga we should consider for the Code, we heard that the te reo Māori translation of the Code is a good source, and that there are many intersecting mātāpono to consider.

Tikanga most commonly identified as being particularly relevant to the Code and complaints resolution processes are set out below, alongside a description of that concept or value in te reo Māori, where appropriate, and an English translation. We are mindful that mātāpono and tikanga are interconnected and ‘that no aspect of tikanga can be properly understood in isolation from tikanga as a whole … Singling out specific principles, and briefly summarising them, cannot fully convey their significance or relevance.’[[6]](#footnote-6)

* **Aroha.** Ko te pū, te kē me te hā | Encompasses the concept of unconditional love, compassion, sympathy, and empathy.
* **Hara.** He kupu mō ngā hē o tētahi tangata/ētahi tāngata | The wrong doings of a person(s).
* **Ihi, wehi, and wana.** Te putanga ki waho o ngā kare ā-roto o te tangata | the connection between te taha tinana (physical being) and te taha wairua (spiritual realm), the tangible and the intangible, the potential, and the realisation of potential. Ihi does not exist in isolation and is the felt effect that begets wehi, that begets wana.
	+ **Ihi** — energy within that is ignited by what is seen, heard, and felt.
	+ **Wehi** — the emotional reaction that acknowledges ihi.
	+ **Wana** — the collection of energy that unites and connects people to the environment and people to kaupapa | purpose.
* **Mana.** Kei ia tangata tōna ake mana | A spiritual force or power that resides in all people(s), in objects, or the environment, that includes respect and autonomy.
* **Manaakitanga.** He kupu mahi hei whakatinana, he manaaki tangata, manaaki kaupapa | The action of caring and supporting someone or something.
* **Mauri**. He mana motuhake nō Io. The life force, vital essence, essential quality and vitality of a being or entity. Also applies to a physical object, individual, ecosystem or social group in which this life force/essence is located.
* **Noa.** Kāore ōna tapu| The realm clear of sacredness, prohibitions, or restrictions.
* **Tapu.** He tapu ngā mea katoa | All things within te ao Māori have tapu. Tapu represents sacredness, reverence, and prohibition. It encompasses spiritual and cultural boundaries that dictate appropriate behaviour and respect for both natural and supernatural elements.
* **Wairua.** Spiritual essence connecting individuals to the divine, ancestors, and the natural world.
* **Whānau.** He herenga tangata, herenga whakapapa | Family inclusive of parents, carers, guardians, grandparents, aunts, uncles, siblings, cousins, etc, and can also include close familial-type relationships between people.
* **Whakanoa.** He mahi hei hiki i te tapu | The process of creating safe spaces.
* **Whakawhanaungatanga.** He tikanga tuitui i te tangata, i te ara whanaunga. | A process of bringing people together by way of engagement, establishing relationships and relating well to others.
* **Whanaungatanga.** Denotes relationships. Relationships in te ao Māori are everything — between people, between people and the physical world, and between people and the atua (spiritual entities). Whanaungatanga creates a sense of unity. It embodies the understanding that individuals are part of a collective who work together to make decisions and act in ways that support the betterment of the whānau.

We’ve heard so far that if we were to incorporate only one element of tikanga, then ‘mana’ encapsulates the essence of other elements and would have the strongest impact. We therefore propose, as a starting point for feedback, to add to Right 1 of the Code (Respect) that every consumer has the right to have their mana upheld. We want to hear from you whether tikanga should be incorporated into the Code, and if so, how?

### Give practical effect to te Tiriti o Waitangi | the Treaty of Waitangi in the Act

When te Tiriti | the Treaty is honoured, it paves the way for Māori to thrive. Currently, the Act gives little practical effect to te Tiriti | the Treaty. There’s no reference to te Tiriti | the Treaty in the Act and the only consideration of Māori is in relation to the HDC’s qualifications for appointment — the Minister must have regard to a person’s ‘knowledge and recognition of the aims and aspirations of Māori’ when considering whether a person is qualified for appointment to the role of HDC (section 10(f)).

The absence of provisions giving practical effect to te Tiriti | the Treaty in the Act means that HDC’s responsiveness to the needs of Māori relies on the discretion of the Commissioner of the time. It also means that there are no legislated safeguards to make sure that the application and interpretation of te ao Māori values and tikanga occurs in a culturally safe way.

Guidance prepared by Te Arawhiti (Office for Crown–Māori Relations) states that there is no one-size-fits-all wording for provisions that uphold the Crown’s obligations under te Tiriti | the Treaty. It identifies two general approaches for legislation:[[7]](#footnote-7)

* **Operative/general Tiriti | Treaty clauses** — these clauses require decision-makers under the Act to place a particular statutory weighting on, or act in accordance with Tiriti | Treaty principles. The responsibility for interpreting these clauses sits with statutory decision-makers and ultimately the courts. This may be appropriate where discretion is delegated to decision-makers, eg, the Urban Development Act 2020 — ‘In achieving the purpose of this Act, all persons performing functions or exercising powers under it must take into account the principles of the Treaty of Waitangi (Te Tiriti o Waitangi).’
* **Descriptive/specific Tiriti | Treaty clauses** — these clauses expressly reference the Crown’s Tiriti | Treaty responsibilities, in a generalised way, and describe how these are given effect to in the Act. The descriptive approach provides greater certainty for decision-makers than the operative clause, but it can be less flexible in application. The effectiveness of descriptive clauses depends on their ability to address Tiriti | Treaty interests.

Suggestions for descriptive/specific Tiriti | Treaty provisions in the Act, ordered by the Articles of te Tiriti | the Treaty are set out below. [[8]](#footnote-8) Suggestions may relate to more than one Article.

* **Preamble: suggestions to ensure that te Tiriti | the Treaty is central and Māori are equal parties in policy development**
	+ Add a Tiriti | Treaty clause (**new Section**). This option had been recommended by previous Commissioners.
	+ Amend the long title of the Act, eg, to provide for the recognition of the Crown’s obligations under te Tiriti | the Treaty, 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.**
	+ 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 Pae Ora Act requires the Board to collectively have *‘*knowledge of, and experience and expertise in relation to, te Tiriti o Waitangi (the Treaty of Waitangi), tikanga Māori, mātauranga Māori, kaupapa Māori services, and cultural safety and responsiveness of services’.
	+ Require the appointment of a Deputy Health and Disability Commissioner Māori (new subsection in **section 9 Deputy Commissioners**). Note that until the establishment of the Mental Health and Wellbeing Commission there was the Deputy Commissioner role of Mental Health Commissioner.
	+ 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.**
	+ 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.
	+ Amend **Section 61 Mediation conference** to explicitly refer to hohou te rongo/hui 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 theRitenga Māori declaration[[9]](#footnote-9)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.**
	+ Functions of the Director of Advocacy to include promotion of equitable outcomes for Māori and all consumers (**section 25 Functions of Director of Advocacy)**.
	+ Addition to **Section 25 Functions of Director of Advocacy** to include promotion of advocacy services to Māori and other communities to ensure equitable access.
	+ Amend **Section 30 Functions of advocates** to explicitly respond to the needs of Māori and promote and provide for processes led by the tikanga of the whānau where appropriate.
	+ Review and amend the legislative process for assessing complaints to enable and better align processes with tikanga **(Part 4 Complaints and Investigations, Sections 31–49,** and specifically **sections 33 preliminary assessment, 38 taking no action** and **40 investigation)**.

