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)

____

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?

Age Concern New Zealand

What type of organisation/group is it?

☐ Consumer organisation/group (please specify below)
☐ Iwi/ Māori organisation/group (please specify below)
☐ Health and/or disability services provider (please specify below)
☐ Central Government
☐ Local Government
☐ University/Academic
☐ Other (please specify below)

Please feel free to provide any further detail:

Age Concern New Zealand is a registered charitable organisation working for the wellbeing, rights, respect and dignity of the older people that call New Zealand home. Local Age Concerns across the country provide a varying range of services that include health promotion, social connection and elder abuse response.

Thank you very much for giving us this opportunity to contribute to your review.

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**?

Identifying the main issues is useful and it is encouraging that you are already trialling some options for improvements. Given your acknowledgement that you are dealing with increased numbers, triaging becomes even more important. People are put off seeking advocacy for change or making a complaint if it is going to take too long for any action to result. In many situations we are involved in, older people don’t have time to wait for a change to the service provided as delays perpetuate the abuse. Most elder abuse that we deal with involves more than one incident and the repetition increases the vulnerability to more manipulative behaviour by abusers.

Placing more focus on restorative processes is imperative as in most situations that older people face, they are not able to leave the service provided and choose another option. Resolving the issues with the current provider is usually the most realistic option. Resolution is more likely with the goodwill of both parties if engaging in a complaints process is honouring of all those involved, and the public.

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

We support broadening the purpose statement to more effectively include mana enhancing approaches to person-centred practice. It is imperative to include the broad definition of cultural responsiveness as older people are part of all the named groups you cover. We believe this helps to ensure that the focus is on people of all ages, regardless of how much they can speak for themselves.

It is extremely important that the role of whānau and family are understood and explicitly recognised to be part of the Code. In many instances older people need to have some form of support in addressing complaints and this usually involves relatives.

Right 3: The change of wording to ‘autonomy’ is significant in that it addresses the reality that very few individuals make choices without consideration of others – even if it is ultimately named as their ‘own choice’.

Right 8: Having whānau involved through phone, online messaging/skype/zoom etc. is standard practice in hui about issues like hospital discharge planning. Elder abuse meetings that we are regularly involved in, frequently need some online input from relatives/friends from out of town, so this should be acceptable practice for complaints resolution too.

Right 10: It is frequently a decisive inhibitor of our efforts to give older people options about complaints processes if they can only make a complaint themselves. Allowing complaints to be made by “support people” will improve the reach of this process. Older peoples’ use of services is frequently because their health needs are compromising their choices and increasing their vulnerability and dependence on others to receive appropriate care.

Thank you for including a “non-retaliation” clause as this is one of the main reasons that older people do not want to progress a complaint. They fear that they will be punished by the people and the services caring for them, who will make their life more difficult – such as not answering bells for toileting needs, being labelled, being verbally or physically abused or being prevented from seeing the people they want to be with.

More inclusive language is going to be a valuable way to encourage those from takatāpui and rainbow elders to feel that this process is safer for them to consider using than HDC process than it currently is.

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

- Strengthening the role of the Advocacy Service is a crucial need. As already highlighted, the current requirements for people themselves to make the complaint and to have already brought the issue to management, are both huge barriers for most older people. It is vital that support people are both able to ask for Advocacy Service involvement and to be involved in the processes that advocates undertake. Advocates are specialists with knowledge of the services and in negotiating with service personnel. Older people's family/whānau (or other informal supporters) need to be able to approach HDC advocates to seek advice and to have input as participants in the complaints process.

- The wording change to "facilitated resolution" is important because "mediation" has some confused (mis)understanding of the legal and/or paid role. Rather than being constrained by the legalities or policies of "mediators", having the focus on the resolution does encourage a variety of ways that this can happen. Tikanga and other resolution processes that used in many cultures to involve facilitators or supporters from a person's own language, and including faith or other community leaders, can be mana enhancing for everyone involved in the process. Meetings/hui/or any other disputes process are daunting for most people (for those who make a complaint, as well as for those who complained against). 'Restorative justice' processes have been set up in many towns under community law auspices and are less formal than court hearings. It is useful to consider other existing processes being used effectively in New Zealand already that can serve as a model and provide alternative ways of approaching "facilitated resolution" for HDC too.

