Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

Act and Code Review consultation questions | Ngā pātai matapakinga

This document contains all the questions we are asking as part of the Act and Code Review consultation. Aside from the required questions, you can answer as many or as few as you'd like. When completed, please either email it to review@hdc.org.nz or post it to us at PO Box 1791, Auckland, 1140.

Please visit https://review.hdc.org.nz to answer these questions online.

Your details (required)

It's important for us to know a bit about you so that we understand whose views are being represented in submissions. It helps us to make sure that any changes we recommend will work well for everyone and have an equitable impact.

1. What is your name? [redacted]

2. What is your email address? [redacted]

3. Are you submitting as an individual, or on behalf of an organisation or group?

☐ I am submitting as an individual
☐ I am submitting on behalf of an organisation or group

4. How did you hear about this consultation? (please select)

☐ HDC website ☐ News media ☐ Social media ☐ Internet
☐ Through my job ☐ Word of mouth ☐ Other (please specify below)

_____

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Please answer the following questions **if you are submitting as an individual**. If you are submitting on behalf of an organisation or group, please go to page 3.

Which of these services do you engage with the most? (Please select all that apply)

☐ Health services ☐ Disability services ☐ Mental Health services

☐ Addiction services ☐ Aged Care Services ☐ Kaupapa Māori services

☐ Other services (please specify) _____

What is your gender?

☐ Female ☐ Male

☐ Another gender (please specify) _____

☐ I don't want to answer this question

How old are you?

☐ Under 15 ☐ 15 - 17 ☐ 18 - 24 ☐ 25 - 34 ☐ 35 – 49

☐ 50 - 64 ☐ 65+ ☐ I don't want to answer this question

What is your ethnicity? (Please choose all that apply)

☐ NZ European ☐ Māori ☐ Samoan ☐ Cook Island Māori

☐ Tongan ☐ Niuean ☐ Chinese ☐ Indian

☐ I don't know my ethnicity ☐ I don't want to state my ethnicity

☐ Other/s (please state):_____

Do you identify as having a disability?

☐ Yes ☐ No

If you are submitting on behalf of an organisation or group:

What is the name of your organisation or group?

Federation of Women's Health Councils Aotearoa NZ

What type of organisation/group is it?

Share 'one big thing'

This survey contains structured questions that ask for your feedback on each chapter in our consultation document. If you would prefer to give us your feedback as a whole, by telling us 'one big thing' – you can do so below.

If this is all you want to provide by way of your submission, that's fine by us. We will consider all the submissions we receive.

What is your 'one big thing'?

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Topic 1: Supporting better and equitable complaint resolution

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

Yes, for the purposes of this document.

However, we are mindful HDC has to work within its available resources, noting budget cuts and a seriously outdated IT infrastructure that impact its effectiveness.

We note HDC is looking to strengthen the Act and Code to support all New Zealanders to raise and resolve their concerns directly with the provider, where appropriate. We trust that this discretion will continue, that there will not be a statutory requirement for the complainant to take their complaint to the provider as a first step in the complaints pathway.

HDC is looking to make better use of Advocacy Services. We note from the 2022/23 Annual Report that the number of advocates has reduced from 48 in 2013/14 to 24 in 2022/23. It is difficult to see how such a dwindling resource can be better used, short of seriously overworking the advocates, and increased use of electronic technology. The latter has its limitations in this sort of work.

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

a) Amend the purpose statement of the Act – agree the HDC too often focuses on processes rather than the people at the centre of the complaint.
We don't disagree with incorporating the concept of upholding mana in the purpose statement but is that sufficient to change what has been an entrenched focus on processes?
b) Clarify cultural responsiveness – agree with proposals.
c) Clarify role of whānau – agree with proposed changes to the Code, noting that the wishes of a consumer to not have family/whānau involved should be respected unless there are valid grounds to do otherwise. We agree the need for guidance to be developed and consulted on, in order to support the changes to the Code.
d) Ensure gender-inclusive language – agree.
e) Protect against retaliation – agree.
f) Clarify provider complaint process – we totally endorse the comments that providers' complaint processes are often invisible or unclear. There is a tendency for providers to prioritise feedback and concerns, presumably because addressing complaints is subject to the process prescribed in the Code. The Health NZ website has proven to be a revelation now that all DHB websites have been decommissioned and respective hospital information has been transitioned to the HNZ website. It means local hospital information is at least one step removed (assuming people know where to look for this information now. The website is a nightmare to navigate if you don't know how). While some hospitals appear to have retained more of their own information about their feedback/complaint processes, others appear to have adopted a more standardised approach to Feedback that, when clicked on, provides relevant email and phone contact details and/or the option of an online Feedback/Enquiry form. The latter has a 4000-character limit including spaces. The word 'Çomplaint' doesn't feature on this form. We believe HNZ services and all other providers have a duty to review their own complaint systems and reflect on how well they promote their own complaint processes and how accessible they are.
g) Strengthen the Advocacy Service – agree. But how? Refer to comments in 1.1 above.
h) Improve the language of complaint pathways in the Act – we agree 'No further action' is disempowering and from a consumer perspective,