### Questions

* 2.2: What do you think of our suggestions for **making the Act and the Code more effective for, and responsive to, the needs of Māori**, and what impacts could they have?
* 2.3: What other changes, both legislative and non-legislative, should we consider for **making the Act and the Code more effective for, and responsive to, the needs of Māori**?

# Topic 3 — Making the Act and the Code work better for tāngata whaikaha | disabled people | Kaupapa 3 — Kia tika Te Ture me Te Tikanga mō ngā tāngata whaikaha

In this section we set out and ask questions about:

* Issues in relation to **making the Act and the Code work better for tāngata whaikaha | disabled people**and the case for change; and
* Suggestions for the Act and the Code to address those issues.

## Issues

We are focusing on making the Act and the Code work better for tāngata whaikaha | disabled people to reflect modern understandings of disability rights. Since the Act and the Code were first developed nearly 30 years ago, there have been shifts in understanding of the rights of tāngata whaikaha | disabled people and changes to supports and services, including in relation to mental health and addiction.

* The New Zealand Government ratified the CRPD;
* Addiction was recognised as a health issue (National Drug Policy 2015–2020);
* The New Zealand Disability Strategy 2016–2026, Enabling Good Lives and the provisional Health of Disabled People Strategy were published. These guide positive change for disabled people, families, communities, and governance structures;
* Whaikaha | Ministry of Disabled People was established and has taken over responsibility for government-funded disability services;
* The Law Commission is reviewing adult decision-making capacity law; and
* The Ministry of Health is looking to repeal and replace the Mental Health (Compulsory Assessment and Treatment) Act 1992.

Over 25 percent of the complaints received by HDC are about care provided to tāngata whaikaha | disabled people. We are hearing from tāngata whaikaha | disabled people that:

* The language relating to disability in the Act and the Code is outdated;
* The promotion of the Code and HDC’s complaints processes are not always accessible;
* Some Code rights could be clarified and strengthened, particularly in relation to accessibility and support to make informed choices and provide informed consent; and
* The Act could also provide for greater consideration of disability issues in HDC functions.

We are also seeking feedback on the initial findings of a review we undertook in 2019. This review looked at whether there are circumstances where adults who are unable to give consent should be able to participate in research and, if so, what safeguards should be in place. While changes to the Code could open opportunities for health and disability service advancements, they must not lessen rights held by tāngata whaikaha | disabled people and others unable to consent.

We believe that making the Act and the Code work better for tāngata whaikaha | disabled people would support the Government to uphold its commitments under the CRPD, and contribute to:

* Greater knowledge and awareness by tāngata whaikaha | disabled people of their rights under the Code;
* Greater understanding and protection of rights to accessibility and supported decision-making in the Code;
* An equitable space for tāngata whaikaha | disabled people’s voices to raise concerns and make complaints; and
* More equitable outcomes for tāngata whaikaha | disabled people accessing health and disability services.

### What we’re doing already

Traditionally, HDC has had a Deputy Commissioner Disability with a particular responsibility for ensuring that HDC is accessible and responsive to tāngata whaikaha | disabled people, and a dedicated delegation for mental health and addiction complaints. The Deputy Commissioner Disability liaises closely with Whaikaha (Ministry of Disabled People) to share information in circumstances where there is a risk to the immediate safety and wellbeing of disabled people, and where there is an opportunity to take a timely, collaborative approach to systemic concerns within the disability sector.

HDC has statutory relationships with the Director of Mental Health and Addiction and te Hiringa Mahara | the Mental Health and Wellbeing Commission. The recently established Aged Care Commissioner within HDC has enhanced our focus on engagement with, and responsiveness to, older people, who are more likely to be disabled than any other community.

We’ve been improving our data collection to better analyse and report on tāngata whaikaha | disabled people’s concerns and their experience of mainstream health services and disability support services. Because of trends we’ve seen in complaints, we’re undertaking thematic analysis of people’s experiences in disability support services and opioid substitution treatment.

We’re reviewing and refreshing our resources to ensure that they remain accessible, modern, and culturally appropriate. We’re also listening to feedback from our experience survey to improve HDC’s accessibility and responsiveness. A particular focus is on hearing from people who have a harder time making their voices heard, including people in residential services.

### Question

* 3.1: Did we cover the main issues about **making the Act and the Code work better for tāngata whaikaha | disabled people**?

## Legislative suggestions for change

We’re seeking feedback on the following suggestions for the Act and the Code to work better for tāngata whaikaha | disabled people. We are also seeking feedback on HDC’s draft 2019 recommendations relating to unconsented research.

### Strengthen disability functions within the Act

Currently, the Act:

* Includes an understanding of the various needs of disability services consumers as a qualification of appointment to the role of Commissioner; and
* Requires that the Commissioner establish and maintain links with representatives of disability services consumers.

Adding a legislated role focused on disability issues could strengthen oversight of complaints from a disability perspective, enhance HDC’s focus on the rights of tāngata whaikaha | disabled people, and support trust in, and engagement with, HDC.

In addition, HDC’s ministerial reporting is only to the Minister of Health. Adding a requirement to also report to the Minister for Disability Issues could strengthen HDC’s ability to promote and protect the rights of tāngata whaikaha | disabled people using health and disability services.

### Update definitions relating to disability

The definitions of ‘disability services’ and ‘disability services provider’ in the Act are broad and cover a range of services that enable tāngata whaikaha | disabled people to live good lives. Disability services include whānau as carers where there is an employer/employee or contractual relationship for services.

While these definitions do not cause problems for HDC to apply, we’ve been told that the language in them reflects outdated concepts of disability. Modern concepts of disability recognise that ‘disability is something that happens when people with impairments face barriers in society; it is society that disables us, not our impairments’.[[10]](#footnote-10)

Current definitions in the Act relating to disability are set out below.

* **Disability services** includes goods, services, and facilities — (a) provided to people with disabilities for their care or support or to promote their independence; or (b) provided for purposes related or incidental to the care or support of people with disabilities or the promotion of independence of such people.
* **Disability services provider** means any person who provides, or holds himself or herself or itself out as providing, disability services.
* **Disability services consumer** means any person with a disability that — (a) reduces that person’s ability to function independently; and (b) means that the person is likely to need support for an indefinite period.

We want to hear from you how the Act’s definitions relating to disability could be changed to be strengths-based, affirming, and aligned with the CRPD.