- While part of the Code is to enable service providers to display their willingness to have a fair complaints process (e.g. a "suggestion box" at the front door), people seldom report feeling heard and understood when they have sought management out initially, and then go on to seek advocacy help for their situation. Often this is due to a lack of transparency about the time it will take to process a complaint and convey the outcome. The lack of clear timeliness raises questions about whether the complaints process is worthwhile. This applies to both the consumer and the person who is the subject of the complaint, let alone the agency who may at times appear more concerned about their reputation than the consumer (and sometimes even for their staff). For both the public and for the Health & Disability workforce, it would be useful to have clearer public-facing information in multiple languages and accessibility channels, that gives clear time frames. In practice, what we hear from many people, is that making a complaint is perceived as taking so long, that the complaint is not worthwhile pursuing.

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**?

Your organisational efforts to make HDC more responsive to tangata whenua are to be applauded. Recognising how equity of access to advocacy and complaint support is significant in addressing concerns for Māori but is also part of upholding the mana of all people. We encourage you to continue your efforts, including using te reo in your publicity. It may help to increase response for Māori and for others if the difference between the Advocacy Service and the Complaints process was explained in your publicity.

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?

It is imperative to ensure te Tiriti of Waitangi responsibilities are incorporated in the Act and the Code. Given that adding a clause has already been recommended previously, it is important that this review endorses adding the clause and the suggestions of engagement with Māori, hapū and iwi particularly around the advocacy guidelines. The advocacy services are often the gateway to HDC complaints services, so ensuring that these incorporate appropriate tikanga is vital.

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**?

Any genuine way to increase tangata whenua participation in HDC processes is useful. We support the wider use of hui ā-whānau and your other suggestions to include whānau as part of the complaints process. As well as in legislation, it is in the day-to-day practices that helps kaumātua/kuia to be supported by whānau to address complaint issues and to feel believed. At the heart of any complaint about a health and disability service is the importance of a consumers' values and beliefs being respected, especially regarding questions about breaches of "informed consent". It is important for health and disability services to demonstrate how information is shared kanohi-ki-te- kanohi rather than in written policies, and that time is given for consumers to consult with whānau about decisions to be made. Decisions about health and wellbeing by older people of any culture are seldom made without considering whānau and family. The Code needs to reflect that decision-making is more than an individualised process for older people and for other age groups too.

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**?

Your recognition of the need to improve the Act and Code is pertinent given the changing understanding of disability over the past 30 years. The wider recognition of a disabling society has been the result of ongoing advocacy from within disability communities. Health and Disability Services are needing to recognise how their policies and practices can exacerbate disability; while the Code provides a benchmark standard for ensuring that disabled people can receive appropriate services. This benchmark is useful even beyond health and disability agencies such as private retail or other trades businesses.

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?

We support the more explicit reference to effective communication, including a competent interpreter as this is foundational for all disabled people regardless of age. We continue to be grateful that the Code has always acknowledged the rights of decision-making even with diminished capacity. The PPPR Act written years before the Code has similar provisions, but in our elder abuse practice we often find that service providers in health and other fields, (as well as individuals) have little understanding of the rights of decision-making even with diminished capacity. Rather, many decisions are made on the presumption of incompetence and without reference to the person/consumer. For these reasons, we wholeheartedly support strengthening the Code to ensure that consumers are involved in decision making. We recommend that “representatives” are precluded from decision-making, unless explicit consultation with the subject person can be evidenced. We agree with the Law Commission’s proposal towards “will and preference” wording for all consumers regardless of decision-making capacity. Although the Law Commission’s decision-making review final report has not yet been released, we encourage the HDC review to implement these additions now. We note that your review recognises that “Supported Decision Making is a developing practice” in this country. The UN Convention on the Rights of Disabled was ratified by New Zealand in 2008, so we can be incorporating supported decision-making practices into the Act and Code now and do not need to wait for the Law Commission’s review to be actioned.