somewhat tarnished in the wake of some inappropriate use in the past. 'No investigative action' has been suggested as an alternative. This may be more appropriate and respectful if the complainant is kept up to date on the steps that have been taken in an assessment of the complaint, and any related findings. See further comment in Topic 4.

Replacing 'mediation conference' with 'facilitated resolution' may resolve the concerns that have been expressed. We support this so long as there are sufficient mechanisms in place to ensure that any agreed settlements or resolutions are indeed acted upon. We have noted and respect the suggested amendment by Māori advisers to s 61 Mediation Conference (pg. 33 Consultation document).

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 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**?

We are not qualified to provide substantive comments. We are supportive of making the Act and the Code more effective for, and responsive to the needs

of, Māori.

2.2: As above

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**?

As above

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**?
We are pleased to see there is a specific focus on tāngata whaikaha I disabled people in this review of the Act and Code. It appears the main issues have been covered but the authoritative view will come from tāngata whaikaha I disabled people themselves.

However, we strongly believe it was incorrect for HDC to incorporate the issue of health and disability research with adult participants who are unable to provide informed consent (unconsented research) within this topic. This effectively frames it as an issue solely impacting disabled people when it is not the case. The HDC's 2019 report identifies emergency situations, head trauma, sepsis, cardiac arrests and stroke as examples for potential unconsented research. These people would not necessarily meet the formal definition of a disabled person. We maintain this is such an important issue it should have been considered as a topic in its own right within this consultation.

Having noted questions 3.1 and 3.2 we believe they are appropriate for

suggestions a) to d) but premature for suggestion e) as it relates to unconsented research. It is our understanding that any feedback on e) i.e. the HDC's 2019 recommendations, cannot amend the Code at this point. It requires a further consultation once the draft wording of the relevant section has been developed. Our feedback, under 3.3, will reflect that understanding in addition to our concerns about how the recommendations of the 2019 report have been misrepresented in this consultation document.

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?

To the extent that we are qualified to comment, we support the proposed changes to the Act and Code as set out in a) – d) to make the Act and Code work better for tāngata whaikaha I disabled people. We note the draft wording in the Code in Appendix 2. Refer to further brief comments under Topic 5.

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**?

Unconsented Research

HDC Review Report: Health and Disability research with adult participants who are unable to provide informed consent

Points to note:

- Public consultation on discussion document was undertaken in 2017
- Review completed and report published 2019
- HDC made recommendations to the then Minister of Health. Our view is they were recommendations, not draft recommendations.
- HDC did *not intend to consult on the proposed amendments to the Code until after my recommendations on pages 10 to 11 are implemented* and
- More detailed drafting of the wording of the Code would take place prior to any formal consultation on the proposed Code changes.

- HDC recommended, A specialist ethics committee being established with responsibility for reviewing all health and disability research involving adults unable to consent. It would have additional responsibilities such as auditing, monitoring and follow-up of outcomes. The consultation document refers to specialist ethics committees overseeing such research.
- HDC 2019 report noted that Ministry of Health advised that between 2006 -2012 about 30 non-consensual studies had been approved by ethics committees; between 2012-2016, about 40 had been approved and 5-6 declined. Our conclusion - these studies were unlawful.
- 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. (consultation document)
- NEAC's outstanding recommendation relates to defining 'minimal foreseeable risk and minimal foreseeable burden'. (consultation document)

There are some inconsistencies that need clarification.

Views on HDC's 2019 recommendations

Undoubtedly the review was comprehensive in its scope, very detailed and carefully considered. The recommendations reflect that and essentially have stood the test of time irrespective of whether we agree with all of them or not, or we support in principle but believe they warrant clarification and/or further discussion.

One example would be 'no more than foreseeable risk and no more than minimal burden'. We think NEAC could or should seek a wider range of views on this before reaching a decision.

We agree that the specialist ethics committee should include in its membership representation from people with lived experience of disability.

It would be useful to have an explicit update from NEAC to clarify all the work they have done to date on the recommendations that apply to them.

Has a specialist ethics committee been established, and if so, by whom?