### Strengthen references to accessibility

The CRPD sets expectations that tāngata whaikaha | disabled people can access services on an equal basis as others. Currently, the Code provides for accessibility in several ways.

* **Effective communication:** Right 5(1) gives people the right ‘to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.’ Right 5(2) gives the right to an environment that enables communication to happen ‘openly, honestly and effectively’.
* **Appropriate standard of service provision:** Right 4(3) gives people the right ‘to have services provided in a manner consistent with his or her needs’.
* **Cultural safety:** Right 1(3) gives people the right to ‘be provided with services that take into account the needs, values, and beliefs of different … groups …’.
* **Freedom from discrimination:** Right 2 gives the right to freedom from discrimination as defined in the Human Rights Act 1993, which includes disability as a prohibited ground for discrimination.
* **Dignity and independence:** Right 3 gives the right to ‘have services provided in a manner that respects the dignity and independence of the individual’.
* **Support:** Right 8 gives people the right to one or more support people of their choice to be present, except where it may compromise safety or unreasonably undermine another consumer’s rights.

We propose changes to the Code to explicitly reference accessibility in Right 5 (Effective Communication); and in Right 10 (Right to Complain) to strengthen the right to accessible services in the Code.

We also propose removing the words ‘and reasonably practicable’ in Right 5 in relation to the right to a competent interpreter. Clause 3 (Provider Compliance) of the Code already recognises that where a provider has taken reasonable actions in the circumstances to meet rights under the Code then a provider is not in breach. Resource constraints can be considered. The additional limitation of ‘and reasonably practicable’ in Right 5 regarding interpreters is redundant and risks being interpreted by providers as a lesser obligation than other rights.

### Strengthen and clarify the right to support to make decisions

Being able to make the same legal decisions as everyone else and have choice and control over their lives is a cornerstone of human rights and the CRPD. Where tangata whaikaha | a disabled person cannot make an independent decision, a supported decision-making process should be used.

The Code currently implies that a person should be supported to make decisions about their care to their fullest decision-making ability. Right 7 (Informed Choice and Consent) includes a starting point that every person is presumed to be able to make decisions about their care (Right 7(2)); that that right is retained to the extent of that person’s decision-making ability (Right 7(3)); and that even where a person is not able to make decisions, services must be provided consistently with that person’s views where they can be known (Right 7(4)), including through the use of advance directives (Right 7(5)).

We acknowledge that supported decision making is a developing practice, and good-practice guidance, education, and resourcing would support providers to put this Right into practice alongside strengthened wording in the Code. We propose changes to:

* Strengthen Right 5 (Effective Communication) in the Code to explicitly reference the right for people to have support to understand information;
* Update the language in Right 7 (Informed Choice and Consent) relating to ‘competence’ and ‘incompetence’ to decision-making capacity and affected decision-making in line with the approach of the Law Commission’s review of adult decision-making capacity law;
* Strengthen Right 7(3) to reference the right to receive support to make decisions;
* Update the language in Right 7(4) from consumers’ ‘views’ to ‘will and preferences’ in alignment with the language of the CRPD; and
* Strengthen Right 7(4)(c)(ii) to ensure that the will and preferences of consumers who will never have legal decision-making capacity are taken into account.

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

Currently health and disability research involving adults unable to consent must, among other things, be in that person’s ‘best interests’ as required by Right 7(4) of the Code. While this is an important safeguard for vulnerable people, there is a view that it is an unworkable test because, prior to the outcome of research being known, it is impossible to determine whether it is in a person’s best interests. The ‘best interests’ test also creates barriers to potentially valuable low-risk research with the result that some groups of people could be missing out on improvements and progress in health and disability service care.

In 2019 following public consultation, including 154 submissions on a discussion document, HDC made draft recommendations to the then Minister of Health to change the rules for health and disability research involving adult participants who are unable to provide informed consent.

The 2019 review concluded that some health and disability research that is not currently permitted should be allowed, in order to build greater knowledge of certain conditions and to improve treatment and services for groups affected by those conditions. However, this should apply only in limited circumstances with very robust safeguards in place, including that:

* The ‘best interests’ test in Right 7(4) of the Code be confined to the provision of treatment and services, and a different test be applied to research of **no more than minimal foreseeable risk and no more than minimal foreseeable burden**;
* Suitable persons interested in the welfare of the person be able to veto their participation in the research; and
* Specialist ethics committees would oversee such research.

Following the 2019 review, the National Ethics Advisory Committee (NEAC) has implemented all but one of the recommendations directed towards it to strengthen specialist ethics committee oversight for research where a person is unable to consent. The outstanding recommendation relates to defining ‘minimal foreseeable risk and minimal foreseeable burden’. The NEAC standards currently define minimal risk as ‘research in which the probability and magnitude of harms in research are not greater than the probability and magnitude of harms ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests’.

What we’ve heard so far, as a generalisation, is that people with a research interest have tended to either be supportive of the recommendations or concerned that they do not allow for enough research to proceed. Tāngata whaikaha | disabled people and whānau have tended to be cautious of any proposed increase in the threshold for unconsented research and of the ability of specialist ethics committees to consider disability interests adequately. We note that HDC’s recommendations did not include a requirement for representation of people with lived experience of disability on the specialist ethic committees.

We would like to know what you think of the HDC’s 2019 recommendations regarding unconsented research, and any suggestions you may have for improvement.

You can read the full 2019 report at: <https://tinyurl.com/unconsented-research>.

### Questions

* 3.2: What do you think of our suggestions for **making the Act and the Code work better for tāngata whaikaha | disabled people**, and what impacts could they have?
* 3.3: What other changes, both legislative and non-legislative, should we consider for **making the Act and the Code work better for tāngata whaikaha | disabled people**?

# Topic 4 — Considering options for a right to appeal HDC decisions | Kaupapa 4 — Kia whakaaro kōwhiringa mō tētahi mōtika hei pīra i ngā whakatau a te HDC

In this section we set out and ask questions about:

* Issues relating to **considering options for a right to appeal HDC decisions**; and
* Suggestions for strengthening pathways to challenge HDC decisions.

## Issues

The Health Select Committee asked HDC to seek feedback on options for a right of appeal to HDC decisions following a petition in 2022.[[11]](#footnote-11) The petitioners argued that there are limited options to challenge HDC decisions, and that introducing a right to appeal HDC decisions would better promote and protect the rights of people using health and disability services.