We acknowledge that your caution about unconsented research is guided by those who have voiced concerns and recognise the reasons behind their hesitation. However, we also hear that older people with disabilities or health conditions can be keen to contribute to research, especially if the research outcome might help their offspring and succeeding generations – even when it will not alleviate their own condition/situation. We support the protections outlined in the 2019 review being adhered to, as well as having disabled people on the specialist ethics committees.

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**?

When the public ask us about making a complaint to HDC, we always explain the difference between the formal written complaint process and the role that advocates can play in negotiating with services. This explanation needs to be clearer in HDC publicity. There needs to be more clarity about informal supporters asking for Advocacy Service involvement much earlier than when a formal complaint is considered.

Even more common is confusion about who should be approached to make a complaint about a hospital, residential care or community service. People are often unclear and receive suggestions of who to approach (in alphabetical not priority order):

- Advocacy organisations IHC, CCS Disability Action, Age Concern, Grey Power
- DHB/Te Whatu Ora ‘Funding & Planning’
- Government departments e.g. Police, Whaikaha, Office for Seniors, Ministry of Health
- Members of parliament, ministers
- Needs Assessment Service Coordination services (NASCS)
- Other service funders
- Overarching organisations e.g. Aged Care Association
- Professional registration bodies or associations e.g. Medical Council, ANZASW, OTNZ

Obviously, these options are in addition to a direct approach to the service provider and to HDC. This illustrates that without a clear and well publicised pathway, confusion and dissatisfaction will continue.

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**?

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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?

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

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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?

We support the aligning of reviews of the Act with reviews of the Code and support them being reviewed every 10 years - unless there is specific need to do so earlier.

The threat of a fine should not be the focus of services that have complaints against them, however, increasing the maximum to $10,000 does signify that obstructing HDC processes is not acceptable.

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

It may be more helpful to identify the requirements for teaching separately from research. Using not- identifiable fictitious scenarios can be helpful for education and training of workers in health and disability settings. Individual cases should only be used in education with a consumer’s consent, and this must remain paramount.

As identified in your Review documents, there is public (or provider?) misunderstanding of where the Code does - or does not - apply in research. Increasing the clarity of definitions is still required.

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

The increasing requirement to have and use online accessibility is creating more barriers and preventing some older people (with or without disabilities) to receive appropriate services for their health. In many situations if older people are not internet connected or cannot use mobile phone technology. they require supporters who can negotiate the technology for them, or they miss out on services they are entitled to and need. Having to rely on others to use advancing technology makes older people even more vulnerable to abuse and neglect.

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

All of the risks of new technologies identified are significant for older people with both advantages and disadvantages. Most have long term health information stored in other services from earlier in their lives. How these are collected or stored in older people's services may appear straight forward in face-to-face situations, but much of the current evolution of AI technologies considers how to incorporate previously recorded information that older people are unlikely to be fully cognisant of - nor necessarily consented to. The HDC Act and Code was such a crucial innovation in New Zealand when it was instituted. Likewise, it is vital that responding to any risks of technological advances must be incorporated into the HDC Act and Code proactively at this point.

Furthermore, it remains questionable whether health and disability services recognise their responsibilities to maintain services into older people's own home environments when there is no response to emails etc. Even when older people have had access to technology in the past, the costs of maintaining technology can become prohibitive. Would it be possible to use the HDC legislation and Code to ensure follow up is continued where a consumer of any age does not respond to contracted health and disability services when the communication about an appointment for example has been sent electronically? In our experience some hospital services are very responsive about following up "DNAs" or ringing with reminders before appointments, but not all services do this. How can the responsibilities be weighted towards services meeting their consumers' needs?. In our experience of elder abuse and neglect, frequently services have lapsed without acknowledgment of the agency's role and responsibilities that has left an older person vulnerable.

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.

☐ 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.