We would expect that a report from HDC on the outcomes of this

consultation will set out the feedback received with an indication of next steps.
This will allow us time to reflect more on these important issues.

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**?
For the purposes of this consultation document, the main issues were covered.
But the back story that resulted in the involvement of the Ombudsman and the petition to Parliament seeking legislative change remains an important one, not only from HDC's unfair processes and lack of transparency, but also from the public safety perspective. It should not be forgotten.

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?

a) Introduce a statutory requirement of review of HDC decisions – agree with this and that this requirement be publicised, along with the process for requesting such a review.
   We acknowledge the need to prevent an endless cycle of appeals on the same complaint but unsure how this would be managed. We agree the original decision-maker should not be part of the review.
   Our expectation is the review of HDC decisions be reported on in HDC's Annual report – the total number, number of decisions overturned, next steps when decisions were overturned.
b) Lower the threshold for access to the HRRT – agree, the current threshold is too high, but what the threshold should be lowered to is a vexed issue. In an ideal world access to justice should be paramount and resourcing issues shouldn't matter, but unfortunately they do. How to strike the right balance is a challenge.
   The compromise could be to lower the threshold to the same level as the Privacy Act which requires the Privacy Commissioner to have investigated the complaint although they do not have to conclude there was substance to that complaint. On the face of it, this seems

straightforward. However not every complaint to the Privacy Commissioner is investigated. s 74 of the Privacy Act sets out numerous reasons why the Commissioner may decide not to investigate the complaint. Most notably s74(1) (a) states if - *the complainant has not made reasonable efforts to resolve the complaint directly with the agency concerned*;

The Human Rights Act requires only that a complaint is first made to the Human Rights Commission. Without further follow up we don't know how many complaints are made and how many progress to the HRRT. However, for the purposes of this discussion the Human Rights Act threshold would be inclusive of the No Further Action (or No Investigative Action) as was raised in the Schutte petition to Parliament. We note nearly 50% (n=1463) of the complaints closed in 22/23 were resolved as No Further Action following assessment. This is significant from HDC, consumer and HRRT perspectives.

We do wonder if the move to a statutory requirement of review of HDC decisions, when requested, would mitigate some of the concerns around too many HDC complaints being appealed to HRRT.

Irrespective, the HDC threshold for access to HRRT must be lowered. A consensus will have to be reached and that will be consulted on when an Amendment Bill comes to Parliament.

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?

a) Revise the requirements for reviews of the Act and Code – agree with reviewing every 10 years with the option for earlier reviews where necessary. What would be the criteria for triggering an earlier review? Noting that the Act and Code may be amended as a consequence of new or other legislative change e.g. End of Life Choice Act 2019, Pae Ora (Healthy Futures) Act 2022.

b) Increase maximum fine for an offence under the Act – agree with raising it to a maximum of $10,000.

c) Give the Director of Proceedings the power to require information – agree

d) Introduce a definition of 'aggrieved person' – support in principle but the suggested substitution the complainant if any or the aggrieved person(s) if not the complainant seems too broad. We would be keen to see some alternative substitutions and related discussion before determining the most appropriate definition.

e) Allow for substituted service – agree

f) HDC to have grounds to withhold information where appropriate – agree

g) Expand requirement for written consent for sedation that is equivalent to

anaesthetic – agree
h) Clarify that written consent is required when there is significant risk of serious adverse effects - agree
i) Clarify the Code's definitions of teaching and research – agree these need to be clarified but we believe it is premature to do this as part of this consultation. We recommend further consultation given the ongoing uncertainties and debate around both issues. With respect to health and disability research involving adults who are unable to give informed consent to participate in research, this is unfinished business. Our expectation from the 2019 report *is that more detailed drafting of the wording of the Code would take place prior to any formal consultation on proposed Code changes.* The consultation document doesn't provide this. Once there is clarity, we suggest HDC, responsible authorities, NEAC and any other relevant authorities update their guidance/guidelines in consultation with stakeholders.

5.2: What other **minor and technical improvements**, both legislative and non-legislative, should we consider?
HDC Act
s 3 Definition of a health care provider
j) any person employed by the School Dental Service – no longer referred to as SDS as significant changes made 2006? Now part of HNZ. Delete (j)
s10 Qualifications for appointment
(1)(f) Maori – Māori
s 14 Functions of Commissioner
(da) to act as the initial recipient of complaints about …. – review the intent of *initial.* This seems to be counter to contemporary practice and/or the intent of much of what is proposed in this consultation document.
s 14(2)(b) requires HDC to consult and co-operate with other agencies, but it is confined to agencies concerned with personal rights.
s 14 Proposed new subsection (or elsewhere in the Act)
We would like to see a specific requirement for HDC to consult/share information with agencies that have a shared interest in quality and safety of health systems,

in addition to responsible authorities and the Ministry of Health. This would strengthen the 'watchdog role' of HDC. The issues with surgical mesh highlight the need for collaboration across HDC, ACC, HQSC, Health NZ, Medsafe (or any new Therapeutic Products regulator) when clusters of similar complaints and claims are made, so systemic and/or public safety issues can be identified and addressed more quickly. This will become increasingly important as new technologies are implemented. We see our suggestion as being different from s 34 Referral of complaint to other agencies.