It's a principle of good law that where an agency such as the HDC makes a decision affecting a person’s rights or interests, ‘that person should generally be able to have the decision reviewed in some way. The ability to review or appeal a decision helps to ensure that those decisions are in accordance with the law. Also, the prospect of scrutiny encourages first-instance decision makers to produce decisions of the highest possible quality.’[[12]](#footnote-12)

Currently, if a person (complainant or provider) is dissatisfied with the outcome of an HDC decision, they can:

* Ask the HDC to review the decision. The decision to review a closed file is at the discretion of the HDC;
* Lodge a complaint with the Ombudsman. The Ombudsman’s review is free for people to access and will focus on procedural fairness (whether the decision was reasonable and made in accordance with the law). While the Ombudsman can look into the reasons for the decision, the Ombudsman would not substitute a fresh decision or remake findings of fact or law. However, the Ombudsman can make recommendations to the HDC for reconsideration of the matter; or
* Seek judicial review in the High Court. Similar to an Ombudsman review, in a judicial review a judge will look at whether the decision was made in accordance with the law. The judge won’t usually decide whether the decision was the ‘right’ decision.

In addition, where a matter has been investigated by the HDC and results in a ‘breach’ finding, then HDC can refer the matter to the Director of Proceedings (DP) for prosecution in the Health Practitioners Disciplinary Tribunal (HPDT) and/or the Human Rights Review Tribunal (HRRT).[[13]](#footnote-13) 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.

The Legislative Design Advisory Committee (LDAC) advises that relevant factors for assessing the value of an appeal right include:

* The scope of appeal rights;
* Potential costs and impacts of delay, which can be dealt with by limiting the right of appeal rather than denying it completely;
* The need for finality; and
* The expertise of the initial decision-maker.

LDAC guidance suggests that where there is a specialist statutory office holder such as the HDC empowered to investigate complaints relating to a particular field, they ‘should be relied on rather than creating new jurisdictions, unless there are good reasons not to … [including] that the body lacks the necessary powers, independence, or governance arrangements to properly address the issues’.[[14]](#footnote-14)

### What we’re doing already

We’ve made recent changes to strengthen the transparency of our decision-making processes and implement recommendations from the Ombudsman.[[15]](#footnote-15) We have:

* Reviewed and improved our ‘closed file review’/internal review process; and
* Reviewed our preliminary assessment process including to clarify decision-making guidance about the complaint resolution pathways to take no further action and notify an investigation. This guidance can be found on our website.[[16]](#footnote-16)

Improvements to our complaints processes, including as a result of this review, will also support people making complaints, and providers who are the subject of complaints, to feel heard and reduce the likelihood of the need to challenge HDC decisions.

### Question

* 4.1: Did we cover the main issues for **considering options for a right of appeal of HDC decisions**?

## Legislative suggestions for change

We are considering the following options in relation to the ability to challenge HDC decisions.

### Introduce a statutory requirement for review of HDC decisions

Currently, HDC has discretion to undertake internal reviews of decisions if requested. An option to challenge HDC decisions would be to include a statutory requirement for HDC to review decisions if requested, and to publicise this requirement. This right could be similar to the provision in the Health Care Complaints Commission Act 1993 (New South Wales), which requires that ‘[t]he Commission must review a decision made under section 39 [action taken after an investigation] if asked to do so by the complainant’ (section 41(3)). As with this example, any provision would need to prevent an endless cycle of appeals by the complainant and provider on the same complaint.

This option formalises processes that already exist and would put minimal burden on people to challenge HDC’s decisions. This option could include a requirement that the original decision-maker was not part of the review, and/or that there was peer involvement. It would also place an obligation on HDC to ensure that people were aware of their right to request a review of the decision. However, there is also the potential for a review process to require additional resources and/or increase the time it takes for HDC to resolve complaints if take-up was significant.

### Lower the threshold for access to the HRRT

The HRRT is a special jurisdiction tribunal that can hear claims relating to breaches of the Human Rights Act 1993, the Privacy Act 2020, and our Act. Unlike the HDC, the HRRT will usually hold public hearings, and can (in limited circumstances) award damages for losses suffered, including injury to feelings, humiliation, and loss of dignity. The HRRT’s decision may be appealed to the High Court.

There is a higher threshold for people to access the HRRT under our Act, as compared to the Privacy Act and Human Rights Act. For access to the HRRT:

* The Human Rights Act requires only that a complaint is first made to the Human Rights Commission; and
* The Privacy Act generally requires that the Privacy Commissioner must first have investigated the complaint. The Privacy Commissioner does not have to conclude that there was substance to the complaint.

Lowering the threshold for access to the HRRT would allow greater challenge of HDC decisions for both complainants and providers. However, it could also lengthen the time it takes for people’s complaints to be resolved. Currently, 75 percent of HRRT decisions are issued within 6 months. There would also be resource implications for both HDC and HRRT.

If the threshold to access HRRT is made too low, resource implications for the HRRT could be significant. In 2022/23 the HDC closed 3,353 complaints, of which 156 were investigated, and in 114 investigations a breach decision was made. Based on these numbers, lowering the threshold for accessing the HRRT to the equivalent of the Privacy Commissioner could result in an additional 40 complaints per year being eligible for proceedings in the HRRT. Thousands more could become eligible if the threshold was lowered to the same level as the Human Rights Commission, including many complaints that are not appropriate for the HRRT (eg, minor, frivolous, or vexatious complaints).

### Questions

* 4.2: What do you think about our suggestions for **considering** **options for a right of appeal of HDC decisions**, and what impacts could they have?
* 4.3: What other **options for a right of appeal of HDC decisions**, both legislative and non-legislative, should we consider?

# Topic 5 — Minor and technical improvements | Kaupapa 5 — He whakapai itinga, mea hangarau hoki

In this section we set out suggestions for minor and technical amendments to the Act and the Code. We also ask how we can future-proof the Act and the Code to respond to the impacts of new technology on service provision.

## Issues and suggestions for change

### Revise the requirements for reviews of the Act and the Code

The Act requires the Commissioner to review the Act at least every five years, and the Code at least every three years. While regular review is important to ensure that the Act and the Code remain fit for purpose, conducting these reviews is significantly time-consuming and resource intensive. Furthermore, they haven’t resulted in substantive change. Previous Commissioners have consulted on this issue and have recommended that the timeframes for these reviews be amended to every 10 years, with the option of earlier reviews where necessary.

The Act also places different requirements on the Commissioner when reviewing the Act versus reviewing the Code. This is because the Act was written with the initial development of the Code in mind. The Act’s requirements for consultation on the draft Code are still in effect any time the Commissioner wants to recommend even the smallest revision. While broad consultation on any change is important, the level and timing of consultation required is incredibly resource intensive and can cause frustration for both HDC and its stakeholders. We think it would be helpful to update these sections of the Act to make them clearer, reflect a context where we are updating an existing Code rather than developing a new Code, and better align the requirements of reviews of the Act and the Code.

### Increase the maximum fine for an offence under the Act from $3,000 to $10,000

The penalty for offences against the Act (s 73) is a fine not exceeding $3,000. Offences include obstruction, failing to provide information, or providing false or misleading information to the Commissioner. $3,000 is a very modest fine for the offences covered and provides little discouragement for those who choose to obstruct the Commissioner’s processes. Increasing the maximum fine to $10,000 would bring it into line with comparable offences under the Health Practitioners Competence Assurance Act 2003.

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

The Act does not provide the Director of Proceedings with the power to require information to inform decisions about whether or not to issue proceedings. The Director often seeks information from providers, consumers, or third parties (for example, ACC) and relies on their cooperation to give information freely. The majority of submissions that have been received on this issue in previous reviews supported an amendment to enable the Director of Proceedings to require any person to provide information, up until the Director decides to issue proceedings.

### Introduce a definition for ‘aggrieved person’

The Act allows an ‘aggrieved person’ to bring proceedings against a health or disability service provider in the Human Rights Review Tribunal. The term ‘aggrieved person’ is not defined in the Act and has resulted in litigation. The High Court and Court of Appeal decisions have interpreted ‘aggrieved person’ as being restricted to consumers of health or disability services — for example, preventing access by family members of deceased consumers.[[17]](#footnote-17) We consider that this makes access to the Tribunal overly restrictive. The 2014 review recommended the substitution of this phrase for the phrase ‘the complainant (if any) or the aggrieved person(s) if not the complainant’.

### Allow for substituted service

Section 43(1) requires HDC to advise specified persons about the results of an investigation as soon as reasonably practicable after the investigation is completed. Sometimes we cannot find the provider or consumer (likely owing to their relocation) despite our best efforts. Repeated efforts to try to track down people who are not contactable, or in some cases, who may even be actively avoiding us, are a waste of resources that could be better directed elsewhere. We think this section should require that we have made ‘reasonable attempts to advise’ or allow substituted service when we can’t find someone — for example, giving them notice via registered post, or through their social media account/s.

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

HDC is subject to the requirements of the Privacy Act and the Official Information Act 1982 (the OIA). This means that HDC is required to undertake an assessment of every request for information held by the Office to assess whether release of that information is required. This is a complex and time-consuming task. Releasing information during the early stages of an investigation tends to favour providers (and their lawyers), who have greater familiarity with HDC’s processes during an investigation and may seek tactical advantages.

The Privacy Commissioner has suggested that HDC should have a similar ability to the Privacy Commissioner’s office to withhold information during the course of an investigation while the investigation is ongoing, as this is an important safeguard for the integrity of a complaint investigation process. Section 206 of the Privacy Act 2020 requires current and former Commissioners and all staff past and present to maintain secrecy in respect of all matters that come to their knowledge in the exercise of their functions under the Act. However, it gives the Commissioner the ability to disclose any matter that they consider necessary for the purpose of giving effect to the Act. We support a similar amendment being made to our Act.

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

Right 7(6)(c) requires that informed consent must be in writing if the consumer will be under general anaesthetic. This is because this form of sedation has a significant impact on a person’s ability to make or remember decisions. However, there are other forms of sedation that would have the same or substantially similar impacts — for example, where a combination of a painkiller and sedatives are used to help a patient cope with unpleasant or painful procedures. We propose changing the Code to capture those situations to ensure a more consistent application of this Right.

### Clarify that written consent is required when there is a significant risk of serious adverse effects

Right 7(6)(d) of the Code requires written consent where there is ‘a significant risk of adverse effects on the consumer’. In practice this has been understood to relate only to situations where there is significant risk of serious adverse effects. We therefore propose changing the Code to reflect this understanding.

### Clarify the Code’s definitions of teaching, and of research

Right 9 (Teaching and Research) extends all the Rights under the Code to situations where ‘a consumer is participating in or it is proposed that a consumer participates in, teaching and research’. These terms are not defined under the Act and the definitions provided by the Code, as set out below, are unhelpfully broad.

* ‘Teaching’ includes training of providers; and
* ‘Research’ means health research or disability research.

Providers and others with an interest in teaching and research have told us that it is difficult to know when the Code applies. We’ve been told that the lack of clarity is often a barrier to activities that ultimately would benefit people and improve service quality. For example, we’ve been told that some providers and researchers are reluctant to undertake retrospective research at a population level where it is impossible to get informed consent for fear of breaching the Code. We are also aware of situations where the Code does apply but people have come to believe that it doesn’t.

We want to hear your views on how to best to clarify the definitions of teaching, and of research, including what factors should be taken into account for determining when the Code should apply.

### Questions

* 5.1: What do you think about the issues and suggestions for **minor and technical improvements**, and what impacts could they have?
* 5.2: What other minor and technical improvements, both legislative and non-legislative, should we consider?

### Respond to advancing technology

There have been significant advances in technological capability, and associated service changes, in the health and disability sector since the Act and the Code were first enacted. These advances have and will continue to change the way that health and disability services are provided. New service models include remote service provision (sometimes by providers based overseas), and the use of artificial intelligence (AI) for diagnostics and primary care (eg, general practitioner chat bots). It is timely to review whether the Act and the Code provide sufficient protection of the rights of consumers in the face of these new technologies.

The use of new technologies raises several potential issues for the protection and promotion of people’s rights under the Code. These include (but are by no means limited to):

* Risks to the privacy of health information, for example when that information can be picked up by interactions with an AI, rather than being shared willingly;
* The difficulty of enforcing rights when the provider of a service is not based in this country (eg, surgery controlled remotely via robots);
* Bias, misleading predictions, adverse events, and even large-scale discrimination by AI models that have been developed through inaccurate or under-representative training data sets;
* Ensuring informed consent for self-improving AI and other technologies that may be learning as they go; and
* Accountability for upholding consumers’ rights if the care is provided by a non-human.

We want to hear what your views and concerns are, and any suggestions you have for changes we could make to the Act and the Code to support them to remain fit for purpose in the context of advancing technology and its use in health and disability service provision. We ask you some questions below to support this.

### Questions

* 5.3: What are your main concerns about **advancing technology** and its impact on the rights of people accessing health and disability services?
* 5.4: What changes, both legislative and non-legislative, should we consider to respond to **advancing technology**?

**Thank you for reading this document. We look forward to your feedback.**

E koekoe te tūī, e ketekete te kākā, e kūkū te kererū[[18]](#footnote-18)

The tui chatters, the kākā cackles, the kererū coos

The whakataukī conveys the sense that while tūī, kākā, and kererū are all birds, each has its own distinctive sound and they are positively different and significant for their own reasons. To that end, this is an acknowledgement to those who have offered their advice, expertise, and lived experience to support and shape this document. It is hoped ‘by appreciating all our voices, our different songs, we make good music for the future’.[[19]](#footnote-19)

# Appendix 1 — Consultation questions | Āpitihanga 1 — Ngā pātai uiui

See [<https://review.hdc.org.nz>](https://review.hdc.org.nz/) to answer these questions through our online survey.

**Topic 1: Supporting better and equitable complaint resolution**

1.1: Did we cover the main issues about **supporting better and equitable complaints resolution**?

1.2: What do you think of our suggestions for **supporting better and equitable complaints resolution**, and what impacts could they have?