Code
Generally supportive of the proposed changes as set out in Appendix 2 noting points below:
Right 3 Right to dignity and independence
Should independence be changed to autonomy to be consistent with content?
Right 5 Right to effective communication
Access to competent interpreter – this includes online interpreter services?
Right 9 Rights in respect of teaching or research
Subject to amendment in due course. Refer to i) above.
This will also be impacted by the outcome of further consultation on health and disability research involving adults who are unable to give informed consent to participate in research.

5.3: What are your main concerns about **advancing technology** in relation to the rights of people accessing health and disability services?
We have identified similar issues to those outlined in the consultation document regarding new technologies that have already been implemented in NZ's health system or are likely to be introduced in the future. An article on Newsroom highlights but one example of the use of AI, in this case to take patient notes:
https://newsroom.co.nz/2024/07/22/im-a-gp-experimenting-with-ai-to-take-

patient-notes-heres-what-i-found/

While new technologies will have their benefits, we are struggling to see how the Code can be adapted to meaningfully protect the rights of people accessing health and disability services in NZ. If the AI gets it wrong, as in the example above, who is responsible? The GP? The practice/organisation that bought the technology? The company that sold the technology which is probably overseas based and therefore outside of NZ jurisdiction?

It is worrying that there is pressure from Government, technology companies which are generally international, for advancing technology to be adopted at pace (on the grounds it's going to free up time, save money) in the absence of a strong regulatory environment and robust evidence that benefits in terms of consumer outcomes will outweigh harms. Given powerful industry interests it is likely the benefits will be overstated and the risks understated. How will consumers know if a particular technology 'got it right'? Some problems may be slow to emerge and authorities need to be open to that possibility, rather than believing it is failsafe, and keep monitoring.

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

We think there should be wide-ranging discussion on the issues with some options as to how the Code would/could work (in conjunction with Office of the Privacy Commissioner perhaps) in this changing environment so more informed decisions can be made about the need for any changes and what they might look like. This is a separate consultation.

Publishing and data protection

This section provides important information about the release of your information. **Please read it carefully.**

You can find more information in the Privacy Policy at hdc.org.nz.

Being open about our evidence and insights is important to us. This means there are several ways that we may share the responses we receive through this consultation. These may include:

- **Publishing all, part or a summary of a response** (including the names of respondents and their organisations)
- Releasing information **when we are required to do so by law** (including under the Official Information Act 1982

Publishing permission

May we publish your submission? (Required)

☐ Yes, you may publish any part of my submission

☐ Yes, but please remove my name/my organisation/group's name

☐ No, you may not release my submission, unless required to do by law

Please note any parts of your submission you do not want published:

Reasons to withhold parts of your submission

HDC is subject to the Official Information Act 1982 (The OIA). This means that when responding to a request made under the OIA, we may be required to disclose information you have provided to us in this consultation.

Please let us know if you think there are any reasons we should not release information you have provided, including personal health information, and in particular:

- which part(s) you think should be withheld, and
- the reason(s) why you think it should be withheld.

We will use this information when preparing our responses to requests for copies of and information on responses to this document under the OIA.

Please note: When preparing OIA responses, we will consider any reasons you have provided here. However, **this does not guarantee that your submission will be withheld.** Valid reasons for withholding official information are specified in the Official Information Act.

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☐ Yes, I would like HDC to consider withholding parts of my submission from responses to OIA requests.

I think these parts of my submission should be withheld, for these reasons:

Follow up contact

If needed, can we contact you to follow up for more detail on your submission? (required)

☐ Yes, you can contact me

☐ No, do not contact me

Further updates

Would you like to receive updates about the review?

☐ I'd like to receive updates about the review

☐ I'd like to receive updates from HDC about this and other mahi

Thank you

We really appreciate you taking the time to share your thoughts with us. If you have provided your details, we'll keep you updated on progress. If not, feel free to check our consultation website https://review.hdc.org.nz for updates or

to contact us if you have any questions. We can be reached at review@hdc.org.nz.