1. Amend purpose statement
2. Clarify cultural responsiveness
3. Clarify the role of whānau
4. Ensure gender inclusive language
5. Protect against retaliation
6. Clarify provider complaints processes
7. Strengthen the Advocacy Service
8. Improve the language of complaint pathways in the Act

1.3: What other changes, both legislative and non-legislative, should we consider for **supporting better and equitable complaints resolution**?

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

2.1: Did we cover the main issues about **making the Act and the Code more effective for, and responsive to, the needs of, Māori**?

2.2: What do you think about our suggestions for **making the Act and the Code more effective for, and responsive to, the needs of Māori**, and what impacts could they have?

1. Incorporate tikanga into the Code
2. Give practical effect to te Tiriti | the Treaty in the Act.

2.3: What other changes, both legislative and non-legislative, should we consider for **making the Act and the Code** **more effective for, and responsive to, the needs of Māori**?

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

3.1: Did we cover the main issues about **making the Act and the Code work better for tāngata whaikaha | disabled people**?

3.2: What do you think of our suggestions for **making the Act and the Code work better for tāngata whaikaha | disabled people**, and what impacts could they have?

1. Strengthen disability functions in the Act
2. Update definitions relating to disability
3. Strengthen references to accessibility
4. Strengthen and clarify the right to support to make decisions
5. Progress consideration of HDC’s draft recommendations relating to unconsented research

3.3: What other changes should we consider (legislative and non-legislative) for **making the Act and the Code work better for tāngata whaikaha | disabled people**?

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

4.1: Did we cover the main issues about **considering options for a right of appeal of HDC decisions**?

4.2: What do you think about our suggestions for **considering options for a right of appeal of HDC decisions**, and what impacts could they have?

1. Introduce a statutory requirement for review of HDC decisions
2. Lower the threshold for access to the HRRT

4.3: What other **options for a right of appeal of HDC decisions**, both legislative and non-legislative, should we consider?

**Topic 5: Minor and technical improvements**

5.1: What do you think about the issues and suggestions for **minor and technical improvements**, and what impacts could they have?

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

5.2: What other **minor and technical improvements**, both legislative and non-legislative, should we consider?

5.3: What are your main concerns about **advancing technology** in relation to the rights of people accessing health and disability services?

5.4: What changes, both legislative and non-legislative, should we consider to respond to **advancing technology**?

# Appendix 2 — How our suggestions could translate into a revised Code | Āpitihanga 2 — Me pēhea ā mātou huatau e whakawhiti ai ki tētahi Tikanga hou

This Appendix brings draft changes to the Code suggested in this document together in one place.

Suggested deletions are shown by **~~bold strike through~~** text and suggested additions are shown in **bold** (headings are underlined in bold and are unchanged). In [square brackets] is a reference to the topic and suggestion the proposal relates to.

**Code of Rights showing draft changes**

**1. Consumers have rights and providers have duties:​**

(1) Every consumer has the rights in this Code.

(2) Every provider is subject to the duties in this Code.

(3) Every provider must take action to—

(a) Inform consumers of their rights **in a form and manner that takes account of their needs**; and

[Proposed change relates to Topic 3, proposal c. Strengthen references to accessibility, and, Topic 1, proposal d. Ensure gender-inclusive language.]

(b) Enable consumers to exercise their rights.

**2. Rights of consumers and duties of providers:**

The rights of consumers and the duties of providers under this Code are as follows:

**Right 1 Right to be treated with respect**

(1) Every consumer has the right to **have their mana upheld and** be treated with respect. [Proposed change relates to Topic 2, proposal a. Incorporate te ao Māori values and tikanga into the Code.]

(2) Every consumer has the right to have **~~his or her~~** **their** privacy respected.

[Proposed change relates to Topic 1, proposal d. Ensure gender-inclusive language.]

(3) Every consumer has the right to be provided with services that take into account the**ir** needs, **culture, language, identity,** values, and beliefs**.** **~~of different cultural, religious, social, and ethnic groups, including the needs, values and beliefs of Māori.~~**

[Proposed change relates to Topic 1, proposal b. Clarify cultural responsiveness in the Code; and Topic 1, proposal d. Ensure gender-inclusive language.]

**Right 2 Right to freedom from discrimination, coercion, harassment, and exploitation**

Every consumer has the right to be free from discrimination, coercion, harassment, and sexual, financial or other exploitation.

**Right 3 Right to dignity and independence**

Every consumer has the right to have services provided in a manner that respects the dignity and **~~independence~~ autonomy** of the individual.

[Proposed change relates to Topic 1, proposal c. Clarify the role of whānau.]

**Right 4 Right to services of an appropriate standard**

(1) Every consumer has the right to have services provided with reasonable care and skill.

(2) Every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards.

(3) Every consumer has the right to have services provided in a manner consistent with **their ~~his or her~~** needs.

[Proposed change relates to Topic 1, proposal d. Ensure gender-inclusive language.]

(4) Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.

(5) Every consumer has the right to co-operation among providers to ensure quality and continuity of services.

**Right 5 Right to effective communication**

(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, **~~and reasonably practicable~~** this includes the right to **appropriate supports and/or support people, including** a competent interpreter.

[Proposed changes relate to Topic 3, proposal c. Strengthen references to accessibility; and Topic 3, proposal d. strengthen and clarify the right to support to make decisions.]

(2) Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

**Right 6 Right to be fully informed**

(1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including—

(a) an explanation of **their ~~his or her~~** condition; and

[Proposed change relates to Topic 1, proposal d. Ensure gender-inclusive language.]

(b) an explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and

(c) advice of the estimated time within which the services will be provided; and

(d) notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and

(e) any other information required by legal, professional, ethical, and other relevant standards; and

(f) the results of tests; and

(g) the results of procedures.

(2) Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer’s circumstances, needs to make an informed choice or give informed consent.

(3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about—

(a) the identity and qualifications of the provider; and

(b) the recommendation of the provider; and

(c) how to obtain an opinion from another provider; and

(d) the results of research.

(4) Every consumer has the right to receive, on request, a written summary of information provided.

**Right 7 Right to make an informed choice and give informed consent**

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

(2) Every consumer must be presumed **to have decision-making capacity ~~competent~~** to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer **does not have decision-making capacity ~~is not competent~~**.

[Proposed changes relate to Topic 3, proposal d. Strengthen and clarify the right to support to make decisions.]

(3) Where a consumer has **affected decision-making capacity ~~diminished competence~~**, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to **their ~~his or her~~** level of **decision-making capacity ~~competence~~**. **Where necessary, this includes the right to support to make decisions.**

[Proposed changes relate to Topic 3, proposal d. Strengthen and clarify the right to support to make decisions; and Topic 1, proposal d. Ensure gender-inclusive language.]

(4) Where a consumer **does not have decision-making capacity ~~is not competent~~** to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where—

(a) it is in the best interests of the consumer; and

(b) reasonable steps have been taken to ascertain the **will and preferences ~~views~~** of the consumer; and

(c) either,—

(i) if the consumer’s **will and preferences ~~views~~** have been ascertained, and having regard to their **will and preferences** **~~those~~** **~~views~~**, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if **they ~~he or she~~** were competent; or

[Proposed change relates to Topic 1, proposal d. Ensure gender-inclusive language.]

(ii) if **7(4)(c)(i) does not apply ~~the consumer's views have not been ascertained~~**, the provider takes into account **the will and preferences of the consumer to the extent they are ascertained, and** the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.

[Proposed changes relate to Topic 3, proposal d. Strengthen and clarify the right to support to make decisions; and Topic 1, proposal d. Ensure gender-inclusive language.]

(5) Every consumer may use an advance directive in accordance with the common law.

(6) Where informed consent to a health care procedure is required, it must be in writing if—

(a) the consumer is to participate in any research; or

(b) the procedure is experimental; or

(c) the consumer will be **given medication designed to alter their level of consciousness, or awareness or recall, for the purpose of undertaking the procedure ~~under general anaesthetic~~**; or

[Proposed change relates to Topic 5, proposal g. expand the requirement for written consent for sedation that is equivalent to anaesthetic.]

(d) there is a significant risk of **serious** adverse effects on the consumer.

[Proposed change relates to Topic 5, proposal h. Clarify the requirement for written consent where there is a high risk of serious adverse consequences.]

(7) Every consumer has the right to refuse services and to withdraw consent to services.

(8) Every consumer has the right to express a preference as to who will provide services and have that preference met where practicable.

(9) Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.

(10) No body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved, or used otherwise than

(a) with the informed consent of the consumer; or

(b) for the purposes of research that has received the approval of an ethics committee; or

(c) for the purposes of 1 or more of the following activities, being activities that are each undertaken to assure or improve the quality of services:

(i) a professionally recognised quality assurance programme:

(ii) an external audit of services:

(iii) an external evaluation of services.

**Right 8 Right to support**

(1) Every consumer has the right to have one or more support persons of **their ~~his or her~~** 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.**

[Proposed changes relate to Topic 1, proposal d. Ensure gender-inclusive language; and Topic 1, proposal c. Clarify the role of whānau.]

**Right 9 Rights in respect of teaching or research**

The rights in this Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, teaching or research.

**Right 10 Right to complain**

(1) Every consumer **and/or their representative** has the right to complain about a provider in any form appropriate to **that ~~the~~** consumer **and/or representative**.

[Proposed change relates to Topic 1, proposal c. Clarify the role of whānau.]

(2) Every consumer **and/or their representative** may make a complaint to—

(a) the individual or individuals who provided the services complained of; and

(b) any person authorised to receive complaints about that provider; and

(c) any other appropriate person, including—

(i) an independent advocate provided under the Health and Disability Commissioner Act 1994; and

(ii) the Health and Disability Commissioner.

(3) Every provider must facilitate the fair, simple, speedy, and efficient resolution of complaints.

**~~(4) Every provider must inform a consumer about progress on the consumer’s complaint at intervals of not more than 1 month.~~**

[See new 10(6) and 10(7).]

**(4)~~(5)~~** Every provider must comply with all the other relevant rights in this Code when dealing with complaints.

**(5)~~(6)~~** Every provider, unless an employee of a provider, must have an **accessible** complaints process which ensures that —

(a) The complaint is acknowledged within 5 working days of receipt, **in a form and manner that takes account of the consumer’s needs,** unless it has been resolved to the satisfaction of the consumer within that period; and

(b) the consumer **and/or their representative** is informed of any relevant internal or external complaints procedures, including the availability of —

(i) Independent advocates provided under the Health and Disability Commissioner Act 1994; and

(ii) The Health and Disability Commissioner; and

(c) the **~~consumer’s~~** complaint and the actions of the provider regarding that complaint are documented; and

(d) the consumer **and/or their representative** receives all information that is relevant to the complaint; and

(e) the consumer **and/or their representative** is regularly provided with updates on the progress of their complaint.

[Proposed changes relate to Topic 3, proposal c. Strengthen references to accessibility; and Topic 1, proposal c. Clarify the role of whānau.]

**(6) On receiving the complaint the provider must —**

**(a) use their best endeavours to resolve the complaint; and**

**(b) ensure that the consumer and/or their representative is informed of what the provider is doing to resolve the complaint in accordance with 6(a) and the reasons why.**

**(7) If the complaint is not resolved within 20 working days, the provider must —**

**(a) inform the consumer and/or their representative of the reasons for the delay and how long they expect it will take to resolve the complaint; and**

**(b) appropriately update and keep the consumer and/or their representative updated about progress.**

**~~(7) Within 10 working days of giving written acknowledgement of a complaint, the provider must-~~**

**~~(a) Decide whether the provider –~~**

**~~(i) accepts that the complaint is justified; or~~**

**~~(ii) does not accept that the complaint is justified; or~~**

**~~(b) if it decides that more time is needed to investigate the complaint, –~~**

**~~(i) determine how much additional time is needed; and~~**

**~~(ii) if that additional time is more than 20 working days, inform the consumer of that determination and of the reasons for it.~~**

(8) As soon as is practicable after a provider **has made a determination on a complaint, ~~decides whether or not it accepts that a complaint is justified~~**~~,~~ the provider must inform the consumer **and/or their representative** of **the determination and** —

(a) the reasons for **the determination ~~the decision~~**; and

(b) any actions the provider proposes to take; and

(c) any appeal procedure the provider has in place.

**(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 that are 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.**

[Proposed change relates to Topic 1, proposal e. Protect against retaliation.]

**(10) Providers must communicate to consumers and/or their representatives ~~—~~**

**(a) accessible information about the existence of the provider’s internal complaints procedures; and**

**(b) accessible information about how to use these procedures.**

[Proposed change relates to Topic 1, proposal f. Clarify provider complaints processes.]

**3. Provider compliance**

(1) 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.

(2) The onus is on the provider to prove that it took reasonable actions.

(3) For the purposes of this clause, the circumstances means all the relevant circumstances, including the consumer’s clinical circumstances and the provider’s resource constraints.

**4. Definitions**

In this Code, unless the context otherwise requires,—

Advance directive means a written or oral directive—(a) by which a consumer makes a choice about a possible future health care procedure; and (b) that is intended to be effective only when **the consumer** **~~he or she~~** is not competent:

[Proposed change relates to Topic 1, proposal d. Ensure gender-inclusive language.]

Choice means a decision—

(a) to receive services:

(b) to refuse services:

(c) to withdraw consent to services:

Consumer means a health consumer or a disability services consumer; and, for the purposes of Rights 5, 6, 7(1), 7(7) to 7(10), and 10, includes a person entitled to give consent on behalf of that consumer.

Discrimination means discrimination that is unlawful by virtue of Part II of the Human Rights Act 1993.

Duties includes duties and obligations corresponding to the rights in this Code.

Ethics committee means an ethics committee—

(a) established by, or appointed under, an enactment; or

(b) approved by the Director-General of Health.

Exploitation includes any abuse of a position of trust, breach of a fiduciary duty, or exercise of undue influence.

Optimise the quality of life means to take a holistic view of the needs of the consumer in order to achieve the best possible outcome in the circumstances.

Privacy means all matters of privacy in respect of a consumer, other than matters of privacy that may be the subject of a complaint under Part 5 of the Privacy Act 2020 or matters to which subpart 4 of Part 7 of that Act relates.

Provider means a health care provider or disability services provider.

**Representative means someone who has been chosen by the consumer to, or is otherwise entitled to, act on behalf of or speak for a consumer.**

[Proposed change relates to Topic 1, proposal c. Clarify the role of whānau.]

Research means health research or disability research.

Rights includes rights corresponding to the duties in this Code.

Services means health services, or disability services, or both; and includes health care procedures.

Teaching includes training of providers.

**5. Other enactments**

Nothing in this Code shall require a provider to act in breach of any duty or obligation imposed by any enactment or prevents a provider doing an act authorised by any enactment.

**5A. End of Life Choice Act 2019**

(1) This clause sets out how this Code operates with the End of Life Choice Act 2019 (the EOLC Act).

(2) For Right 4(2) of this Code, contravening section 10(1) of the EOLC Act may be found or held to be providing services that do not comply with relevant legal standards.

(3) Right 6(1)(b) and (c), and (2) of this Code is overridden by section 10 (assisted dying must not be initiated by health practitioner) of the EOLC Act.

(4) Right 7(2) to (5) of this Code is overridden by section 6 (meaning of competent to make an informed decision about assisted dying) of the EOLC Act.

(5) Under clause 5 of this Code (and without limiting that clause), nothing in this Code requires a provider to act in breach of any duty or obligation imposed by the EOLC Act or prevents a provider from doing an act authorised by the EOLC Act.

Schedule clause 5A: inserted, on 6 November 2021, by section 41 of the End of Life Choice Act 2019 (2019 No 67).

**6. Other rights**

An existing right is not overridden or restricted simply because the right is not included in this Code or is included only in part.

1. 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. [↑](#footnote-ref-1)
2. See, for example, The National Collaborative for Restorative Initiatives in Health, *He Maungārongo ki Ngā Iwi: Envisioning a Restorative Health System in Aotearoa New Zealand.* Wellington: The National Collaborative for Restorative Initiatives in Health; 2023. [↑](#footnote-ref-2)
3. Te Tāhū Hauora | Health Quality and Safety Commission, *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.* Wellington: Te Tāhū Hauora | Health Quality and Safety Commission; 2023. [↑](#footnote-ref-3)
4. See, for example, Medical Council of New Zealand, Statement on Cultural Safety: <https://www.mcnz.org.nz/assets/standards/b71d139dca/Statement-on-cultural-safety.pdf>; October 2019. [↑](#footnote-ref-4)
5. Curtis E, Jones R, Tipene-Leach D *et al*., ‘Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition’. *International Journal for Equity in Health* 2019; 18, 174. [↑](#footnote-ref-5)
6. Review of Adult Decision-Making Capacity Law: Preliminary Issues Paper NZLC IP49. [↑](#footnote-ref-6)
7. Te Arawhiti (Office for Crown–Māori Relations), *Providing for the Treaty of Waitangi in Legislation and Supporting Policy Design.* Wellington: Te Arawhiti (Office for Crown–Māori Relations); 2012. [↑](#footnote-ref-7)
8. We used Critical Tiriti Analysis to help identify suggestions: O’Sullivan D, Came H, ‘A new way of thinking: Critical Tiriti analysis’. Public Sector 2022; 45(3): 14–15. See also the Community Research critical Tiriti analysis collection: <https://tinyurl.com/critical-Tiriti-analysis>. [↑](#footnote-ref-8)
9. The Ritenga Māori declaration (often referred to as the ‘fourth article’) was drafted in te reo Māori and read out during discussions with rangatira (Māori leaders) concerning te Tiriti | the Treaty. The declaration provides for the protection of religious freedom and the protection of traditional spirituality and knowledge (Te Puni Kōkiri, *A Guide to the Principles of the Treaty of Waitangi as expressed by the Courts and the Waitangi Tribunal*. Wellington: Te Puni Kōkiri; 2001. pp.40–41). [↑](#footnote-ref-9)
10. Ministry of Social Development, *New Zealand Disability Strategy 2016–2026*. Wellington: Ministry of Social Development; 2016, pg 12. [↑](#footnote-ref-10)
11. Health Select Committee, *Petition of Renate Schütte: A right to appeal decisions made by the Health and Disability Commissioner.* Wellington: House of Representatives; 2022. [↑](#footnote-ref-11)
12. Legislation Design and Advisory Committee, *Legislation Guidelines: 2021 Edition.* Wellington: Legislation Design and Advisory Committee; 2021, page 130. [↑](#footnote-ref-12)
13. The HPDT hears and makes decisions on disciplinary proceedings brought against registered health practitioners. Disciplinary proceedings against a health practitioner can be brought before the HPDT only by either the Director of Proceedings or a Professional Conduct Committee (a committee set up by a regulatory authority such as the Medical Council).

The HRRT hears claims about breaches of the Code as well as breaches of the Human Rights Act 1993 and the Privacy Act 2020. The HRRT considers the matter afresh and has the power to award damages (monetary awards), including punitive damages, but not compensatory damages where they are barred by the Accident Compensation Corporation Act 2001. [↑](#footnote-ref-13)
14. Legislation Design and Advisory Committee, *Legislation Guidelines: 2021 Edition.* Wellington: Legislation Design and Advisory Committee; 2021. [↑](#footnote-ref-14)
15. Peter Boshier, *Investigation into the Health and Disability Commissioner’s assessment of three complaints*. Wellington: Ombudsman; 2021: <https://www.ombudsman.parliament.nz/news/final-opinion-hdc-complaints>. [↑](#footnote-ref-15)
16. Health and Disability Commissioner, *Complaint Process.* Wellington: Health and Disability Commissioner; 2024: <https://www.hdc.org.nz/making-a-complaint/complaint-process/>. [↑](#footnote-ref-16)
17. In *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. [↑](#footnote-ref-17)
18. Edwards, S., *Titiro Whakamuri Kia Marama Ai Te Wao Nei: Whakapapa Epistemologies and Maniapoto Māori Cultural Identities.* Massey University Research Repository; 2009: <http://hdl.handle.net/10179/1252>. [↑](#footnote-ref-18)
19. Description given in Department of Conservation, Te Taura Whiri i Te Reo Māori, Ministry of Education, *Kia Kaha te Reo Taiao Phrasebook.* <https://tinyurl.com/Kia-kaha-te-Reo-Taiao.> [↑](#footnote-ref-19)